CANCER REHABILITATION AND SURVIVORSHIP: TRANSDISCIPLINARY APPROACHES TO PERSONALIZED CARE

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In 1976, I was a nursing student working my first day on an oncology unit; I had never even heard the term oncology. While on the unit that day, a great controversy occurred: the hospital engineer arrived to install a large metal sign indicating “Oncology Unit.” This hospital had recently decided to create a dedicated oncology floor rather than continue the practice of having patients with cancer scattered throughout the hospital on various units. Contrasting opinions abounded: Should we really put up a sign? Maybe people wouldn’t want to know they had cancer. Maybe nurses wouldn’t want to work in oncology.

The sign was installed and the unit began. A few months later, additional controversial issues emerged: perhaps there should be an outpatient clinic where chemotherapy would be given, and maybe we even needed nurses with special training to administer chemotherapy. The 35-year history since that time has revealed that oncology has indeed become a specialized practice, led by oncology professionals who have diligently forged ahead to pioneer new aspects of care. It was a sign that specialized oncology practice could improve the care of people with cancer.

Another significant memory I have of these earlier years was the common practice of celebrating the day a patient received a final dose of chemotherapy. I was one of the nurses who would join in the celebration, completed often with balloons, a cardboard “crown,” or cake as we celebrated a rare positive moment on our unit. I also remember, after several such celebrations, the first time a patient confided in me that while we were celebrating, she was terrified. She explained that once her treatment ended, there was no plan. She also said she was afraid because now she wouldn’t be coming in to see us or her physician, so how could she possibly know if she was “okay”? Encounters such as this began conversations among many oncology professionals that perhaps the end of treatment signified another challenge for our practice. Our patients
were survivors, and survivors needed care. It was a sign, this time not in the form of a metal plaque or a clinic structure but in the form of a patient voice.

In 2006, I had the opportunity to serve on the Institute of Medicine’s Committee on Cancer Survivorship, which resulted in the publication of key reports addressing cancer survivorship in both children and adults. Those reports have triggered enormous attention to the needs of now more than 15 million cancer survivors.

The chapters of this book reflect potential solutions to the many clinical challenges identified in the Institute of Medicine reports. This text addresses the physical, psychological, and practical challenges of surviving cancer, building on a solid foundation of oncology practice. Survivorship is more than delayed toxicities, unresolved symptoms, or heightened risk for recurrence. Survivorship is the all-encompassing experience of having lived beyond those initial words of “you have cancer” and toward a life embracing both the gifts and the burdens of life beyond that diagnosis and treatment. This text is interdisciplinary in its authorship and content, as it should be—indicative of the reality that quality survivorship care will always be interdisciplinary, bringing together the best of all disciplines to address the multidimensional needs of survivors and families.

The book you are holding in your hands at this moment is also a sign. It is a sign that we heard the voice of the terrified woman with the cardboard crown surrounded by the celebrating oncology team and that we have decided to take seriously this critical dimension of oncology we now call survivorship.

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In the early 1980s, I was a clinical nurse specialist in Vancouver, British Columbia. With my colleagues, I facilitated many public cancer education meetings throughout British Columbia. We always discussed the myths and misconceptions about cancer. I distinctly remember a participant at one meeting saying, “People who are alive and doing well after cancer should wear a button saying ‘I survived.’” Her point was that cancer was still a disease that was not openly discussed. There are many people who might pass by you every day who have had cancer, and you would not know about their cancer or the challenges they were experiencing as a result. Thus, she thought a survivor button would be a powerful way to dispel people’s misconceptions that cancer ends after treatment. How prescient she was.

Subsequently, in 1986, the National Coalition for Cancer Survivorship (NCCS) formed. Survivorship was a minimally discussed topic except for the challenges encountered in the long-term care and follow-up of pediatric patients. In recent years, NCCS and other organizations such as the Lance Armstrong Foundation have created a public platform for the voices of cancer survivors and are influential in the national survivorship movement.

Just as all cancers are not the same, survivorship has not had the same definition over the years. Some people have defined survivorship as disease-free status after a period of time, typically five years. Others have identified survivorship as a period of time that begins once active treatment ends. Today, more people are suggesting that survivorship begins at diagnosis. Cancer is now regarded as a chronic disease and not the immediate death sentence that people once assumed.

The image that people with cancer are not victims but survivors is an essential message to extend beyond the boundaries of cancer care professionals. Statistics inform us that one in three people will have cancer in their lifetime.
With approximately 12 million people alive with a history of cancer, healthcare providers in all settings will interact with cancer survivors. Not all cancer survivors will see cancer specialists routinely. The management of the care of people with a cancer history will become an even greater challenge as the population continues to age and as the healthcare workforce faces shortages.

The chapters in this section will provide the background on the survivorship movement from the personal, practice setting, and policy perspectives. Raising the consciousness of the public about survivorship has been critical for the recognition of the unique, ongoing needs—physical, social, emotional, spiritual, and financial—of people with cancer. The perspective of a cancer survivor gives power to the necessity of survivorship care. Unifying cancer care professionals to identify the changes that are needed in clinical practice has resulted in many initiatives to increase the consistency of communication and reduce fragmentation of care. Survivorship programs exist, specialized clinics have been developed, and standardized care plans and treatment summaries are evolving.

However, one solution alone will not guide survivorship care. Policies at the national and state levels are essential to eliminate discrimination in the workplace and in access to health insurance. The authors in this section are leaders who have been at the forefront of the evolution of survivorship care, as well as oncology health care and their professional organizations, including the Oncology Nursing Society. These professionals have elevated survivorship care to be equal in importance with screening, early detection, treatment, palliative and end-of-life care, and clinical research. The woman at that public education meeting almost 30 years ago would be proud of their work and progress toward a program of survivorship care.

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CHAPTER 1

Personalized Cancer Care

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INTRODUCTION

The term cancer survivor usually is defined as including anyone who has been diagnosed with cancer, from the time of diagnosis until death. As such, it includes those in all phases of cancer, including the process of diagnosis and all phases of treatment, those who have been cured of cancer, and those in periods of remission and relapse and at the end of life. According to the National Cancer Institute (NCI, 2010b), approximately 12 million cancer survivors were alive in the United States in 2007. This number has tripled over the past 30 years and is expected to increase as the population ages and treatments for cancer improve. NCI (2010a) emphasizes that cancer survivorship also affects the family members, friends, and caregivers of the person with cancer.

A major consideration in cancer survivorship is changing the focus of cancer care from merely fighting the disease to caring for patients and helping them live as fully and productively as possible despite the fact that they have, or have had, cancer. This change is necessitated by our success in treating cancer, thereby extending the lives of patients years or even decades beyond their diagnosis. However, improved survival has not come without a cost. The legacy of cancer survivorship may include persistent physical or psychological problems, strained or disrupted relationships, financial hardships, employment problems, and anxiety related to the possibility of recurrence (Cayless, Forbat, Illingworth, Hubbard, & Kearney, 2010; la Cour, Johannessen, & Josephsson, 2009). This transition is sometimes referred to as “the new normal” for patients with cancer, a term that recognizes the profound change in perspective that cancer often produces.

PERSONALIZED CANCER CARE

Because the term personalized cancer care is a broad concept with many dimensions, it is possible for different people to use this or a similar term to
mean quite different things. For example, many investigators use the term *personalized cancer care* to refer exclusively to the biologic aspects of treating individuals with cancer, as summarized in a recent review by Yeatman, Mule, Dalton, and Sullivan (2008):

> Personalized medicine in cancer care will need to use molecular signatures to match the right patients to the right drugs, first in clinical trials, then in clinical practice. This is a new paradigm in which information technology, science, and clinical treatment are combined to improve health outcomes and patient satisfaction. It will require unusually large databases, relating both molecular and clinical data, such that patients can be proactively selected for the most appropriate therapies. (p. 7250)

Other investigators, however, take a more holistic approach, including psychosocial, cultural, and spiritual elements within the concept of personalized medicine. Indeed, to limit the concept of personalized medicine, or personalized cancer care, to the realm of the biologic is to disregard those very aspects of ourselves that most people believe make us the person we are. Furthermore, expanding the concept in this way emphasizes not only optimizing one’s health but also incorporating the values and goals that make one’s life productive and meaningful.

Accepting this broader conception of personalized cancer care may appear to conflict with the imperative to encourage evidence-based practice, which also is often understood as favoring biologically based research. Yet, it is precisely the challenge to include this broader concept of personalized medicine that ultimately will permit evidence-based practice to incorporate a more complete and realistic concept of evidence. Furthermore, as discussed by Henry, Zaner, and Dittus (2007), the evidence-based practice movement continues to struggle with the role of clinician judgment and patient values in medical practice. In the face of these challenges, the evidence-based practice movement is evolving in an effort to clarify the relationship of different kinds of evidence and to recognize the importance of nonbiologic data in caring for patients.

Taking this broader perspective encourages a transdisciplinary approach to cancer care and research. Indeed, a transdisciplinary perspective is required to fully incorporate all the nonbiologic aspects of personhood in evidence-based practice. A recent review by Satterfield, Spring, Brownson, Mullen, and Newhouse (2009) proposed a transdisciplinary model of evidence-based practice that integrates medicine, nursing, psychology, social work, and public health perspectives; this could certainly be expanded to incorporate spiritual and other perspectives as well. Their model emphasizes shared decision making as an essential feature of transdisciplinary evidence-based practice.

This text is an effort to respond to the challenge of providing integrated, holistic, personalized care for patients with cancer. Only then will we serve our patients in the manner they deserve as they strive to embrace cancer survivorship.
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CHAPTER 2

From Anecdote to Evidence: The Survivor’s Perspective

Susan Leigh, BSN, RN

Tell me a fact and I’ll listen.
Tell me a truth and I’ll learn.
But tell me a story,
And it will live in my heart forever.

—Native American Wisdom

INTRODUCTION

Storytelling is the foundation for the concept of survivorship. Without the stories of individuals struggling to survive the difficult treatments, persistent side effects, unexpected life disruptions, and bewildering unknowns of long-term survival, there would be no knowledge of the true impact of this disease. Only through anecdotal reporting or storytelling do we ever progress to systematic observation and evidence-based care. Thus, stories become an important and integral component of current everyday practice, transitional care, and long-term follow-up.

I feel compelled to admit to personal bias in this chapter, as my own experiences with cancer have greatly influenced my professional life as an oncology nurse and advocate. I always struggle with the decision to include my cancer history within my writing because anecdotal accounts usually are considered “unprofessional” in an academic sense. Yet, it is from these experiences that I have been able to make contributions to my chosen profession of oncology nursing. Also, stories from untold numbers of survivors over the past decades have surely influenced the other authors who are contributing to this book. Consequently, I have added an occasional encapsulated snippet from my own encounters with cancer to illustrate this theme of survivorship.
ONCE UPON A TIME

Sometimes I feel like a primitive artifact that survived the early era of cancer care, as my personal experiences have paralleled that of oncology as a medical and nursing specialty. When I received treatment for Hodgkin disease (now called Hodgkin lymphoma) in 1972, there were no effective antiemetics, no colony-stimulating factors, and no central vascular access devices. There were also no support groups, extremely limited patient resources, and very few nurses specializing in cancer care. Technicians were employed to deliver radiation therapy treatments and monitor side effects, and in the beginning, only physicians could administer chemotherapy. Because cancer treatment initially was available only in limited academic settings, chemotherapy drugs were sometimes sent home with instructions for local physicians to deliver an occasional dose. I still remember receiving nitrogen mustard in my antecubital vein from an older physician who had never before given chemotherapy. He chided me for my vanity in wanting to save my hair as I sat there with a tourniquet around my hairline! Needless to say, many antecubital veins were irreparably damaged, and countless hair follicles failed to survive various tourniquets and ice packs. Fortunately for patients everywhere, nurses soon became interested in cancer care as a separate specialty and, in 1975, started the Oncology Nursing Society. The safe delivery of these new therapies, along with offering supportive care and symptom management, became their priorities.

Finally, a new sense of hope emerged. From a provider perspective, the hope that some types of cancer might become treatable, controllable, and maybe even curable offered tenuous yet exciting possibilities. From a patient perspective, hope became entangled with an undefined yet encouraging sense of “future” that cohabitated with undercurrents of anxiety and fear. Meanwhile, success was still measured numerically in months and years of life, and survivors were often told how lucky they were to be alive and how grateful they should be. No complaining allowed. End of story.

DOWN THE WINDING ROAD

As survival advanced from months into years, cancer-related issues changed for both survivors and caregivers. Throughout the 1980s, physical survival was no longer considered the only measure of success. As increasing numbers of patients lived longer after receiving different forms of cancer therapy, attention turned to the quality of the lives being saved. Symptom management quickly became the responsibility of oncology nursing, yet crisis management for psychosocial problems was hit-and-miss depending on staff availability. With limited support services, oftentimes no one was present to hear the stories of insurance and employment discrimination; of lingering or delayed psychological trauma; of destroyed relationships,
infertility, or sexual difficulties. This collateral damage simply represented the price patients paid for survival.

More collateral damage occurred as care became increasingly fragmented. As much of the physical care moved from acute inpatient settings to ambulatory outpatient environments, psychosocial care remained extremely limited, undervalued, underfunded, and rarely a priority. While oncology nurses and social workers became increasingly frustrated with the lack of psychosocial resources for those in active treatment, the increasing number of long-term survivors was far down the list of priorities for continued attention. Consequently, survivors and caregivers took it upon themselves to create opportunities for continued support.

The complexities of surviving a life-threatening disease were generally identified not by systematic follow-up within oncology clinics but rather through individual and collective stories shared by survivors whenever and wherever they could find each other. While many survivors simply wanted to forget the entire experience, others were desperate to find fellow survivors with similar issues and fears. They gathered in church basements and at each others’ homes. They started support groups, hotlines, and organizations, all so that they could share their stories and prevent others from suffering in silence. One of the first newsletters dedicated solely to patients and survivors was created by Pat Fobair, a social worker at Stanford University, and was called Surviving. I remember reading every single word and saving every single issue. It felt like a lifeline for so many survivors and helped to create a sense of connection while validating the complexities of survival. The entire content of this publication was composed of stories! Patient stories. Survivor stories. Caregiver stories. Wounded lives now had an outlet for healing.

TRANSFORMING WOUNDS

Often we forget that the medical narrative of someone’s disease and treatment describes but one piece of a complex life story. In The Wounded Storyteller: Body, Illness, and Ethics, Arthur Frank (1995) wrote that people who have been affected by illness “need to become storytellers in order to recover the voices that illness and its treatment often take away” (p. xii). For years I didn’t even realize that I had a voice. In Building a Legacy: Voices of Oncology Nurses (Leigh, 1995), I wrote, “Over the years as I had mentioned some of my concerns to physicians and nurses, I often found myself patronized, ignored, or labeled a hypochondriac” (p. 290). Why was I still afraid? Would I ever feel safe again? How do my colleagues deal with their emotions and the intensity of this work (oncology nursing)? The nurses and physicians I worked with simply did not understand my lingering anxieties. What more did I want? After all, I was one of the lucky ones because I was in remission. So I shut down and said nothing, as did many survivors who had lost their voices. But that all changed in 1986.
SURVIVORS UNITE

From the mid-80s and into the next decade, we saw the beginning of a consumer movement. The Wellness Community, Candlelighters, Cancervive, Commonweal, Vital Options, Cancer Lifeline, and (People) Living Through Cancer are just a few examples of the very early programs that started independently around the country to support patients and families who were dealing with cancer. As these consumer groups were creating diverse models of community-based care, psychosocial support programs were also beginning to emerge in hospitals and clinics. Surely one of the most recognized and respected programs was I Can Cope, started by Judi Johnson and Pat Norby (Johnson & Klein, 1994)—visionary nurses who blended academic pursuits and clinical experience into an educational support program that was subsequently adopted by the American Cancer Society.

Along with these programs and community resources came multiple consumer-oriented books. Titles such as Hanging in There: Living Well on Borrowed Time (Spingarn, 1982), From Victim to Victor (Benjamin, 1987), The Road Back to Health: Coping With the Emotional Side of Cancer (Fiore, 1984), and Cancervive: The Challenge of Life After Cancer (Nessim & Ellis, 1991) represent an early sampling of works written about and by survivors or caregivers. At the same time that survivors were sharing their experiences through writing, oncology physicians, nurses, and social workers joined in and helped organize these many sources of support. To help coordinate this movement, a diverse group of advocates came together in 1986 and founded the National Coalition for Cancer Survivorship (NCCS, n.d.). The founding members began to change the language about survival to reflect the lived experience of this new population. The term survivor replaced victim, and the concept of survivorship illustrated the multiple dimensions and stages of survival. Fitzhugh Mullan (1996), the cofounder of NCCS, wrote eloquently about survivorship and described it as

the act of living on, no matter what happens, the challenge faced daily by millions of Americans who are engaged in defiance of disease and in affirmation of life, and lifelong, beginning with the diagnosis of cancer and continuing for the balance of life. (p. xvii)

In the beginning, survivorship was qualitative and had no boundaries. It described the dynamic process of survival rather than containment in time frames (five years) or outcomes (cure). In metaphorical terms, it was initially seen more as a journey than a destination.

THE NEVER-ENDING STORY

Although significant progress has been made in the field of survivorship, challenges continue. As the number of survivors increases, so does the need to expand the continuum of care to include adequate, affordable, and accessible long-term follow-up care. Yet, even if money becomes available to cover
long-term costs, the question still remains about who will care for the long-term cancer survivors and how. The good news is that earlier diagnoses and better treatments are improving survival. The not-so-good news is that the longer we live, the greater risk we have to develop other cancers and delayed effects of treatment.

Furthermore, at the same time the needs of survivors are increasing, the numbers of both oncologists and primary care providers are decreasing. So, who will care for survivors? If resources are limited, choices must be made. Obviously, patients in need of life-saving treatments for active disease are top priority for oncologists. But how long will they be able to continue caring for an increasing population of survivors who are at risk for possible problems? As more and more survivors experience second malignancies and late effects of treatment, there is growing anxiety about who is available, willing, and qualified to oversee their follow-up care.

I like to think that oncology nurse practitioners (ONPs) will be the answer to these dilemmas. ONPs have been at the forefront of survivorship care in pediatric oncology for years. Although they are now playing a larger role in adult follow-up care, there simply are not enough of them. But it is still a place to start. Most ONPs have “knowledge gained through delivering and monitoring treatments and managing side effects. They also develop relationships with family members and loved ones, assess for psychosocial problems, refer to appropriate specialists, and generally work within a model of wellness promotion rather than disease management” (Leigh, 2007, p. 11). ONPs have the opportunity to position themselves as preeminent providers of survivorship care.

**IMPROVING SURVIVORSHIP CARE**

Oncology nurses in general play an ever-expanding role in preparing their patients for life beyond cancer. Although clinic nurses may no longer see long-term survivors for anything but a quick hello during an annual checkup, they play a critical role in helping patients transition to post-treatment care. Here are some of my own personal recommendations from a survivor perspective for improving transitional and long-term care (see Figure 2-1).

- **Celebrate, but with a dose of reality.** Help prepare survivors for the transition to post-treatment care. Obviously, it is exciting to see your patients

| Figure 2-1. Recommendations to Improve Transitional and Long-Term Care of Cancer Survivors |
|---|---|
| • Celebrate, but with a dose of reality. | • Encourage survivorship care plans. |
| • Complete a treatment summary. | • Honor survivors’ “labels.” |
| • Prepare survivors to leave their safety net. | • Look outside the (evidence-based) box. |
| | • Value survivors’ stories. |
complete treatment and graduate to follow-up care. But be aware that this can be a frightening time for survivors. After you celebrate the end of treatments with graduation certificates, songs, cupcakes, or bubbles, many survivors leave the clinic, sit in their cars, have panic attacks, and wonder, “What do I do now? How will I know if the cancer is coming back? Why am I feeling afraid when I should be feeling happy that treatments are over?” Remember to offer the tools of resources, referrals, and reassurance to help them survive the unknowns.

- **Complete a treatment summary.** Hopefully, most survivors will soon have one of these important documents. This is a simple historical report listing the specifics of the patient’s diagnosis and treatments. It includes any problems that occurred during treatment, along with any lingering effects. Can anything be done to alleviate or treat these problems, and who is responsible for follow-up? Who can be contacted if a problem or question arises? Make sure that all survivors have a copy of their individual treatment summary and care plan and that copies are sent to their primary care provider and other specialists.

- **Prepare us to leave our safety net.** Oncology physicians and nurses have been our safety net for months and even years. It can be frightening to think about returning to primary care providers who may not know how to care for us or how to identify possible treatment-related problems. How long can survivors continue to come to the oncology clinic for checkups? Will an oncology nurse be available to take calls and answer questions that can arise months or years after treatment is completed? Who will help update survivorship care plans?

- **Encourage survivorship care plans.** The Institute of Medicine released its report *From Cancer Patient to Cancer Survivor: Lost in Transition* in early 2006. It then published *Implementing Cancer Survivorship Care Planning: Workshop Summary* in 2007; this was such an important component of the original work. It highlighted the role of nurses in coordinating cancer survivorship care planning. While the treatment summary is a static report, the survivorship care plan is an ever-changing, living document. Because it changes, it requires time and regular attention. Gathering the team to first develop, and then update, this plan can be daunting. But this is where survivors learn to be well again. Even though surveillance is a critical part of post-treatment care, it is always frightening to think about what might be found during follow-up visits. A more palatable component of follow-up care is health maintenance and health promotion. If survivors are informed that future clinic visits will focus on learning how to be well, many will feel much more enthusiastic about coming in for follow-up appointments. Teach survivors about diet and nutrition, exercise, and stress reduction. Ask about relationships, sexual problems, or any other issue that needs attention. Make referrals when necessary, and personalize plans with tools and resources that will help survivors regain a sense of control and reduce their fears.
• **Honor our “labels.”** Some of us love to be called *survivors*. Others hate the label. Whether we prefer to call ourselves *thrivers, victors, warriors, activists, cancer killers,* or simply *cancer patients,* honor how we view ourselves. I like to think that arguing about how we want to be labeled or what we want to be called is a real sign of progress! But you may occasionally need to remind us that we are much more than our cancer diagnosis and that a cancer label is only one part of who we are.

• **Look outside the (evidence-based) box.** Although few evidence-based guidelines are available to direct survivorship care, we can no longer use this lack of evidence to ignore appropriate follow-up. Initially, common sense determines the testing and timelines for follow-up care. The next step is to agree on consensus-based guidelines while waiting for the research-based evidence.

• **Value our stories.** Storytelling is how we find meaning through suffering. It makes our experiences unique and gives dimension and texture to our lives. Continue to listen to us, as it is through each of our stories that you will learn how to care for us. Survivors continue to be guides to the unknowns.

**FROM SURVIVING TO THRIVING**

Oncology care surely has come a long way over the past four decades. But there is still a long way to go. As scientific research continues to unlock the mysteries surrounding cancer, more effective treatments are emerging to extend and improve the lives of those affected by this disease. Meanwhile, the voices of the survivors themselves must never be lost in discussions and decisions surrounding survivorship care. This passage from the Institute of Medicine report (2006) *From Cancer Patient to Cancer Survivor: Lost in Transition* serves as a reminder and guide:

By also reviewing reports that summarize the anecdotal and compelling stories of survivorship, we heard the voices of survivors who underwent a life-changing experience—learning that large numbers of them are dealing with a legacy of physical, psychological, social, vocational, spiritual, and economic consequences. Hearing about their experiences further opened our eyes to the unspoken and hidden disabilities that follow successful treatment for cancer. (p. xxiv)

It is my hope that this increased awareness about the consequences of survival will expand access to comprehensive follow-up services, increase research in the area of lingering and late effects, encourage more systematic follow-up and inclusion in databases, and enhance our focus on “wellness” and improved quality of life. Oncology nurses need to make sure that survivors have access to insurance coverage for rehabilitation, along with referrals to specialists, mental health services, and end-of-life care, and need to afford all survivors the opportunity to not only survive but to thrive after cancer.
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INTRODUCTION

Not so long ago, cancer was considered a virtual death sentence. Despite recent successes in treating and managing some forms of cancer, its side effects, and the untoward effects of treatment, cancer remains a dreaded disease in most societies. Eloquent historical reviews depict the challenges experienced by nurses who cared for patients, families, and communities affected by cancer in earlier and more difficult times (Haylock, 2008; Johnson, 1985; Johnson, Baird, & Hilderley, 2001; Lusk, n.d.; Yarbro, 1991). Their work contributed to the evolving ways in which cancer is considered and care is provided. For nurses who entered practice in the latter half of the 20th century, the ability to consider cancer survivorship care planning was astonishing, and we shared with patients and families the fulfillment of hopes for longer and better lives after cancer. The realities of current survivorship require changes in the scope and practice of oncology nursing (Haylock, 2006).

Today, nearly 12 million people in the United States are living after a cancer diagnosis, and the number increases every day (Altekruse et al., 2010). While we celebrate these successes and look forward to further improvement in survival, limited resources, evidence, and information are available to address the physical, psychosocial, economic, and quality-of-life needs of cancer survivors and their families. With the exception of childhood cancer survivors, evidence-based guidelines for health promotion and ongoing follow-up are scarce (Children’s Oncology Group, 2008; Ellenberg et al., 2009; Landier et al., 2004; Recklitis et al., 2010). This is especially true for long-term cancer survivors, who are likely to face one or more challenging sequelae in the months and years after primary therapy ends. This chapter provides an overview of national efforts to improve care and services of
cancer survivors, the evolving role of nurses in survivorship care, and the changes within healthcare systems that are necessary to address the needs of this growing population.

STATE OF THE SCIENCE

Before 1985, the notion of cancer survivorship was unidentified and unnamed. Although Fitzhugh Mullan introduced the concept of survivorship in the classic article “Seasons of Survival” in 1985 and the National Coalition for Cancer Survivorship (NCCS) formed the following year, survivorship remained a low priority among healthcare providers and was rarely a component of healthcare services. When primary treatment ended, survivors often were reminded that they were lucky to be alive (Leigh, 1992), and thus they were unlikely to bring up post-treatment concerns for fear of being viewed as ungrateful or demanding (Siegel & Christ, 1990).

Cancer survival has traditionally been measured in mortality metrics or completion of primary therapy with little attention devoted to lingering or long-term health problems. As treatment effectiveness increased length of survival, organized survivor groups, including NCCS, embraced the philosophy that “survivorship does not focus on the disease, but on the person living with, through, and beyond the disease” (NCCS, 2005, p. 3). Houts, Yasko, Kahn, Schelzel, and Marconi (1986) identified unmet needs of survivors relating to physical care, emotional support, advice for healthy living, job loss and discrimination, and affordability of and access to health and life insurance. However, an international survey of women with breast cancer conducted more than two decades later reveals disappointingly similar findings (Mayer & Grober, 2009).

A national database designed to identify and monitor health status, problems, or needs of cancer survivors does not exist in the United States. The exact numbers of survivors and the extent of problems and challenges they face are unknown. Long-term cancer survivors often receive health care from primary providers who may be unaware of specific needs and the sequelae of cancer, cancer treatment, and related health needs that can change over time (Curtiss, Haylock, & Hawkins, 2006). Long-term follow-up is frequently inconsistent and fragmented (Institute of Medicine [IOM], 2006). Evidence-based guidelines are currently available for survivors of a very few select and common cancers (breast, colon, lung, lymphoma) that affect adults (American Society of Clinical Oncology, 2010). Although research to explore survivorship is increasing, survivorship after adult cancers remains a vastly underexamined and underaddressed social dilemma. Evidence-based guidelines for follow-up and surveillance for survivors of childhood cancers have been available since 2004 but have yet to be universally adopted (Children’s Oncology Group, 2008; Landier et al., 2004).
SURVIVOR CARE PLANNING: CREATION, DELIVERY, AND OUTCOMES

Survivorship care includes promotion of healthy lifestyles and behaviors after cancer, prevention and early detection of cancer recurrence and second cancers, and identification and management of physical, psychosocial, economic, and spiritual/existential needs of survivors and their families. The majority of these issues are challenges nurses deal with on a daily basis (Houldin, Curtiss, & Haylock, 2006). Yet, although several nurses have made significant contributions to national survivorship issues, nursing’s voice has been largely absent or at least unheard related to planning for survivorship care and improving outcomes. A complicating issue is the reality that most healthcare systems remain based on illness models that rarely address wellness education, support for healthy behaviors, or holistic provision of care and services. Individual nurses and professional oncology nursing organizations continue to primarily focus on acute patient care, especially during active treatment and symptom management at the end of life.

NATIONAL ACTIVITIES AND PUBLICATIONS

A variety of national organizations and initiatives during the past several decades have supported the need to conceptualize cancer survivorship as a distinct phase of cancer care and enhance services for survivors, but progress is slow. Appendix A chronicles major developments aimed at identifying and promoting optimum services for cancer survivors.

Before the publication of “Seasons of Survival” (Mullan, 1985), literature on survivorship did not exist, although the need for continuing support was growing. NCCS adapted Mullan’s notion of survivorship and defined survivorship as “From the time of discovery and for the balance of life, an individual diagnosed with cancer is a survivor” (NCCS, 1986). NCCS, the National Cancer Institute’s Office of Cancer Survivorship, the Lance Armstrong Foundation, and other organizations have expanded the definition to include family, friends, and caregivers.

In 2003, IOM called for the development of guidelines to direct care for survivors of childhood cancers, and in 2004, the Children’s Oncology Group published guidelines for screening and follow-up (Landier et al., 2004). In 2003, a report commissioned by the National Cancer Policy Board and IOM identified contributions made by oncology nurses and recognized oncology nursing as central to all aspects of survivorship care (Ferrell, Virani, Smith, & Juarez, 2003). The report called for nursing education to improve coverage of survivorship issues at all levels, additional nursing research, and inclusion of survivorship content in oncology nursing certification examinations. The following year, the Centers for Disease Control and Prevention and the Lance Armstrong Foundation (2004) collaborated on a special report, A
National Action Plan for Cancer Survivorship: Advancing Public Health Strategies, which proposed specific strategies to address survivors’ needs. Infrastructure development, a comprehensive cancer survivor database, development and maintenance of patient navigation systems that facilitate optimum care, establishment and dissemination of public education programs that empower cancer survivors to make informed decisions, and ongoing evaluations of all activities to determine outcomes and ensure continuous quality improvement were among the report’s key recommendations.

Even though nurses have participated in the efforts identified in Appendix A, the nursing profession has not pursued a leadership role in creating strategies to improve survivorship and wellness outcomes. In an initial attempt to stimulate and enhance nursing’s voice in survivorship-related efforts, the American Journal of Nursing (AJN) in 2005 collaborated with the American Cancer Society, NCCS, and the University of Pennsylvania School of Nursing to convene “The State of the Science Conference on Nursing Approaches to Managing Late and Long-Term Sequelae of Cancer and Cancer Treatment” (Curtiss & Haylock, 2006). Invited experts crafted recommendations to enhance nursing’s leadership in cancer survivors’ care (Houldin et al., 2006; Lewis, 2006), identified survivor-focused practice models (Lewis, 2006), and established a nursing research agenda for long-term survivor issues (Houldin et al., 2006). Along with the recommendations described in Appendix B, participants urged AJN leaders to convene stakeholder organizations to strengthen nursing’s role in cancer survivorship.

Soon after the state of the science conference, the IOM report From Cancer Patient to Cancer Survivor: Lost in Transition was released in 2006. The report called for development and dissemination of an individualized, written survivor care plan for all individuals completing primary treatment. Recommended content of the plan included a treatment summary, identification of the risks for sequelae, and plans for health maintenance after cancer treatment. AJN convened a cancer survivorship stakeholders’ summit in 2006. Nursing organizations and others at the summit recognized that non-oncology nurses in a variety of settings, including primary care, school nursing, and occupational health, frequently provide care for long-term cancer survivors but have little information to guide care planning. Participants agreed that non-oncology nursing organizations have a stake in increasing awareness of survivors’ needs. The need for a paradigm shift in thinking and resource development from an illness to a wellness focus was emphasized. At the time of the summit, several national organizations were piloting survivor care plans, but examples of plans to guide practice had not been published. Summit participants collaborated to develop and publish a survivor care plan template for nurses to use, adapt, evaluate, and change as the template evolved. The “Prescription for Living” was published in AJN in 2007 (Haylock, Mitchell, Cox, Temple, & Curtiss, 2007). A master plan of organizations’ commitments made during this meeting can be found at www.nursingcenter.com//upload/static/701558/Cancer_Plan.pdf. Appendix C identifies goals generated during the stakeholders’ summit.
GUIDELINES FOR SURVIVORSHIP CARE

Evidence-based guidelines for follow-up and surveillance for childhood cancer survivors identify cancer- and treatment-specific late effects, identify additional risk factors, and offer recommendations for screening and follow-up (Children’s Oncology Group, 2008; Landier et al., 2004). The “Passport for Care” is an example of an Internet-based resource for childhood cancer survivors that combines individualized medical information and evidence-based guidelines (Baylor College of Medicine & Texas Children’s Cancer Center, 2010). Even though similar guidelines do not yet exist for survivors of most adult cancers, Internet-based resources are available or under development to enhance survivorship care planning. An example is Journey Forward, a collaborative effort of NCCS, UCLA Cancer Survivorship Center, WellPoint, Inc., and Genentech (Journey Forward, n.d.).

The Nursing Imperative in Cancer Survivorship

The patients to whom we skillfully administer chemotherapy and biotherapy, and the patients whom we guide through surgery and radiation, are indeed living “with, through, and beyond cancer,” creating an imperative for nurses to assume responsibility for addressing survivors’ needs. No professional discipline or specialty has assumed leadership and accountability for cancer survivorship. Without designated accountability, forward momentum will be limited. Former NCCS president and chief executive officer Ellen Stovall claimed that, quite simply, “Someone has to own it” (personal communication, February 19, 2008).

The survivorship movement started more than a quarter century ago. Nursing is underrepresented in the survivorship arena overall, and nurses’ roles in survivorship care planning continue to be undervalued. Ferrell et al. (2003) reported that compared to the oncology nursing population, relatively few nurses are active advocates in the survivorship arena. Evidence of nursing’s contributions and nursing research is largely invisible or absent in the literature. Among 80 references cited in a review of survivorship and survivorship research, Rowland and Bellizzi (2008) included only three from nurse authors or sources. An entire issue of Hematology/Oncology Clinics of North America (Travis & Yahalom, 2008) devoted to cancer survivorship included 21 contributors to 13 papers with only one nurse identified as a contributor. These examples are not meant to illustrate the absolute lack of nursing publications but rather the lack of nurses’ involvement in the national movement.

Despite commitments made by participants in the two AJN-hosted conferences, the survivorship agenda for nursing (see Appendix D) has yet to be adopted or pursued, in part or completely, by any nursing organization. During the 2007 workshop “Implementing Cancer Survivorship Care Planning,” contentious debate surrounded whether nurses are prepared to assume central roles in survivorship care planning (IOM, 2007). Identified barriers to nurses’
involvement in survivorship care planning were inadequate staffing, lack of recognition of a nursing role, and limited reimbursement. Creation of the treatment summary was viewed as an especially time-consuming element of care planning.

Other noteworthy obstacles included access to support services for patients, including social workers, nutritionists, and financial counselors, particularly in office-based settings; the need to allocate additional resources; and changes in practice patterns to accommodate survivorship visits. Finally, it was reported that in nurses’ views, needed practice innovations “will be predicated on physicians ‘blessing’ their [nurses’] role in survivorship planning and committing the necessary resources” (IOM, 2007, p. 41). The summary statement of nurses’ perception of their roles in survivorship care planning was, “Nurses can and want to take a key role, but they cannot assume these new responsibilities unless there is agreement on collaboration and innovation” (IOM, 2007, p. 42). Similar reservations are noted in the IOM (2009) report on oncology workforce issues, highlighting the need for cultural change in healthcare delivery systems.

The Call to Action: Nursing and the Shifting Paradigm of Cancer Survivorship

“Blueprint for a Better Cancer Care System” (Rose, Stovall, Ganz, Desch, & Hewitt, 2008), supported by the Cancer Quality Alliance, identified six aims for a 21st-century health system: safe, effective, patient-centered, timely, efficient, and equitable. These aims are well within the purview and expertise of nurses. Stovall (personal communication, February 19, 2008) offered a vision for nursing’s multiple roles in cancer survivorship that is worthy of nursing’s commitment. She stated, “I see oncology nurses as primary to follow-up care: doing survivorship care planning, staying actively involved in survivors’ lives, playing a coordinating role, arranging and facilitating access to resources . . . coordinating an integrated model of holistic care.”

The question for both organized nursing and individual nurses is: Do we passively wait until others come to agreement on collaboration and innovation, and invite nurses’ participation in a yet-to-be-created national survivorship agenda? Or, do nurses actively and aggressively pursue roles that promote survivorship care planning and provision of services? We can start by exploring answers to these questions: Where are we now? Is the status quo acceptable? What is acceptable? How can we make a difference? What are our priorities? Who needs to be involved? Who are champions? Who owns it?

Next, nurses must assume accountability and responsibility in cancer survivorship, including facilitation of interdisciplinary collaboration. Collectively, we must (a) challenge the value of the medical (illness) model as opposed to a holistic (healthiness) model, (b) reconsider and challenge the traditional role of physicians as gatekeepers to healthcare services, (c) look outside cur-
rent and traditional roles of health care, (d) adapt healthcare education accordingly, (e) devise and coordinate community-based, holistically designed service delivery models, and (f) collaborate with non-oncology providers to provide needed services.

A multifaceted survivorship agenda for nursing is outlined in Appendix D. Nurses in all settings can aggressively pursue opportunities to participate in the evolving cancer survivorship arena and contribute to public policy efforts to advance a cancer survivorship agenda that includes the following: (a) survivorship research, (b) development of models for care and services, (c) recognition, valuing, and support of emerging nursing roles in survivorship services, (d) funding and support to conduct rigorous studies to identify and explore the needs of cancer survivors, (e) interventions and services to address identified needs, (f) development and implementation of cost-effective care delivery models, programs, and services, and (g) innovative strategies to increase awareness of and education to address cancer survivorship issues.

SUMMARY

Nursing is an untapped resource with the potential to make significant contributions to the cause of cancer survivorship. Individual nurses and organized nursing need to believe in the importance of what the voice and wisdom of nursing brings to the survivorship movement and then make the commitment to do so. From that point on, organized nursing and nurses can and must be present, active, visible, articulate, and passionate contributors and collaborators in the survivorship arena. “The degree to which these strategies succeed depends on whether survivorship care planning becomes a routine and expected part of cancer care, regardless of provider specialty or practice setting” (Haylock et al., 2007, p. 60).

REFERENCES


CHAPTER 4

Survivorship Care Settings

Elizabeth Sherwood, RN, MS, ANP, and Donald L. Rosenstein, MD

“One goal of the [survivorship] initiative is to raise the awareness that survivorship care is every nurse’s responsibility.”
—Brenda Nevidjon, RN, MSN, FAAN, past president of the Oncology Nursing Society (ONS, 2008)

INTRODUCTION

The Institute of Medicine (IOM) reports From Cancer Patient to Cancer Survivor: Lost in Transition (2006) and Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs (2008) serve to highlight and champion many of the challenges that confront the person with cancer. Advances in early detection, screening, and treatment have led to 12 million cancer survivors in the United States and an expected doubling of that number by 2030 (Grant & Economou, 2009). These hallmark IOM reports call for improving and expanding cancer survivorship care. In response, oncology nurses and their professional colleagues across the United States and internationally are creatively and ardously working to improve survivorship care.

Although this chapter is focused on descriptions of specific cancer survivorship settings, it is important to appreciate that cancer survivorship care occurs in most healthcare settings and is provided by clinicians within and outside of dedicated oncology settings. As the population of cancer survivors continues to grow, so too do the number and variety of settings offering survivorship care.

PLANNING FOR SURVIVORSHIP CARE

There is a growing consensus that cancer survivorship care is enhanced by providing patients with a treatment summary and care plan at the end of active cancer treatment. Unfortunately, these important documents are often
not made available to patients. Consequently, patients receive little guidance in terms of risk reduction, health promotion, provider role delineation, or coping with residual physical and emotional symptoms that limit their quality of life (Deimling, Bowman, Sterns, Wagner, & Kahana, 2006; Hewitt, Rowland, & Yancik, 2003; Jefford et al., 2008). An individualized and proactive survivorship care plan, based on the patient’s cancer diagnosis and treatment, genetic factors, lifestyle behaviors, and comorbid health conditions, can help the patient and the patient’s providers prioritize their survivorship needs and choose the best settings in which to meet those needs. However, multiple challenges exist in providing a treatment summary to the patient and the primary care provider (PCP), including designation of who should complete the summary, allocation of the time needed to complete the summary, lack of reimbursement for preparing a treatment summary, the best location of the treatment information if the patient is treated in multiple practices, and selection of a treatment summary format that provides succinct information for both the patient and PCP. These are formidable challenges for many practices and institutions, and solutions are often site specific.

**Needs Assessment**

Completing a survivorship needs assessment, as well as determining what is available at an institution or medical practice, can help to identify existing services and gaps in services for the survivorship setting. This may then help justify the need for sustainability of existing services and programs being offered or can provide the rationale to develop new programs or partner with others (e.g., providing referrals to the YMCA/LIVESTRONG™ programs for post-treatment physical rehabilitation). Thus, cancer centers can utilize existing services and staff and partner with community providers and programs to expand cancer survivor care without greatly increasing the financial and staffing commitments of their center (Grant & Economou, 2009).

Across the country, the number and variety of survivorship settings continue to increase. To provide survivorship care efficiently and sustainably, oncology practices and institutions typically work from their strengths and toward what seems practical for their particular patient population (Grant & Economou, 2009). For example, programs with a strong psychosocial component may expand support groups, post-treatment therapeutic services, and educational events for patients as they approach the end of their treatment or after treatment.

A clear benefit of providing a survivorship program within a comprehensive cancer care setting is the inclusion of resources and personnel to conduct research focused on problems faced by cancer survivors. Several such institutions have incorporated a comprehensive clinical model into clinics for adult survivors (Dana-Farber Cancer Institute, n.d.; Seattle Cancer Care Alliance, n.d.; University of Colorado Hospital, n.d.). General adult survivorship clinics welcome patients who have experienced a variety of
cancers. Cancer site–specific clinics are another option for survivorship care (e.g., breast cancer or prostate cancer survivorship clinics). In either case, survivorship care can be delivered via a consultative model or a model that integrates ongoing survivorship services within the clinic (McCabe & Jacobs, 2008; Oeffinger & McCabe, 2006).

**Domains of Survivorship Care**

To understand the variability in scope and function of different survivorship settings, it is helpful to consider the components of survivorship care as outlined in the previously mentioned IOM reports. Comprehensive survivorship care should address the survivor’s identified medical and psychosocial needs, surveillance for recurrent and new cancers, and interest in health-promoting and wellness-based interventions (IOM, 2006). Additionally, several consensus reports call for improved coordination of survivorship care between oncologists and PCPs, as well as connecting patients with appropriate medical and community resources and services during and after treatment (Centers for Disease Control and Prevention & Lance Armstrong Foundation, 2004; IOM, 2006, 2008; Jacobs et al., 2009).

Cancer survivors may face risks for future health problems related to their cancer treatment, including a higher risk of cardiovascular disease and metabolic syndrome disorders, second cancers, and a variety of late effects (Ganz, Greendale, Petersen, Kahn, & Bower, 2003; Hewitt et al., 2003; Meacham et al., 2010; Oeffinger & McCabe, 2006; Oeffinger, Nathan, & Kremer, 2010; Redig & Munshi, 2010). In a report from the American Cancer Society, Jacobs et al. (2009) outlined the critical importance of health-promoting behaviors for cancer survivors because of the increased potential for morbidities related to treatment. In recognition of the broad range of survivor needs, this report noted the necessity of health-promoting interventions that are generalizable to a variety of settings and account for the preferences of patients.

**Collaborations and Partnerships**

The immenseness of survivorship care planning challenges the providers of oncology care to work collaboratively within their own institutions as well as within their local communities and national cancer advocacy organizations. Many, if not most, healthcare institutions face both staffing and monetary constraints in the programs and services they are able to provide. Assessing what is available both in one’s local community as well as within the national community will facilitate the provision of appropriate services within these constraints.

Cancer survivorship advocacy groups have active partnerships with many communities to provide interventions designed to enhance health-promoting behaviors for cancer survivors. For example, the Wellness Community and the Lance Armstrong Foundation partnered to develop a program titled “Cancer
Transitions: Moving Forward After Treatment” (Miller et al., 2009). This six-week program offers cancer survivors the opportunity to learn more about incorporating nutrition and fitness guidelines into everyday life (Miller et al., 2008, 2009). Based on the Wellness Community’s Patient Active™ Concept, the “Cancer Transitions” series encourages cancer survivors to explore the benefits of stress reduction and improving coping skills while advocating for their own survivorship care. Another example of a partnership serving the needs of post-treatment cancer survivors involves LIVESTRONG at the YMCA. The aim of this program is to help cancer survivors reach their health and well-being goals, with a focus on physical activity and support.

CANCER SURVIVORSHIP CARE SETTINGS

Too many cancer survivors experience fragmented care as a result of having multiple providers and inadequate communication between clinicians, as well as a lack of understanding of critical components of their care after treatment (McCabe & Jacobs, 2008; Oeffinger & McCabe, 2006). Patients who live in rural areas often travel long distances from their homes for their treatment and face additional challenges because of obstacles to returning for surveillance visits and follow-up care. The setting in which cancer survivorship care occurs is closely linked to the survivorship services available. The institutional practices that guide the care of patients after the end of active treatment or a shift to an extended treatment phase (e.g., extended hormonal treatment for breast cancer) also are key.

Most patients with cancer receive their treatment in either community cancer centers or community hospitals. The National Cancer Institute (NCI) estimates that only 15% of people with cancer in the United States receive their care at academic cancer centers (NCI, n.d.). However, many survivorship programs are located at large NCI-designated comprehensive cancer centers, thereby serving only a fraction of cancer survivors. To address the growing need for community-based cancer survivorship care, programs like City of Hope’s “Survivorship Education for Quality Cancer Care” (Grant, Economou, Ferrell, & Bhatia, 2007) and LIVESTRONG’s “Excellence in Cancer Survivorship Care: Developing Sustainable Programs” (E. Estes, personal communication, January 26, 2010) have trained more than 200 teams to bring survivorship programs and services to rural and urban communities.

A wide range of hospital, clinic, and community settings provide various aspects of cancer survivorship care (e.g., programs that provide physical rehabilitation and exercise training for the treatment of fatigue and loss of muscle mass, consultative psychiatric care for the treatment of insomnia, anxiety, and depression, and pain management clinics for peripheral neuropathy). The challenge for the medical and cancer advocacy communities is to provide this care efficiently and effectively. Formal survivorship programs have been
developed only recently, and several key questions remain unanswered: What settings and what services optimally affect outcomes? How do we best serve rural and urban, young and old, male and female, rich and poor survivors of cancer? How do we assess the value and benefit of an individualized plan of care after the active treatment phase is complete? Who should be responsible for developing and implementing survivorship care plans and treatment summaries, when cancer clinicians are already burdened with excessive clinical responsibilities and record-keeping tasks?

All models of survivorship care share the goal of improving the quality of care for cancer survivors. Ideally, the quality of cancer care will be informed and improved by a comprehensive assessment of the patient at the end of treatment, which, in turn, leads to an individualized treatment summary and care plan. One goal of the care plan is to facilitate the delivery of coordinated and tailored follow-up care. The care plan educates the cancer survivor about the ongoing surveillance schedule, helps facilitate referrals for identified issues and concerns, and addresses the benefits of health-promoting behaviors and cancer risk reduction. Identifying the role of specific providers in the treatment plan can reduce unnecessary physician visits and medical procedures (Gilbert, Miller, Hollenbeck, Montie, & Wei, 2008). Examples of exemplary programs in urban and rural settings will be described next.

**Urban Setting**

The Queens Cancer Center (QCC) of Queens Hospital is the only full-service cancer center in New York City’s public hospital system and serves any New York City resident regardless of ability to pay or immigration status. More than 80% of QCC patients fall below the national levels of poverty, and 56% speak a primary language other than English (Goytia et al., 2009). Additionally, many patients seen at QCC present with late-stage disease, which is unfortunately common in ethnic minorities and patients with lower socioeconomic status; almost two-thirds present with one or more comorbidities and no PCP (Goytia et al., 2009). How best can survivorship care be provided to this ethnically and culturally diverse, underserved population? Innovative programs and services are needed to improve cancer survivorship care among minorities and populations struggling financially (Guidry, Torrence, & Herbelin, 2005; Lengerich et al., 2007).

QCC provides survivorship care at the time of diagnosis and across the cancer care continuum by combining oncology care with internal medicine services in a clinic staffed by medical internists. Their goal is to provide comprehensive, long-term medical and psychosocial survivorship services. Any new patient with cancer who enters QCC without a PCP is referred to this survivorship clinic. The PCP also follows survivors who are many years beyond their treatment. The roles of the internists and oncologists are clearly delineated and establish the PCP as the coordinator for survivorship care (Gilbert et al., 2008). The oncologist provides care for any short-term
treatment-related sequelae and disease recurrence. The QCC survivorship clinic model includes the PCP providing cancer surveillance, treatment of medical comorbidities, and management of long-term and late effects of treatment, as well as health promotion and cancer prevention services for the family.

**Rural Setting**

Providing care to cancer survivors who reside in rural areas can be challenging in different ways than in an urban setting. These challenges include transportation, poverty, health literacy, and access to care (Campbell, Mayer, Abernethy, & Carroll, 2008; Lengerich et al., 2007). The University of North Carolina N.C. Cancer Hospital (UNC-NCCH) is charged with improving cancer care for North Carolinians throughout the state and thereby serves many patients who come from rural areas. To address the survivorship needs of these rural patients, UNC-NCCH entered into an innovative partnership with a community hospital. This community hospital does not provide cancer care but does offer a cardiac rehabilitation program. A partnership between the cardiac rehabilitation program and the UNC Carolina Well Survivorship Program enabled UNC to bring the six-class series Cancer Transitions: Moving Forward After Treatment to the rural hospital setting. A UNC-NCCH nurse practitioner with experience facilitating the series partnered with the cardiac rehabilitation nurse to co-facilitate the class. This partnership benefits not only the cancer survivors, who were able to attend a health-promoting educational program close to home, but also the healthcare professionals, who worked together to expand their knowledge about cancer survivorship in a rural setting. Furthermore, by working within an existing program that was interested in expanding their services to cancer survivors, the sustainability of the program was enhanced.

**SUMMARY**

As the number and needs of cancer survivors continue to grow, oncology nurses, oncology nurse practitioners, and nurses in a variety of healthcare settings will play critical roles in meeting the demands of the expanding population of cancer survivors, most of whom will be 65 years old and older. Innovative models of care using a variety of healthcare professionals will be needed to meet the anticipated needs of this population (Erikson, Salsberg, Forte, Bruinooge, & Goldstein, 2007; Shulman et al., 2009).

Improving educational opportunities for nurses, PCPs, and other healthcare professionals is crucial as we strive to provide survivorship care. Ideally, as we move toward 2020, we will work to establish more evidence-based clinical guidelines for survivorship care. Although we have a good idea of what services patients with cancer might benefit from, further research is needed to fully
determine the cancer survivorship services and settings that are the most cost effective and beneficial to improve survivor outcomes.

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The goals of cancer survivorship care are to restore health, promote healthy lifestyle behaviors to reduce cancer and non-cancer-related health risks, and monitor survivors for recurrence, second cancers, and late treatment effects. Restoring physical functioning is paramount in survivorship care. Physical symptoms after the completion of treatment persist across patients regardless of cancer sites; physical late effects continue to be documented in long-term survivors. Most cancer survivors report the need for more information about managing persistent symptoms and what to do to stay healthy (Beckjord et al., 2008).

An individualized survivorship treatment summary (Shapiro et al., 2009) provides the foundation for identifying persistent and late physical effects of therapy. This is an essential first step in developing a personalized survivorship care plan. Many survivors have complex health issues associated with comorbidities; survivorship care must adopt a comprehensive patient-centered approach to the management of symptoms and risk reduction for all causes of mortality. Such a comprehensive personalized approach requires a paradigm shift to a wellness-centered model of care with coordination of care established across providers. In the current healthcare system, cancer survivors do not have a single provider or lead coordinator of care for their multiple residual symptoms (Feuerstein, 2009).

The chapters in this section provide a review of currently known physical effects of treatment. Each chapter addresses unique symptoms; however, cancer survivors frequently experience multiple symptoms. The following two examples of survivors of breast and colorectal cancer identify the complexity of persistent physical symptoms and late effects of treatment. Women with
breast cancer in the first year of treatment commonly report persistent symptoms including fatigue, insomnia, pain, muscle stiffness, menopausal symptoms (hot flashes, vaginal dryness), weight gain, difficulty concentrating and remembering, and changes in sexuality and sexual function (Cappiello, Cunningham, Knobf, & Erdos, 2007). Accelerated bone loss is associated with induced menopause and aromatase inhibitors, both of which can significantly increase the risk for osteopenia and osteoporosis. Cardiac toxicity with compromised left ventricular function is a known side effect of anthracycline therapy and trastuzumab, and long-term survivors who received primary breast irradiation have a higher risk of cardiovascular disease.

To effectively manage these physical sequelae, a survivor may well need the expertise of providers from multiple disciplines. Women have described this as “struggling with the system” (Knobf, 2002), meaning going from one specialty provider to another with no one person coordinating the evaluations and recommendations. A multidisciplinary strategy has been recommended for managing some treatment-related risks (e.g., cardiovascular risk) (Lenihan & Esteva, 2008). Although this represents a strategy to coordinate care, it is an insufficient approach to address the multiplicity of symptoms that occur after treatment, as evidenced in breast cancer survivors.

Colorectal cancer survivors have reported lower physical and functional aspects of health-related quality of life. Fatigue, insomnia, oxaliplatin-induced peripheral neuropathy, decreased physical functioning, and bowel dysfunction are common post-treatment sequelae (Denlinger & Barsevick, 2009). Additionally, patients with rectal cancer treated with radiotherapy have an increased risk for pelvic fractures and a higher risk of persistent urogenital symptoms. As with breast cancer survivors, these people may require multidisciplinary expertise to manage their symptoms. Data support physical activity as a health promotion strategy to restore physical functioning and one that may reduce recurrence risk for colorectal cancer survivors (van Weert et al., 2008). Recommendations such as these need to be tailored to individuals, specifically for colorectal cancer survivors who report common side effects such as increased number of daily bowel movements and pain and stiffness associated with residual peripheral neuropathy.

Significant progress has been made in recognizing the need to assess survivors’ physical symptoms and side effects of therapy, as well as in the management of symptom distress and the negative impact on physical functioning. As clinicians, we need to think “outside of the box” (Feuerstein, 2009, p. 74) and create systems that will support coordinated personalized survivorship care. As researchers, we need to develop and test interventions to restore health and minimize the risks associated with the long-term and late physical effects of cancer therapy.

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REFERENCES


INTRODUCTION

Pain is a common symptom associated with cancer. Approximately 50% of patients experience pain at some time during the disease process, and up to 75% experience pain in the advanced stages of cancer (van den Beuken-van Everdingen et al., 2007). For those who survive cancer, pain or discomfort can linger throughout the survivorship trajectory and negatively affect quality of life. According to a National Health Interview Survey that examined symptom burden among cancer survivors, 34% of cancer survivors reported ongoing pain compared to 5%–30% for the general population (depending on pain location) (National Center for Health Statistics, 2010). Ongoing pain assessment among cancer survivors is pivotal in detecting recurrent disease, chronic pain syndromes, and other comorbidities that can occur after treatment. Early identification of pain or discomfort can ensure that patients and clinicians can employ effective pain control strategies.

PAIN SYNDROMES IN CANCER SURVIVORS

Pain in cancer survivors is most often attributed to cancer treatment, including surgery, chemotherapy, and radiation therapy. Less commonly, pain can persist from residual damage of the disease itself (Levy, Chwistek, & Mehta, 2008). The following sections include descriptions of common pain syndromes found in cancer survivors (see Table 5-1).

Postsurgical Pain

Postsurgical pain can persist beyond the normal healing time, thereby becoming chronic in nature. The etiology of postsurgical pain most often is related to nerve damage at the surgical site or the formation of scar tissue. However, surgical complications such as hematomas, infection, and wound
disturbance also can lead to ongoing pain. Risks for chronic postoperative pain include the presence of preoperative pain, repeated surgeries, psychological factors such as passive coping, surgeries with potential nerve damage, poor postsurgical pain control, radiation therapy or chemotherapy, and anxiety (Perkins & Kehlet, 2000; Sentürk et al., 2002). Common postsurgical pain syndromes are discussed in the following sections.

**Postmastectomy pain:** Postmastectomy pain syndrome (PMPS), described as burning, pins and needles, and electric shock–like sensations at the surgical site, is attributed to intercostobrachial nerve damage. One study of women undergoing mastectomy revealed that 46% experienced pain described as mild or moderate six or more months after cancer treatment, while another study revealed that 52% continued to report PMPS up to nine years after surgery (Macdonald, Bruce, Scott, Smith, & Chambers, 2005). Predictors of PMPS include younger age, heavier weight, existence

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Pain Syndromes</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anus</td>
<td>Lumbosacral plexopathy</td>
<td>Radiating pain from the pelvis down the associated lower extremity</td>
</tr>
<tr>
<td>Breast</td>
<td>Phantom breast pain</td>
<td>Location of pain can be the arm, neck, shoulder, chest wall, or breast.</td>
</tr>
<tr>
<td></td>
<td>Intercostobrachial neuralgia</td>
<td>Pain can be localized or can radiate down the affected arm.</td>
</tr>
<tr>
<td></td>
<td>Neuroma</td>
<td>Sensations include paresthesias, dysesthesias, hyperalgesia, and allodynia.</td>
</tr>
<tr>
<td></td>
<td>Lymphedema</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Postradiation brachial plexopathy</td>
<td></td>
</tr>
<tr>
<td>Head and neck</td>
<td>Neck and shoulder pain</td>
<td>Can involve neck, shoulder, and myofascial pain</td>
</tr>
<tr>
<td></td>
<td>Facial, mouth, dental, or mandibular pain</td>
<td>Pain includes loss of sensation and neuropathic pain syndromes.</td>
</tr>
<tr>
<td>Lung</td>
<td>Intercostal neuralgia</td>
<td>Sensations include paresthesias. Pain decreases over the course of a year.</td>
</tr>
<tr>
<td>Prostate</td>
<td>Chronic pelvic pain</td>
<td>Pain is usually only present during urination or is exacerbated during urination.</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>Stump pain</td>
<td>Stump pain can be related to a poorly fitting prosthesis. Phantom limb pain decreases over the course of a year; pain present at one year is likely to persist chronically.</td>
</tr>
</tbody>
</table>

*Note.* Based on information from Aksnes & Bruland, 2007; Badin et al., 2008; Eades et al., 2009; Hayes et al., 2008; McNeely et al., 2008; Sagen et al., 2009; Saxena & Kumar, 2007; Sun et al., 2008; Yang, 2009.
of an implantable prosthetic, extent of axillary dissection, and postoperative radiation therapy (Burton, Fanciullo, Beasley, & Fisch, 2007; Gulluoglu et al., 2006; Macdonald et al., 2005). In addition to PMPS, some women may experience phantom pain, described as painful sensations in the removed breast region (Gulluoglu et al., 2006).

**Post-thoracotomy pain:** Pain following thoracotomy is caused by injury to the intercostal nerve; it occurs in up to 80% of patients during the first few months after surgery. Post-thoracotomy pain is characterized by severe pain followed by gradual improvement, although 60% of patients continue to have pain at one year significant enough to warrant the use of analgesics. Pain can be long-lasting in 50% of patients, with half reporting moderate to severe intensity (Polomano & Farrar, 2006; Sentürk et al., 2002).

**Postsurgical head and neck cancer pain:** Pain related to head and neck cancer surgery is caused by injury to the accessory and superficial cervical plexus (Burton et al., 2007) followed by denervation and atrophy of the trapezius muscle, subsequent downward and lateral scapula displacement, and finally, shoulder dysfunction and debilitating pain (Eades, Chasen, & Bhargava, 2009; McNeely et al., 2008). Therefore, this pain syndrome can be both neuropathic and visceral, involving the neck and shoulder nerves and muscles. Approximately 25%–40% of patients reported pain at one year after surgery, and 15% reported pain at five years. Pain was reported as severe in 5% of patients (Eades et al., 2009).

**Postamputation pain:** Pain following limb amputation occurs in 7%–72% of patients (Burton, 2009), depending on the definition used for pain or discomfort. The pain can be localized to the stump area or can be exhibited as phantom pain derived from central nervous system mechanisms. It is estimated that all patients experience some type of phantom sensations, but some patients progress to develop chronic phantom pain. Predictors of postamputation pain include female gender, poorly fitting prosthesis, more proximal amputation, and postoperative chemotherapy (Burton et al., 2007).

**Lymphedema:** Lymphedema can result from any cancer or cancer surgery that affects the lymphatic system, but most commonly it is associated with breast and gynecologic cancers. The syndrome presents as arm or shoulder fullness or heaviness with associated discomfort or pain in the operated breast region; similar sensations occur with the leg and thigh in gynecologic patients. Studies estimate that between 57% (Chachaj et al., 2010) and 70% (Hayes, Janda, Cornish, Battistutta, & Newman, 2008) of women experiencing lymphedema reported pain. Women who underwent a mastectomy and subsequently developed lymphedema were found to have significantly larger pain areas compared to those without lymphedema (Jud et al., 2010). Gynecologic surgery accompanied by extensive pelvic node dissection is associated with lymphedema, but the specific incidence is unknown (Lockwood-Rayermann, 2007). This phenomenon warrants further investigation.
Chemotherapy-Induced Pain and Discomfort

Pain or discomfort can occur at the onset of, during, or after chemotherapy administration. The type, duration, and severity of pain are related to a number of factors, including the chemotherapeutic agent or agents, preexisting pain or discomfort, and specific host characteristics.

Chemotherapy-induced neuropathies associated with sensory or motor dysfunction are increasingly common painful toxicities resulting from chemotherapy. Peripheral neuropathies, described as burning, numbness, or tingling sensations in the hands or feet, may range from discomfort to severe pain (Polomano & Farrar, 2006). The incidence and severity depend on the chemotherapeutic agents administered. The most common neurotoxic chemotherapy agents include the taxanes, vinca alkaloids, cisplatin, oxaliplatin, bortezomib, and thalidomide. Preexisting nerve conditions, such as diabetes, and a combination of neurotoxic agents may increase the incidence and severity of the problem (Cavaletti, 2008; Cavaletti & Nobile-Orazio, 2007; Land et al., 2007).

Necrosis

Avascular necrosis and osteonecrosis of the jaw can result in chronic pain syndromes in cancer survivors. Avascular necrosis is associated with steroid use during cancer treatment and is characterized by progressive joint damage, limited range of motion, and arthritis. It usually involves weight-bearing joints and occurs about three years after treatment (Burton et al., 2007). Osteonecrosis of the jaw, on the other hand, can occur shortly after bisphosphonate administration for bone metastases or for the prevention or treatment of osteoporosis.

Radiation-Induced Pain

Radiation-induced pain is thought to begin as a vascular injury with axonal damage. The damage leads to entrapment of nerves and blood vessels, causing further ischemia. Studies have demonstrated that larger radiation doses and fields may cause more extensive damage and subsequent pain, but overall results have been inconclusive (Aksnes & Bruland, 2007; Burton et al., 2007). Some of the most common radiation-induced pain syndromes are discussed in the following sections.

Plexopathies: Radiation-induced brachial plexopathy is a pain syndrome that can occur following chest wall, axillary, or lower neck radiotherapy. It occurs in up to 9% of patients with breast cancer and is severely disabling in 1%–5% of these patients (Polomano & Farrar, 2006). The onset of symptoms can range from 3 months to 20 years. Radiation-induced brachial plexopathy begins with dysesthesias in the shoulder and affected arm and can progress to severe pain and a flaccid arm. High-dose techniques have
been associated with a higher incidence of brachial plexopathy (Polomano & Farrar, 2006).

Lumbosacral plexopathy is a potential complication following treatment with chemotherapy and radiation therapy for anal cancer (Badin, Iqbal, Sikder, & Chang, 2008). The onset is one to five years after treatment, characterized by anal pain and pruritus that increase with defecation and walking. The pain described in two case studies was extensive with radiation down the lower buttocks and posterior thighs (Badin et al., 2008).

**Myelopathy:** Radiation-induced myelopathy is a deleterious complication with spinal cord injury caused by ionizing radiation therapy. The syndrome usually presents with pain and paresthesias at or below the level of injury. Muscle weakness, usually in the legs, progresses to gait changes and hemiplegia. The syndrome is dose related at 4,000–6,000 cGy (centigray). Radiation-induced pain syndromes can occur years after radiation therapy; therefore, clinicians should be aware of these potential symptoms and assess for pain throughout the patient’s life span (Levy et al., 2008; Polomano & Farrar, 2006).

**Chronic Graft-Versus-Host Disease**

Patients with chronic graft-versus-host disease (cGVHD) resulting from hematopoietic stem cell transplantation can experience an array of pain syndromes. The pain is likely related to both high-dose chemotherapy and radiation therapy. One study revealed that patients with cGVHD were 4.2 times more likely to experience pain than those without cGVHD (Fraser et al., 2006). Further exploration of chronic pain in this population is needed.

**PAINFUL COMORBIDITIES**

Although many chronic pain syndromes in cancer survivors result from cancer treatment or the disease itself, comorbid conditions also play a role. In a study of older adult breast, prostate, and colorectal cancer survivors (N = 321), the occurrence of pain was attributed to age rather than cancer-related factors (Deimling, Bowman, & Wagner, 2007). Age-related factors accounted for 14% of the variance in pain, whereas cancer-related factors accounted for 2%. Another study revealed that older adult cancer survivors experienced pain at one month (38.5%, n = 52) and three months after treatment (53%, n = 47) (Beck, Towsley, Caserta, Lindau, & Dudley, 2009). Further study is warranted in this population.

**PAIN ASSESSMENT IN CANCER SURVIVORS**

Patient-reported outcomes, which are documented by the patient or patient proxy rather than by sole evaluation by the practitioner, are receiving
much attention as healthcare professionals seek to accurately assess and document patients’ pain. The National Institutes of Health, the American Cancer Society, and the Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (referred to as IMMPACT) are examples of several organizations with initiatives in support of patient-reported outcomes (Lipscomb, Gotay, & Snyder, 2007). Patient-reported outcomes are critical in gathering patients’ perceptions of pain and the effectiveness of pain interventions.

The pain assessment should be comprehensive and include the locations of the pain, the severity using a 0–10 scale, the amount of discomfort, and the pain quality. Important to note is that many patients may be reluctant to report an injury as “painful” but rather may describe the affected area as “discomfort.” Clinicians should gather information from the patient about any discomfort. Quality descriptors can be used to diagnose the pain syndrome according to one of three pathophysiologic categories: somatic, visceral, or neuropathic. For example, somatic pain often is described as well localized, dull, or aching, whereas visceral pain is described as cramping and may be poorly localized. Neuropathic pain syndromes often are described as numb or radiating (Levy et al., 2008).

Temporal factors also should be examined, including timing of the worst pain, what makes the pain better, and the interference of pain with daily activities and function. Additionally, physical behaviors may be related to chronic pain, such as an altered gait, splinting or guarding to protect a painful area, or psychological behaviors such as medication misuse (Burton et al., 2007). Finally, fatigue and sleep disturbance should be assessed in conjunction with pain (see Figure 5-1), as these symptoms are commonly clustered (Honea, Brant, & Beck, 2006).

**PAIN MANAGEMENT IN CANCER SURVIVORS**

Control of pain in cancer survivors begins with the optimal management of pain at the onset and throughout the cancer trajectory. Clinicians should be reminded that patients who experience poorly controlled pain early in the course of their disease may be more likely to develop chronic pain; therefore, optimal acute pain control is critical (Burton et al., 2007). The healthcare team should employ an interdisciplinary approach, useful in the chronic non-cancer arena, to manage pain in cancer survivors (see Figure 5-2). Clinicians also should address related physical, psychosocial, and spiritual concerns (Ferrell, Paice, & Koczywas, 2008).

**Exercise and Physical Therapy**

Exercise and physical therapy are integral components of pain management. Postsurgical physical therapy may be helpful to relieve or prevent frozen-
shoulder pain syndrome as experienced with PMPS (Eades et al., 2009). In head and neck cancers, trapezius muscle atrophy is thought to contribute to chronic pain. Strengthening the muscle can potentially improve shoulder alignment and alleviate pain. In a study examining the effectiveness of progressive resistance exercise training (n = 27) compared to a standardized therapeutic exercise protocol (n = 25) in head and neck cancer survivors,

<table>
<thead>
<tr>
<th>Figure 5-1. 10-Step Comprehensive Pain Assessment in Cancer Survivors</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Type and stage of cancer</strong></td>
</tr>
<tr>
<td>a. Disease site (or sites)</td>
</tr>
<tr>
<td>b. Stage at diagnosis</td>
</tr>
<tr>
<td><strong>2. Type of treatment; treatment timeline (dates of interventions)</strong></td>
</tr>
<tr>
<td>a. Surgery—type and extent</td>
</tr>
<tr>
<td>b. Chemotherapy—specific agents employed, use of steroids</td>
</tr>
<tr>
<td>c. Radiation therapy—fields, dosages</td>
</tr>
<tr>
<td><strong>3. Comorbid conditions that may contribute to pain, for example:</strong></td>
</tr>
<tr>
<td>a. Diabetes</td>
</tr>
<tr>
<td>b. Arthritis</td>
</tr>
<tr>
<td><strong>4. Specific pain assessment</strong></td>
</tr>
<tr>
<td>a. Location of the pain—document for each pain site</td>
</tr>
<tr>
<td>b. Intensity of the pain on a 0–10 scale, best and worst</td>
</tr>
<tr>
<td>c. Quality descriptors</td>
</tr>
<tr>
<td>d. Temporal factors</td>
</tr>
<tr>
<td>i. Constant or intermittent</td>
</tr>
<tr>
<td>ii. What increases the pain?</td>
</tr>
<tr>
<td>iii. What alleviates the pain?</td>
</tr>
<tr>
<td>e. Pain behaviors (e.g., gait, splinting)</td>
</tr>
<tr>
<td><strong>5. Evaluation of diagnostics</strong></td>
</tr>
<tr>
<td>a. Computed tomography or magnetic resonance imaging scans</td>
</tr>
<tr>
<td>b. Electromyogram</td>
</tr>
<tr>
<td>c. Laboratory analysis (e.g., lactate dehydrogenase)</td>
</tr>
<tr>
<td><strong>6. Pain management treatment strategies tried</strong></td>
</tr>
<tr>
<td>a. Exercise, other therapies</td>
</tr>
<tr>
<td>b. Invasive procedures</td>
</tr>
<tr>
<td>c. Pharmacologic interventions</td>
</tr>
<tr>
<td>d. Complementary therapies</td>
</tr>
<tr>
<td><strong>7. Functional assessment</strong></td>
</tr>
<tr>
<td>a. Pain interference</td>
</tr>
<tr>
<td>b. Ability to work and perform activities of daily living</td>
</tr>
<tr>
<td><strong>8. Psychosocial history</strong></td>
</tr>
<tr>
<td>a. Depression</td>
</tr>
<tr>
<td>b. Anxiety</td>
</tr>
<tr>
<td>c. Coping abilities</td>
</tr>
<tr>
<td><strong>9. Spiritual history—impact of pain on belief system</strong></td>
</tr>
<tr>
<td><strong>10. History of substance abuse</strong></td>
</tr>
<tr>
<td>a. Family</td>
</tr>
<tr>
<td>b. Personal</td>
</tr>
</tbody>
</table>

*Note. Based on information from Brant, 2010; Brant et al., 2010; Sun et al., 2008; Zaza & Baine, 2002.*
researchers found progressive resistance exercise training to be superior in relieving shoulder pain and disability (McNeely et al., 2008).

**Nerve Blocks and Surgical Interventions**

Nerve blocks and surgical interventions can be considered in select patients. Nerves transmit pain signals to the brain, and blocking the nerve can eliminate this pain transmission process. For example, intercostal nerve blockade can relieve post-thoracotomy pain. Joint replacement can be used to improve the pain caused by avascular necrosis of the hip or knee. These examples reinforce the need to involve anesthesia and surgical services in the interdisciplinary effort to manage pain.

**Pharmacologic Strategies**

Pharmacologic interventions often are used to control both acute and chronic pain in cancer survivors. Multiple barriers exist in cancer pain management, including lack of knowledge about pain control, fears of addiction, and opioid side effects (Palos, 2008; Sun, Borneman, Piper, Koczywas, & Ferrell, 2008). Education of providers and cancer survivors is necessary to
optimize the positive effects of pharmacologic strategies and minimize the effect of myths.

Pharmacologic strategies are targeted at controlling or eliminating various pain syndromes. Nonsteroidal anti-inflammatory drugs (NSAIDs) are used for somatic pain that is commonly experienced in the muscles, bones, and joints. Antidepressants and anticonvulsants are the agents of choice for neuropathic pain syndromes. Additionally, these drugs can be used in combination with NSAIDs or opioids to potentiate their effect. Opioids are used singularly or in combination with other drugs to control pain that is not alleviated with other modalities. Long-acting opioids should be considered for continuous pain, whereas immediate-release opioids are used for intermittent and breakthrough pain (American Pain Society, 2008; Burton et al., 2007; Levy et al., 2008). The goals of treatment should focus on reducing the pain, improving function, and minimizing adverse events. Table 5-2 describes common pharmacologic options for care.

<p>| Table 5-2. Common Pharmacologic Pain Management Strategies for Cancer Survivors |</p>
<table>
<thead>
<tr>
<th>Drug Class</th>
<th>Specific Agents</th>
<th>Pain Syndromes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticonvulsants</td>
<td>Gabapentin</td>
<td>Neuropathic pain</td>
</tr>
<tr>
<td></td>
<td>Pregabalin</td>
<td></td>
</tr>
<tr>
<td>Nonsteroidal anti-inflammatory drugs</td>
<td>Ibuprofen</td>
<td>Somatic pain</td>
</tr>
<tr>
<td></td>
<td>Naproxen</td>
<td>Inflammatory pain</td>
</tr>
<tr>
<td></td>
<td>Fenoprofen calcium</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ketoprofen</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Oxaprozin</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Indomethacin</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sulindac</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Etodolac</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Celecoxib</td>
<td></td>
</tr>
<tr>
<td>Opioids</td>
<td>Hydrocodone</td>
<td>Moderate to severe pain syndromes</td>
</tr>
<tr>
<td></td>
<td>Oxycodone</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Morphine</td>
<td>Long-acting opioids preferred for constant pain</td>
</tr>
<tr>
<td></td>
<td>Fentanyl</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hydromorphone</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Methadone</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Levorphanol</td>
<td></td>
</tr>
<tr>
<td>Serotonin norepinephrine reuptake inhibitors</td>
<td>Duloxetine</td>
<td>Neuropathic pain</td>
</tr>
<tr>
<td></td>
<td>Venlafaxine</td>
<td></td>
</tr>
<tr>
<td>Tricyclic antidepressants</td>
<td>Amitriptyline</td>
<td>Neuropathic pain</td>
</tr>
<tr>
<td></td>
<td>Nortriptyline</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Desipramine</td>
<td></td>
</tr>
</tbody>
</table>

Note. Based on information from American Pain Society, 2008; Burton et al., 2007; Levy et al., 2008; Morrison & Morrison, 2006.
CASE STUDY

T.T. is a five-year cancer survivor who was diagnosed at age 16 with osteogenic sarcoma. His initial treatment included a combination of chemotherapy and radiation therapy. He had a complete response to treatment and suffered no long-term sequelae. Most recently, he suffered a spontaneous pneumothorax. A chest computed tomography scan revealed a solitary lung lesion. He underwent an open thoracotomy and removal of the lesion. Four months after the surgery, he continued to experience numbness and electric shock–like pain at the thoracotomy incision site. He rated the intensity as 6 on a 0–10 scale. Pain increased with movement and activity, especially late in the day. He remained on immediate-release oxycodone, the regimen used to control his postoperative pain. Gabapentin was added for the neuropathic component of the pain, which alleviated some of the electric-shock sensation, but pain intensity remained the same. Duloxetine was added to the regimen to potentiate the opioids, and the oxycodone was changed from immediate to controlled release to provide extended coverage for the constant pain. The combination of agents reduced his pain intensity to 2 on a 0–10 scale, and T.T. was able to continue his college studies and maintain his job at a group home. During the treatment plan, he expressed fears of cancer recurrence and of “becoming addicted” to the oxycodone; he attends a weekly cancer support group to discuss his concerns. He reduced the oxycodone in an attempt to discontinue the pain medication but was unsuccessful, as the pain limited his functional status and ability to focus in school. T.T. continues to see the medical oncologist on a monthly basis to evaluate his post-thoracotomy pain syndrome. At one year after surgery, he was able to reduce the oxycodone and gabapentin dosages, with a pain rating of 2 out of 10.

SUMMARY

Pain is a deleterious long-term consequence of cancer. It is most frequently attributed to cancer treatment but can be a manifestation of the disease itself. Comorbidities also can contribute to pain in cancer survivors, especially in the older adult population. The post-treatment cancer survivorship plan includes ongoing assessment for pain syndromes that can occur months to years after cancer treatment. Early identification and prompt management of pain can alleviate suffering and improve quality of life.

REFERENCES


INTRODUCTION

Estimates of the frequency of chemotherapy-related cognitive changes (CRCCs) range as high as 75% during therapy (Ahles & Saykin, 2002) and 17%–34% two or more years after completion of therapy (Ahles & Saykin, 2007). CRCCs can have a dramatic effect on survivors’ quality of life (Ahles & Saykin, 2001; Tannock, Ahles, Ganz, & Van Dam, 2004). The impact has been recognized by the President’s Cancer Panel (2004), the National Coalition for Cancer Survivorship, and the Oncology Nursing Society as a national research priority (Berger, 2009). Participants on the President’s Cancer Panel noted that insufficient care may result from healthcare professionals’ failure to acknowledge, or their minimization of, the problem and may be due in part to a lack of information about this treatment-related effect.

To date, much of the research for CRCCs has been conducted in patients with breast cancer because of the prolonged survival time and patients’ assertiveness in communicating concern about cognitive changes (Castellon et al., 2004; O’Shaughnessy, 2003; Schagen, Muller, Booger, & Van Dam, 2002). Up to 75% of breast cancer survivors who received chemotherapy reported some degree of cognitive dysfunction (O’Shaughnessy, 2003). Evidence supports the occurrence of CRCCs or memory problems in other tumor types, such as lymphoma (Ahles et al., 2002), testicular cancer (Shapiro, 2005), and ovarian cancer (Malmstrom & Karlsson, 2003; Myers, Sousa, & Donovan, 2010). Some controversy still exists over the role that chemotherapy plays in cognitive changes experienced by survivors compared to the general effects of the cancer, including cancer-related distress or worry about recurrence (Jim et al., 2009).

Mild cognitive impairment following chemotherapy often is referred to as “chemobrain” by the lay public (Matsuda et al., 2005). Cull et al. (1996) de-
scribed CRCCs as subjective and objective changes in cognitive function related to chemotherapy. The impact of CRCCs typically is subtle and is believed to diminish over time. The specific domains of cognitive function that may be affected include executive function, information processing speed, language, motor function, spatial skills, learning, and memory (Jansen, Miaskowski, Dodd, Dowling, & Kramer, 2005). Patients describe the effects on cognitive function as forgetfulness, absentmindedness, and an inability to focus when performing daily tasks (Hess & Insel, 2007). Common complaints also include difficulty with word finding, geographic orientation when driving, and the ability to multitask (Downie, Mar Fan, Houédé-Tchen, Yi, & Tannock, 2006). Patients have expressed concern about CRCCs and their subsequent ability to resume previous professional, scholastic, and social activities (Wefel, Lenzi, Theriault, Davis, & Meyers, 2004).

FACTORs ASSOCIATED WITH CHANGES IN COGNITIVE FUNCTION

A variety of potentially associated factors have been identified that may contribute to changes in cognitive function (see Figure 6-1). Advancing age has been associated with memory problems unrelated to cancer therapy (Barnes, Yaffe, Satariano, & Tager, 2003) and thus may exacerbate the risk of CRCCs. Research indicates that younger age may be associated with an increased perception of changes in cognitive function and, therefore, a greater impact on quality of life (Cimprich, So, Ronis, & Trask, 2005). Mental changes associated

<table>
<thead>
<tr>
<th>Figure 6-1. Factors That May Be Associated With Chemotherapy-Related Cognitive Changes</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Age</td>
</tr>
<tr>
<td>- Education level</td>
</tr>
<tr>
<td>- Social support</td>
</tr>
<tr>
<td>- Anxiety</td>
</tr>
<tr>
<td>- Depression</td>
</tr>
<tr>
<td>- Fatigue</td>
</tr>
<tr>
<td>- Disease site</td>
</tr>
<tr>
<td>- Disease stage</td>
</tr>
<tr>
<td>- Comorbidities</td>
</tr>
<tr>
<td>- Treatment regimen/timing/duration</td>
</tr>
<tr>
<td>- Concomitant therapies</td>
</tr>
<tr>
<td>- Hormonal levels</td>
</tr>
<tr>
<td>- Cytokine levels</td>
</tr>
<tr>
<td>- Damage to neuroprogenitor cells</td>
</tr>
<tr>
<td>- Apolipoprotein E ε4 allele</td>
</tr>
</tbody>
</table>

*Note.* Based on information from Hess & Insel, 2007; Jansen et al., 2005.
with age may be due in part to decreased levels of circulating endogenous sex hormones (estrogen and testosterone) (Shumaker et al., 2003; Yaffe et al., 2007). Low levels of bioavailable estradiol have been shown to be associated with decline in global cognitive function and verbal memory (Yaffe et al., 2007). Abrupt onset of treatment-induced menopause may enhance the perception of changes in cognitive function (Klemp, Stanton, Holmes, Khan, & Fabian, 2009). Early evidence supports an association between exposure to hormonal therapy for breast cancer and more significant declines in cognitive function for women who also received chemotherapy (Bender et al., 2006; Castellon et al., 2004).

Higher levels of education and intelligence are hypothesized to be associated with high baseline function and cognitive reserve, which may influence the effects of chemotherapy on cognitive performance (Jansen, Miaskowski, Dodd, & Dowling, 2007). Lack of social support, anxiety, depression, and fatigue may contribute to decreased mental acuity. The timing, intensity, and composition of the chemotherapy treatment regimen may contribute to the severity of changes in cognitive function as well (Jansen et al., 2007).

**HYPOTHESES FOR CAUSALITY**

The exact etiology of CRCCs is not known, but a number of etiologies have been proposed (see Table 6-1). Genetic predisposition to CRCCs is under investigation. Prospective trials with genetic measurements (Ahles & Saykin, 2007) may help answer the question of whether some patients are genetically predisposed to long-term damage, and results could have a significant impact on individualized treatment options for cancer.

<table>
<thead>
<tr>
<th>Hypothesis</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct injury to cerebral gray and white matter</td>
<td>Wefel et al., 2004</td>
</tr>
<tr>
<td>Microvascular injury</td>
<td>Ahles &amp; Saykin, 2007; Chen et al., 2007</td>
</tr>
<tr>
<td>DNA damage and oxidative stress</td>
<td>Ahles &amp; Saykin, 2007; Chen et al., 2007</td>
</tr>
<tr>
<td>Cytokine-induced inflammatory response</td>
<td>Ahles &amp; Saykin, 2007</td>
</tr>
<tr>
<td>Chemotherapy-induced anemia</td>
<td>Mancuso et al., 2006; Massa et al., 2006</td>
</tr>
<tr>
<td>Chemotherapy-induced menopause</td>
<td>Jansen et al., 2005</td>
</tr>
<tr>
<td>Neural progenitor cell injury</td>
<td>Dietrich et al., 2006, 2008</td>
</tr>
</tbody>
</table>
ISSUES WITH ASSESSMENT

Consensus has not been achieved regarding the selection of the most effective neurocognitive tests for objective identification of CRCCs. Existing tests were not designed to capture the subtle changes in cognitive function typically manifested by patients who have received chemotherapy.

Neurocognitive Testing

The disparity between objective testing for CRCCs and patients’ self-report of cognitive changes has been attributed to a lack of sensitivity to subtle deficits (Jansen et al., 2007). Patients with high baseline cognitive function may continue to score within normal limits on objective tests but report cognitive deficits that affect their ability to perform at their previous level of function (Wefel et al., 2004). Survivors describe an inability to multitask, which is difficult to replicate in a testing situation (Cimprich et al., 2005).

Substantive work remains to be done to identify the neurocognitive tests most sensitive to CRCCs and to develop new tests more closely related to real-life situations where cognitive changes are noted (Ahles & Saykin, 2007). Patients’ self-report of perceptions of cognitive change may be more sensitive to subtle deficits in function than standard neurocognitive tests (Schagen et al., 2002). Researchers are beginning to advocate the position that patient-reported cognitive function is an important end point in its own right because of the profound impact of perceived cognitive function on quality of life and evidence of an association between patient-reported cognitive decline and increased cognitive effort demonstrated by neuroimaging (Ferguson, McDonald, Saykin, & Ahles, 2007; Lai et al., 2009; Wagner, Sweet, Butt, Lai, & Cella, 2009).

Neuroimaging

The use of neuroimaging is gaining favor as an important component of research designed to measure baseline cognitive function and prospectively evaluate changes in cognitive function during and after chemotherapy. Testing with magnetic resonance imaging first revealed white-matter changes in conjunction with high-dose chemotherapy associated with bone marrow transplantation (Brown et al., 1995). Positron-emission tomography has been used to evaluate regional cerebral metabolism following the completion of chemotherapy. The relationship of cerebral blood flow and metabolism with cognitive function after chemotherapy has been assessed by positron-emission tomography and neurocognitive testing for women who have received chemotherapy for breast cancer within 5–10 years (Silverman et al., 2007).

Importance of Validation

A common complaint of survivors is a lack of acknowledgment by the medical community of the experience of CRCCs (Boykoff, Moieni, & Subramanian, 2007).
2009). These authors conducted focus groups and in-depth interviews with 74 women who had completed adjuvant radiation and/or chemotherapy at least one year prior. Cognitive impairment was reported by 70% of the sample. Participants noted that they wished they had received some warning about the potential for CRCCs.

The need for acknowledgment and education is supported by other qualitative work. Thielen (2009) conducted a phenomenologic study of the experience of neurocognitive changes in women undergoing chemotherapy for breast cancer. Unstructured interviews were performed with 13 participants who were receiving therapy or were within three months of completing therapy. Participants reported changes in memory, attention, or concentration since undergoing chemotherapy. Participants reported feeling as though they did not know what was happening to them, which added to the distress associated with the cognitive changes they were experiencing. This finding lends support to the need for healthcare professionals to provide appropriate pretreatment education and true informed consent and to validate patients’ experiences as they are identified or reported.

MULTIDISCIPLINARY CARE

Education about the potential for cognitive changes as a result of chemotherapy enhances the informed consent process prior to the initiation of therapy. Education lays a foundation for patients and family members to share pertinent information with the healthcare team when and if the patient begins to experience changes in cognitive function.

Referrals to neuropsychologists are appropriate for the administration and interpretation of neurocognitive tests to assess and document cognitive deficits, as well as the facilitation of psychosocial support to assist patients in coping with lifestyle changes resulting from changes in cognitive function. Neuropsychologists can assist with cognitive retraining strategies designed to maximize patients’ potential to return to baseline cognitive function or adapt to long-term cognitive deficits. Neuropsychologists can recommend or prescribe antidepressants or neurostimulants when appropriate.

Together, the oncology nurse, oncologist, and neuropsychologist (or other qualified healthcare professional) can customize an individualized plan of care for patients experiencing cognitive changes in conjunction with or following the completion of chemotherapy. Acknowledgment of patients’ experiences of CRCCs by the healthcare team is a necessary component of providing quality cancer care.

CASE STUDY

A 49-year-old premenopausal female, J.R., was diagnosed with a 6 cm left breast cancer (estrogen/progesterone and HER2/neu negative) and partici-
pated in a clinical trial including neoadjuvant capecitabine and docetaxel followed by bilateral mastectomies. J.R. then received four cycles of adjuvant doxorubicin and cyclophosphamide. She experienced chemotherapy-induced menopause, having only a single period immediately after initiating chemotherapy. J.R. complained of changes in her memory during her six-month follow-up after chemotherapy and was reassured these symptoms would resolve over time.

Two years since completing her chemotherapy, J.R. continued to complain to her oncologist about persisting cognitive dysfunction. J.R. reported she had difficulty remembering how to complete common tasks such as the sequence of a recipe for baking bread that she had regularly completed several times per week. She could not remember which ingredients were required, the amount, and what sequence was necessary to complete a task she had done hundreds of times before. Even with her recipe card (which she had never required before), she found completing the task to be challenging. J.R. also reported frequently getting lost while driving. She described calling her husband on her cell phone to assist in navigating to her home, where she had lived for more than 20 years.

Initially, J.R. was referred to a neurologist for evaluation. Neurocognitive testing and magnetic resonance imaging of the brain were within normal limits. She then was referred to a breast cancer survivorship clinic for additional clinical and psychological evaluation by a breast oncology nurse practitioner and health psychologist. A complete physical and psychological evaluation was performed. Social history was pertinent for report of poor sleep hygiene, including difficulty getting to sleep and frequent arousals. Current sleep time was estimated at five hours of sleep per night. J.R. did not complain of hot flashes or night sweats but did report a constant feeling of warmth, a significant change from prediagnosis. J.R. acknowledged minor symptoms of depression; however, the symptoms did not meet the clinical threshold for diagnosis. The patient had gained approximately 15 pounds over the past two years and had not been regularly exercising because of fatigue.

The nurse practitioner and health psychologist acknowledged J.R.’s frustration with her symptoms and collaborated to recommend a plan of care. Lack of sleep and related fatigue were addressed with a program of improved sleep hygiene, including setting a regular bedtime to encourage approximately seven to eight hours of sleep per night. Regular follow-up with the health psychologist was recommended for training in the use of cognitive-behavioral therapy for insomnia. The nurse practitioner told J.R. that a prescription for short- or long-acting sleep medications could be provided to address continuing sleep issues as needed.

The health psychologist outlined the following behavioral therapy measures to address the changes in cognitive function: (a) incorporate behavioral skills such as using an organizer, lists, and sticky notes to keep track of daily activities and important dates, (b) use a GPS device in the car to assist with navigation, (c) engage in brain-strengthening activities such as working on crossword
puzzles, taking up a new hobby, or practicing an existing activity (i.e., playing a musical instrument), and (d) increase physical activity starting with walking and mild stretching or yoga.

The nurse practitioner and health psychologist instructed J.R. that alternative strategies could be explored if her symptoms persisted. These strategies included the use of neurostimulants, occupational therapy and/or vocational rehabilitation skill development to assist with activities of daily living, and referral to a neuropsychologist for cognitive rehabilitation, cognitive training to improve cognitive skills, and measures to cope with remaining cognitive deficits.

J.R. self-reported cognitive improvement after several months of strict adherence to improving her overall quality and quantity of sleep. She also initiated a light to moderate walking program and began to work out with a cancer-certified trainer two times per week. J.R. learned how to use her smartphone to keep track of her daily activities and important dates and to make daily to-do lists that she could regularly update. She wanted a consultation to learn more about cognitive training and was referred to a neuropsychologist to determine whether additional skills might be useful as she planned to return to her job as a teacher.

**SUMMARY**

Significant work remains to be done to determine who is at risk for CRCCs, pinpoint the causal mechanism or mechanisms, and develop effective strategies for prevention and treatment of CRCCs once they occur. Collaboration by oncology nurses, oncologists, and neuropsychologists (or other qualified healthcare professionals) is important to the development of individualized plans of care based on patients’ individual risk factors and the onset, severity, and duration of CRCCs.

**REFERENCES**


CHAPTER 6. CHEMOTHERAPY-RELATED COGNITIVE CHANGES


INTRODUCTION

Skin and mucosal toxicities are common acute side effects that patients frequently experience while undergoing cancer treatment. The incidence of these acute toxicities related to chemotherapy treatments, radiation therapy, and oncologic surgery has been studied and reviewed extensively in the literature. However, the long-term toxicities of treatment-related skin and mucosal changes that survivors may encounter have received limited attention. A need exists for expert guidance in long-term screening and follow-up along with continued advances and research into minimizing skin and mucosal late consequences from cancer treatment.

Patients with cancers of the head and neck, female genital tract, breast, prostate, or gastrointestinal tract, as well as patients who have undergone bone marrow transplantation, may experience long-term skin and mucosal toxicities related to their treatment. Although research into long-term skin and mucosal toxicities conducted among cancer survivors is limited, this chapter will provide an overview of the potential changes in cancer survivors along with some recommendations for follow-up care.

DERMATOLOGIC CHANGES RELATED TO CANCER TREATMENT

Changes within the skin and mucosa can present throughout the entire trajectory of the cancer experience. These changes can occur prior to diagnosis or months to years after cancer treatment. Agha, Kinahan, Bennett, and Lacouture (2007) categorized these changes in three phases of the cancer experience: (a) malignancy-associated dermatoses, which tend to occur prior to or during the initial diagnosis, (b) therapy-related toxicities, which occur during treatment, and (c) late events, which usually are chronic or persistent
sequelae of therapeutic regimens or are indicative of recurrence (see Figure 7-1).

The clinical presentations of skin changes or toxicities are dependent on where the patient is in the cancer trajectory and the specific treatment received. Patients can have long-term skin changes related to all three cancer treatment modalities: surgery, chemotherapy and targeted therapy, and radiation therapy. These long-term skin changes can include scars, fibrosis, dermatitis, graft-versus-host disease (GVHD), and secondary malignancies affecting the skin (see Table 7-1).

<table>
<thead>
<tr>
<th>Figure 7-1. Cutaneous Issues in the Cancer Trajectory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer diagnosis</td>
</tr>
<tr>
<td>Malignancy associated</td>
</tr>
<tr>
<td>Inherited</td>
</tr>
<tr>
<td>Environmental carcinogens</td>
</tr>
<tr>
<td>Paraneoplastic</td>
</tr>
</tbody>
</table>

GVHD—graft-versus-host disease


**Skin Changes With Radiation Therapy**

The skin is the largest organ system. Although radiation therapy can affect any area of the skin, the anatomic location and underlying structures will influence the severity and impact of late effects on quality of life and function. Radiation-induced late skin effects are associated with a number of factors (Hymes, Turner, Champlin, & Couriel, 2006; McQuestion, 2010; Peeters et al., 2005; Phan et al., 2009), including

- Anatomic location and treated tissue volume
- Daily fractions of 2 Gy (gray) or greater
- Administration of concurrent chemotherapy or androgen deprivation therapy in prostate cancer
- Presence of comorbid illness
- Age and general medical condition
- Genetic factors
- Radiation fibrosis and atrophy
- Vascular and neural changes.

The following sections will detail late effects according to anatomic field or skin affliction.
Chronic Radiation Dermatitis

Any area of skin can develop chronic radiation dermatitis months to years after treatment on the exposed skin or mucosa. These changes can include hyper- or hypopigmentation, scaling, xerosis, and thickened or hyperkeratotic skin changes. Irradiated areas are devoid of hair follicles and sebaceous glands. Telangiectasias also can occur in the radiated area (Agha et al., 2007); this most commonly occurs in patients treated for head and neck or breast cancers.

Breast Cancer

Patients with breast cancer receive partial or total breast irradiation following breast-conserving therapy such as a surgical lumpectomy. Radiation

<table>
<thead>
<tr>
<th>Disease and Treatment</th>
<th>Secondary Cancer</th>
<th>Screening/Surveillance</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hematopoietic cell transplant (HCT)</td>
<td>• Oral/buccal mucosa malignancies</td>
<td>Regular examination of oral cavity and skin at least annually</td>
<td>If HCT received before age 40, increased risk of basal cell carcinoma; use of immunosuppressive drugs for chronic graft-versus-host disease markedly increases risk (Schwartz et al., 2009) Increased melanoma and oral cancers Increased risk of buccal cavity cancers associated with oral GVHD (Bhatia et al., 2001; Filipovich et al., 2005)</td>
</tr>
<tr>
<td>Head and neck cancer</td>
<td>• New oral/buccal cancer</td>
<td>As above</td>
<td>–</td>
</tr>
<tr>
<td>Hodgkin lymphoma Mantle radiation therapy prior to age 30</td>
<td>• Breast cancer</td>
<td>See American Cancer Society’s guide for high-risk screening (Smith et al., 2010), including use of breast magnetic resonance imaging screening</td>
<td>–</td>
</tr>
</tbody>
</table>
is indicated for the affected axilla or chest wall in patients at increased risk for local recurrence. Cutaneous late effects due to radiation therapy can affect overall cosmesis and are influenced by the radiation field, dose, and surgical intervention.

Fibrosis, retraction, breast and arm edema, and telangiectasia have been documented in most radiation therapy clinical trials that examined acute and late toxicities although typically were reported as qualitative data (Chen et al., 2006). Radiation changes may take months or years to develop and vary in severity (McQuestion, 2010).

**Head and Neck Radiation**

Radiation to the whole brain or head and neck region can result in numerous late effects. Xerosis or dry skin, chronic dry eyes in the case of brain irradiation, and xerostomia in head and neck cancers are the most frequently experienced changes and often further compromise the complex tasks of swallowing, speech, nutrition, and dental health. Additionally, chronic fibrosis can result in trismus, scar formation, dental decay, dysphagia, and chronic lymphedema with functional and psychosocial consequences (Trotti, 2000). Most late effects in the head and neck develop within the first three years of treatment; a few appear, or progress, after three years. The most common long-term side effects of head and neck radiation are xerostomia, dysphagia, and laryngeal toxicity (Trotti, 2000).

Several researchers have investigated the impact of these late effects on the quality of life of patients with head and neck cancers and noted that xerostomia; trismus; swallowing difficulties; dry, sticky saliva; and dental problems can all negatively affect quality of life for years following treatment (Hammerlid, Silander, Hörnestam, & Sullivan, 2001; Langendijk et al., 2008). As such, follow-up visits for survivors of head and neck cancer should focus on detailed oral assessment for changes in the oral mucosa related to decreased saliva production, dental health, swallowing and speech deficits, and detection of new or recurrent disease. In addition, assessment should include (a) risk reduction strategies, (b) distress from chronic side effects, (c) reinforcement of coping skills, and (d) healthy behaviors related to smoking cessation, alcohol use, and sun safety.

**Pelvic Skin and Mucosal Changes**

Curative therapies for diseases of the pelvis (female reproductive tract, gastrointestinal tract, and prostate) often involve surgical resection and radiation therapy. The sequelae of treatment are lifelong and can have both physical and psychological consequences. Women who have been treated for cervical cancer with surgery and radiation frequently report vaginal changes that result in sexual dysfunction. These may include dyspareunia, vaginal shortening, mucosal dryness, and vaginal stenosis (Jensen et al., 2003).
Frumovitz et al. (2005) studied 144 cervical cancer survivors who received surgery or radiation. Findings showed that patients who received radiation and surgery experienced significantly more sexual dysfunction than patients in the radical hysterectomy-alone group. Maduro, Pras, Willemse, and DeVries (2003) reviewed acute and long-term toxicities following treatment with radiation therapy alone or in combination with chemotherapy for locally advanced cervical cancer. The most serious toxicities noted were rectovaginal and vesicovaginal fistulas, which occurred in 1%–2% of the patients treated.

The timing of follow-up care is important in these patients. Following radiotherapy, the chronic fibrotic changes in pelvic tissue create persistent or even worsening vaginal atrophy at least up to two years after treatment. Additionally, it is not uncommon to find continued adverse sexual functioning in these women five years or more beyond treatment (Frumovitz et al., 2005; Jensen et al., 2003).

Bowel and bladder function can be adversely affected as a result of chronic radiation changes in patients who have undergone pelvic irradiation. The prevalence of chronic radiation enteritis (CRE) in cervical and endometrial cancer survivors was noted in a study by Abayomi, Kirwan, and Hackett (2009). They observed that 50% of women reported symptoms of decreased coping and fatigue-related CRE because of a lack of warning signs and struggle with bowel frequency. Risk factors for the development of CRE include low body mass index, prior abdominal surgeries, radiation dose, fractionation, technique, and use of concurrent chemotherapy during radiation treatment (Theis, Sripadam, Ramani, & Lal, 2009).

In a review of 10 years of data of patients who underwent pelvic radiation (N ≥ 14,000), 48 patients were referred to a university surgical service for evaluation of refractory complications that had failed conservative management (Turina, Mulhall, Mahid, Yashar, & Galanduik, 2008). The majority of patients were diagnosed with colorectal, prostate, or cervical cancers. Enteritis, strictures, fistulae, nonhealing wounds, and de novo cancers in the treatment field were the reasons for referral. Low anastomotic strictures were treated with dilatation under sedation, and six patients with severe enteritis and distal strictures required permanent diversion. All fistulae were surgically treated.

**Ostomy Considerations**

For patients who undergo intestinal or bladder diversion, lifelong care of ostomy stomas, meticulous skin care for surrounding tissue, and prevention and early detection of complications are crucial. Care and concerns related to ostomies affect all domains of health-related quality of life (McMullen et al., 2008). In a qualitative analysis of open-ended survey questions from 178 colorectal cancer survivors with ostomies, participants reported the following as very challenging: skin care related to stomas; obtaining the right appliances; dealing with supplies and management of long-term complications such as hernias, infections, diarrhea, and vomiting; and repeated ostomy surgeries
Having access to skilled ostomy nurse specialists, support groups, and the informal support of spouses or partners were important components of psychological coping. The researchers found that this group of cancer survivors had experienced side effects that affected day-to-day living, including physical aspects of stoma management, intimate relationships, and the ability to work, travel, and live life.

Chronic Radiation Proctitis

Chronic radiation proctitis can develop up to two years after brachytherapy in prostate cancer survivors (Phan et al., 2009). Symptoms include rectal urgency, incontinence, pain, mucous discharge, and rectal bleeding. Vasculopathy related to radiation-induced telangiectatic vessels accounts for the cause of rectal bleeding. Risk factors for the development of chronic radiation proctitis include the pre-radiation use of androgen deprivation therapy, radiation dose to the prostate, pretreatment symptoms, and comorbid diabetes (Peeters et al., 2005; Phan et al., 2009).

Late complications to the bladder mucosa from pelvic irradiation are dependent on the volume and area of bladder exposure, radiation dose rate (daily fraction size), and total bladder dose. Radiation damage can result in luminal occlusion, vascular ectasia (dilation), and necrosis of the vessel wall with clinically significant symptoms of dysfunctional voiding and pain (Muruve, 2009). Careful evaluation of clinical symptoms will guide interventions. Frequency and urgency may respond to anticholinergic medicines. Hemorrhagic cystitis is a much more serious complication and may respond to aggressive bladder irrigation or instillation of alum, aminocaproic acid, formalin, or sodium pentosan polysulphate. The use of hyperbaric oxygen therapy may be able to reverse some of the radiation-induced ischemic changes by stimulating angiogenesis, with a response rate as high as 70% (Muruve, 2009).

Scars

Oncologic surgeries can cause long-term scarring issues in many patients with cancer. Patients with head and neck cancer can have disfiguring skin changes related to surgery with an increased incidence of anxiety and depression (Langendijk et al., 2008). Patients with breast cancer who have had partial or full mastectomies may experience long-term psychological challenges related to their surgery (Casey & Mahon, 2007).

Mucosal and Cutaneous Changes Caused by Hematopoietic Cell Transplantation

Skin and mucosal long-term effects are primarily related to chronic GVHD (cGVHD) with effects on oral and gastrointestinal mucosa. Mucosal lining irritation from cGVHD can appear as white lines and lacy-appearing lesions.
on the buccal mucosa and tongue. Symptoms can vary in intensity and affect patient comfort and ability to eat and speak. Xerostomia, characterized as sicca syndrome (dryness of the mouth), compounds the already injured mucosa and further exacerbates the risk of dental caries. Chronic mucosal irritation and injury contribute to an increased risk of intraoral secondary malignancies (Filipovich et al., 2005). Oral hygiene, artificial saliva, treatment of cGVHD, and regular and frequent dental assessment with particular attention to screening for intraoral malignancies are important aspects of follow-up care. Smoking cessation and other lifestyle habits that may contribute to risk are important issues to discuss with survivors.

Gastrointestinal mucosal risk following hematopoietic cell transplantation includes the cGVHD features of esophageal webbing, stricture, and stenosis. Symptoms of dysphagia, nausea, vomiting, and inability to swallow dry foods or pills may be manifestations of these problems. Additionally, mucosal changes in the bowel and pancreas can lead to diarrhea and malabsorption. Treatment of underlying cGVHD and use of pancreatic enzymes can help improve symptom control and quality of life for patients experiencing these symptoms (Latchford, 2010).

Although cGVHD can affect multiple organ systems, cutaneous involvement is the most common (Latchford, 2010). Filipovich et al. (2005), as part of a consensus project to develop diagnostic and staging criteria for cGVHD clinical trials, identified five subtypes of cutaneous cGVHD (see Table 7-2). Acral erythema, loss of sweat glands, and development of alopecia also can occur. With severe sclerotic features, skin can become fragile with poor wound healing and ulceration from minor trauma (Hymes et al., 2006).

Filipovich et al. (2005) recommended the categorization of cGVHD as classic or overlap (features of both acute and chronic). The older categorizations, less than 100 days post-transplant and greater than 100 days post-transplant incidence, are no longer accurate given the use of newly developed nonmyeloablative conditioning regimens and donor lymphocyte infusions. These interventions have changed the previous natural history of GVHD (Filipovich et al., 2005; Hymes et al., 2006). The new scoring system uses a scale of 0–3, with 0 = no GVHD; 1 = mild, defined as less than 18% body surface area (BSA) involvement without evidence of sclerotic features; 2 = 19%–50% BSA affected or involvement with superficial sclerotic features, able to pinch skin; and 3 = greater than 50% BSA affected or deep sclerotic features with hidebound or impaired mobility (Latchford, 2010).

No evidence-based guidelines exist for the treatment of cGVHD. Similar to acute GVHD, immunosuppressive drugs are the backbone of treatment for cutaneous cGVHD. Steroids such as prednisone and calcineurin inhibitors (tacrolimus and cyclosporine) are used (Latchford, 2010). Extracorporeal photopheresis has been reported to be helpful in patients with cGVHD, particularly with skin involvement, but the exact frequency and time to best response are unknown. Some clinical trials are investigating novel schedules of current therapies, such as tacrolimus/sirolimus and methotrexate, as well as
one phase III study that is investigating the use of extracorporeal photopheresis for acute GVHD (National Cancer Institute, n.d.).

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
<th>Typical Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poikiloderma</td>
<td>Atrophic changes with areas of hypo- and hyperpigmentation, variegated coloring, “cigarette paper–thin skin” suggestive of lupus on face</td>
<td>Face, neck, and trunk</td>
</tr>
<tr>
<td>Lichen planus–like features</td>
<td>May begin with xerosis that resembles fish scales (ichthyosis)</td>
<td>Dorsum of hands, forearms, and trunk</td>
</tr>
<tr>
<td></td>
<td>Classic lichenoid features may be focal, confluent linear, folliculocentric, or dermatomal; must distinguish vesicular rash from zoster</td>
<td>May coexist with lichen sclerotic changes</td>
</tr>
<tr>
<td>Deep sclerotic features</td>
<td>Deep sclerosis that involves dermis and muscular fascia</td>
<td>Joint contractures, hidebound with devastating consequenc-</td>
</tr>
<tr>
<td></td>
<td>Smooth, waxy, indurated skin</td>
<td>es for patients (i.e., “pipestem legs” in lower extremities often accompanied by painful neuropathy). Affects mobility, independence, and quality of life.</td>
</tr>
<tr>
<td>Morphea-like features</td>
<td>Superficial, sclerotic, localized, moveable, shiny, leathery skin patches</td>
<td>Extremities and trunk</td>
</tr>
<tr>
<td>Lichen sclerosis–like features</td>
<td>Gray to white moveable, discrete, coalescent plaques or papules with shiny to leathery appearance</td>
<td>Scalp, extremities, and trunk</td>
</tr>
</tbody>
</table>

*Note.* Based on information from Filipovich et al., 2005; Hymes et al., 2006; Latchford, 2010.

**CASE STUDY**

M.S. presented at age 51 with stage I, estrogen receptor–positive left breast cancer, which was treated with partial mastectomy, radiation, and tamoxifen. She developed postradiation fibrosis with retraction of the breast. Four years after initial treatment, M.S. developed recurrent disease in her left breast, requiring surgical treatment with a simple mastectomy. She developed a postoperative infection of the mastectomy scar with wound
dehiscence, which required intensive wound care at home with prolonged wound healing. Unfortunately, a fistula tract developed, complicated by several episodes of chest wall cellulitis that required hospitalization. After years of struggling with a nonhealing fistula, M.S. sought a surgical opinion regarding wound closure, which would require resection of the ribs and skin grafting. Biopsies documented no evidence of recurrent malignancy, although this remained a concern. M.S. eventually underwent a chest wall resection with removal of two ribs and wound closure using a latissimus dorsi flap graft. Postoperatively, M.S. experienced complete wound healing and has remained without complications, nearly 12 years after her postradiation mastectomy.

SUMMARY

Cancer survivors who have been treated with radiotherapy, chemotherapy, surgery, or bone marrow transplantation can experience long-term skin and mucosal toxicities. The skin or mucosal changes include fibrosis, dermatitis, dysphagia, scars, xerostomia, secondary skin malignancies, and cutaneous cGVHD, as well as other less common symptoms. Surveillance, assessment, and identification of potential long-term effects or secondary malignancies related to cancer treatment need to be a part of comprehensive follow-up care for cancer survivors.

REFERENCES


CHAPTER 8

Optimizing Bone Health in Adult Cancer Survivors

Maryam B. Lustberg, MD, and Charles L. Shapiro, MD

INTRODUCTION

Health promotion, including maintenance of bone health, is important in cancer survivors. Aging, natural menopause, and standard treatments for cancer can cause bone loss and may increase the incidence of subsequent osteoporosis and bone fractures. This chapter will review the risk factors for osteoporosis, the mechanisms of bone loss, and treatment options for osteoporosis, with breast cancer as the case exemplar. The definitions, processes, and interventions can be considered for all survivors affected by cancer treatment.

RISK FACTORS FOR BONE LOSS

Treatment-associated bone loss in cancer survivors results from estrogen and androgen deprivation. The development of osteoporosis can be thought of as an equation (Ramaswamy & Shapiro, 2003): on one side of the equation is peak bone mass, usually attained by about age 30, and on the other side is ongoing bone loss due to normal aging, menopausal-mediated bone loss, and genetic determinants such as family history, race, and low body mass index, as well as exposures or conditions that are potentially modifiable, such as current cigarette smoking, alcohol intake greater than two drinks per day, and chronic glucocorticoid therapy (Kanis, McCloskey, et al., 2008). Each individual will have a peak bone mass and a unique set of risk factors for bone loss that determines whether he or she will experience a nontraumatic fracture or osteoporosis.

Often, cancer survivors suffer from secondary causes of bone loss that are potentially avoidable and treatable (Mann, Kang, Brand, Ebeling, & Miller,
One common secondary cause is vitamin D deficiency with or without secondary hyperparathyroidism. Low vitamin D levels are prevalent because of multiple factors, including decreased sunlight exposure, decreased intake of foods rich in vitamin D, and decreased vitamin D absorption and metabolism (Holick, 2007). Although no consensus exists on the frequency of vitamin D monitoring or the optimal level, recent studies suggest that many women with a history of breast cancer have vitamin D insufficiency (defined as 50–75 nmol/L) and deficiency (less than 50 nmol/L) (Camacho et al., 2008; Mann et al., 2009). Detection of vitamin D levels is performed by serum blood testing for 25-OH D level; correction with vitamin D₃ replacement may be beneficial for improving bone health. In the case study later in this chapter, the woman was found to have vitamin D deficiency (25-OH D level of 40 nmol/L) and was repleted with ergocalciferol (D₃) prior to initiating bisphosphonate therapy. Several trials have suggested an improved response to bisphosphonate treatment when vitamin D deficiency was corrected (Adami et al., 2008; Geller, Hu, Reed, Mirocha, & Adams, 2008).

MECHANISMS OF BONE LOSS

Normal bone remodeling is a balanced, dynamic process between new bone formation and bone resorption. This process is mediated by two cell types: the osteoclasts that resorb bone and the osteoblasts that make new bone. When resorption exceeds the formation of new bone, bone loss occurs. Osteoclasts and osteoblasts are tightly regulated by a variety of signals, including hormones such as estrogens, growth factors, and cytokines that act on the receptor activator factor-kappa B ligand (RANKL) pathway (Manolagas & Jilka, 1995). RANKL, a member of the tumor necrosis family, is a transmembrane protein produced by osteoblasts that binds to the receptor activator of NF-kappa B on osteoclasts and their precursors, leading to the activation of osteoclasts and subsequent bone resorption (Kostenuik, 2005). Increased osteoclast activity leads to bone loss with impaired bone structural changes, which increases the risk of fracture.

Counterbalancing the action of RANKL is osteoprotegerin (OPG), a protein secreted by osteoblasts that binds RANKL, thereby reducing activation of the RANK receptor and decreasing osteoclast-mediated bone resorption. The dynamic balance between the ratio of RANKL and OPG governs normal bone remodeling; dysregulation of this process leads to bone loss (Kearns, Khosla, & Kostenuik, 2008). Osteoporosis is a consequence of a net loss of bone mass with associated micro-architectural changes that increase the risk of nontraumatic fractures (Kanis, McCloskey, et al., 2008).

Estrogens are one of the primary factors that influence the ratio of RANKL to OPG (Weitzmann & Pacifici, 2006). Estrogens stimulate osteoblasts to increase OPG and inhibit production of RANKL. The main effect of estrogens is to decrease bone resorption; estrogen deficiency, as caused by menopause
or breast cancer treatments, disturbs the dynamic balance between RANKL and OPG and increases bone resorption and bone loss.

Natural menopause and breast cancer treatments such as oophorectomy, gonadotropin-releasing hormone (GnRH) agonists, chemotherapy-induced ovarian failure (CIOF) (Saarto et al., 1997; Shapiro, Manola, & Leboff, 2001), and aromatase inhibitors (AIs) all cause bone loss. The magnitude of bone loss is proportional to the severity of estrogen deprivation. Similarly, men receiving androgen deprivation therapy (ADT) lose bone because testosterone deficiency increases bone resorption, which is likely from the decreased aromatization of testosterone to estrogen. The effects of these various standard treatments on bone loss will be reviewed next.

Chemotherapy-Induced Ovarian Failure

CIOF, or early menopause, is one of the most frequent consequences of breast cancer treatment in premenopausal women (Goodwin, Ennis, Pritchard, Trudeau, & Hood, 1999; Molina, Barton, & Loprinzi, 2005; Schover, 2008). The best predictor of a woman’s risk for CIOF is age: in women younger than 40, the incidence of CIOF is 20%–40%, whereas in women over age 40, the incidence is 50%–90% (Bines, Oleske, & Cobleigh, 1996; Goodwin et al., 1999). Other predictive factors of CIOF may include a higher bone mineral density (BMD) before the start of adjuvant chemotherapy (Shapiro et al., 2005).

CIOF leads to loss of fertility, menopausal symptoms, and accelerated bone loss (Schover, 2008; Shapiro et al., 2001; Shapiro & Recht, 2001). Premenopausal women receiving adjuvant chemotherapy may experience a 4%–8% loss of BMD in the lumbar spine within 12 months of treatment. Even higher rates of bone loss have been reported in those trials that specifically defined either ovarian failure or prolonged amenorrhea (Fogelman et al., 2003; Hershman et al., 2008; Hines et al., 2009; Saarto et al., 1997; Shapiro et al., 2001).

Chemotherapy-Induced Bone Loss

The effects of adjuvant chemotherapy on bone loss independent of ovarian failure–caused estrogen deprivation are not well understood. In small prospective studies, premenopausal women who had prolonged durations of amenorrhea or developed CIOF had lower BMD versus those who retained menstrual function, suggesting that the major contributor to bone loss was lowered estrogen levels (Fogelman et al., 2003; Saarto et al., 1997; Shapiro et al., 2001). In postmenopausal women, two small studies have suggested that adjuvant chemotherapy can independently contribute to bone loss (Crandall, Petersen, Ganz, & Greendale, 2004; Greep et al., 2003); however, these studies are limited by the small sample sizes and the trial design. Additional studies are required to confirm that adjuvant chemotherapy alone can cause bone loss in postmenopausal women.
Antiestrogen Therapy and Bone Loss

Adjuvant antiestrogen therapy improves outcomes in hormone receptor–positive breast tumors, which comprise more than two-thirds of breast tumors. Tamoxifen is a selective estrogen receptor modulator and, depending on the specific tissue, has estrogen agonist and antagonist activity. In bone, tamoxifen acts as an estrogen agonist and preserves BMD in postmenopausal women, whereas in premenopausal women, tamoxifen has been associated with bone loss (Love et al., 1992).

Tamoxifen was previously used in both premenopausal and postmenopausal women with breast cancer until randomized trials showed the superiority of AIs to tamoxifen in the adjuvant and metastatic settings. Current guidelines recommend initial treatment of postmenopausal women with endocrine-positive breast cancer with AIs or to switch to AIs sequentially after two to three years of tamoxifen (Winer et al., 2005). AIs inhibit the aromatase enzyme, decreasing the peripheral production of estrogen in postmenopausal women. Randomized clinical trials demonstrate a higher incidence of fractures in women treated with AIs than in those receiving tamoxifen. The rate and magnitude of AI-associated bone loss is lower than that observed after oophorectomy or CIOF, with the majority of women who have normal BMD prior to the start of AI therapy not developing clinically significant bone loss after one or two years of therapy (Pant & Shapiro, 2008). Screening by dual energy x-ray absorptiometry (DEXA) scans plus adequate calcium and vitamin D intake is recommended for women treated with AIs (Winer et al., 2005).

Androgen Deprivation Therapy and Bone Loss

Similar to CIOF, the highest magnitude of bone loss occurs during the first year of ADT. A study of more than 50,000 men with prostate cancer compared fracture rates with exposure to ADT and showed that men treated with ADT experienced increased fractures (Shahinian, Kuo, Freeman, & Goodwin, 2005). Treatments for prevention of bone loss in men with prostate cancer include intermittent ADT regimens, estrogens, and selective estrogen receptor modulators (e.g., raloxifene and bisphosphonates) (Israeli et al., 2007). However, the optimal dosing, schedule, and duration of therapy are not known.

MEASUREMENT OF BONE MINERAL DENSITY AND BONE LOSS RISK ASSESSMENT

DEXA scanning of the hip and spine is the standard recommended test for screening for osteoporosis (Cummings, Bates, & Black, 2002). DEXA scan results are reported as T- and Z-scores. The T-score is defined as the number of standard deviations (SDs) that the individual woman’s BMD falls above or
below the mean BMD of women 30 years old at the peak of BMD; the Z-score is the number of SDs the BMD falls above or below the mean BMD of an age-matched normal population. The T-score defines the fracture risk and guides decisions about instituting bisphosphonate treatment, whereas the Z-score is most useful in considering secondary causes of osteoporosis. The World Health Organization (WHO) defines osteopenia as a T-score of –1 to –2.5 and osteoporosis as a T-score of –2.5 or below (Kanis, 2002).

In addition to DEXA monitoring, the WHO Fracture Risk Assessment Tool (FRAX, see www.shef.ac.uk/FRAX) is a helpful clinical aid to assess an individual’s 10-year risk of fracture (Kanis, Johnell, Oden, Johansson, & McCloskey, 2008). This online program allows specific risk factors such as age, weight, and family history of fractures, as well as the most recent femoral BMD, to be entered to estimate an individual’s fracture risk.

**MANAGEMENT OF OSTEOPENIA AND OSTEOPOROSIS**

An individual’s BMD as measured by DEXA, the estimated risk of fracture as predicted by FRAX, and the risk of further bone loss on ongoing cancer therapy are guides to clinical decision making for the management of bone loss. Low BMD and history of fractures are the strongest risk factors for future fragility fractures. Current guidelines for women with postmenopausal osteoporosis and cancer treatment–induced bone loss include supplemental calcium (1,000–1,200 mg/day) and vitamin D (800–1,000 IU/day) (Geller et al., 2008).

Bisphosphonates are analogs of inorganic pyrophosphate, a major constituent of the bone mineral matrix. They also are potent inhibitors of osteoclast-mediated bone resorption. The U.S. Food and Drug Administration (FDA) has approved several oral bisphosphonates, including oral alendronate, risedronate, and ibandronate, in weekly or monthly schedules. The most frequent toxicity of oral bisphosphonates is esophagitis. A 5 mg annual IV dose of zoledronic acid is FDA approved for osteoporosis on the basis of a large, randomized, placebo-controlled trial that demonstrated statistically significant reductions in vertebral and hip fractures in postmenopausal women with osteoporosis (Black et al., 2007). As illustrated in the case study, the main advantages of yearly IV therapy are decreased gastrointestinal toxicity compared to oral bisphosphonates and improved compliance.

**TOXICITIES OF TREATMENT**

The primary toxicities of IV zoledronic acid are fevers, transient myalgias and arthralgias, pain, and dose-related renal insufficiency. Osteonecrosis of the jaw (ONJ) is a rare complication of bisphosphonate therapy. ONJ is defined formally by the presence of exposed bone in the mouth that does not heal
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after six to eight weeks of appropriate intervention (American Association of Oral and Maxillofacial Surgeons, 2007; Khosla et al., 2007). The most commonly identified risk factors for developing ONJ are monthly dosing administration and duration of therapy greater than two years in patients with skeletal metastases receiving IV bisphosphonates (Bamias et al., 2005). Dental procedures such as tooth extractions and implants are possible predisposing factors for the development of ONJ. A screening dental examination and, if necessary, completion of dental surgery prior to initiation of IV bisphosphonate therapy are advisable, although the incidence of ONJ is very infrequent with annual IV dosing in women with osteoporosis.

Current American Society of Clinical Oncology guidelines recommend the initiation of bisphosphonate therapy in women with T-scores of –2.5 or lower or with prior fragility fractures (Hillner et al., 2003). For osteopenic breast cancer survivors with risk factors such as low body mass index, tobacco use, alcohol use greater than three drinks per day, ongoing AI treatment, CIOF, oophorectomy, or treatment with a GnRH agonist, therapy with bisphosphonates should be individualized.

Similarly, men initiating ADT should be evaluated for osteoporosis risk factors, including family history of osteoporosis, low body mass index, prior fractures, chronic glucocorticoid use, heavy alcohol use, and tobacco use. The National Comprehensive Cancer Network (2010) guidelines for men undergoing ADT recommend daily supplemental calcium and vitamin D, risk assessment using the FRAX algorithm, and initiation of therapy for men who are at high risk for fracture.

CASE STUDY

A 62-year-old woman was recently diagnosed with stage I breast cancer that was estrogen receptor–positive and HER2 non-overexpressing. Following surgery and radiation therapy, adjuvant endocrine therapy with an AI was initiated. A baseline DEXA scan prior to starting AI therapy revealed osteopenia (T-score of –1.7 in the spine and T-score of –1.6 in the hip). She did not have major risk factors for bone loss. She was a nonsmoker, consumed one to two alcoholic beverages per week, and had no reported personal or family history of nontraumatic fractures. She did not exercise regularly or take calcium and vitamin D supplements. To optimize her bone health, she was referred to an exercise walking program and instructed to take 1,200 mg calcium a day with 800 units of vitamin D. Two years later, a follow-up screening DEXA scan showed worsening osteopenia (T-score of –2.3 in the spine and T-score of –2.4 in the femur).

Additional laboratory studies were ordered to look for a secondary cause of bone loss, including thyroid-stimulating hormone, parathyroid hormone, and 25-OH D levels. All studies were within normal ranges except for the 25-OH D level, which was low (40 nmol/L). She was prescribed weekly dosing of
vitamin D, 40,000 units for six weeks and an oral bisphosphonate, alendronate (Fosamax®, Merck & Co., Inc.) 70 mg per week. She did not tolerate alendronate because of moderate dyspepsia that did not respond to proton pump inhibitor therapy. She had a dental screening examination by her dentist and was switched to once-a-year IV zoledronic acid 5 mg (Reclast®, Novartis Pharmaceuticals Corp.). A DEXA scan two years later showed improvement in BMD (T-score of –1.8 in her spine and T-score of –1.7 in her hip). She tolerated annual IV bisphosphonate therapy without difficulty and successfully completed a five-year treatment course of AI. She remains without any clinical evidence of disease recurrence and has not experienced any bone fractures.

SUMMARY

Many individuals diagnosed with cancer will be long-term survivors. Therefore, optimal management of osteoporosis and prevention of osteoporotic fractures are high priorities in this group. Medical providers who participate in the care of these patients should be aware that cancer treatments may cause bone loss, which may increase the risk of subsequent osteoporosis. Supplemental calcium and vitamin D are recommended, and modifications of risk factors such as decreasing alcohol intake, smoking cessation, and encouraging weight-bearing exercise will not only contribute to bone health but also are important for overall health. Recent studies have shown that secondary causes of bone loss, including vitamin D deficiency, are common, and these should be investigated in cancer survivors with osteoporosis. Healthcare providers caring for survivors have a responsibility and an opportunity by recognizing “teachable moments” to reinforce the importance of lifestyle changes that promote overall health (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005).

REFERENCES


INTRODUCTION

Peripheral neuropathy is a common problem experienced by cancer survivors. It occurs as a result of neurotoxic chemotherapy-, radiation-, or surgery-associated nerve injury. Other causes of peripheral neuropathy include tumor infiltration into nerves or nerve plexuses, viral infection as in postherpetic neuralgia, malignancy-related gammopathies, and paraneoplastic syndromes that produce neurotoxic antibodies. This chapter will begin with a brief description of clinical signs and symptoms, as well as the known and theoretical risk factors that may contribute to the severity and chronicity of neuropathy. Neuropathy assessment techniques will be briefly outlined, along with prevention and treatment approaches. A case study will illustrate how neuropathy influences the various domains of quality of life, as well as the nurse’s role in assessment and overall patient care. The chapter will conclude with a focus on future directions related to personalized approaches to prevention and treatment.

CLINICAL FACTORS

Peripheral neuropathy occurs with damage to the nerve’s cell body, axon, myelin sheath, internal cellular structures, and vascular supply (Corbo & Balmaceda, 2001; Kirchmair et al., 2007). Internal cellular structures that may be affected include the various ion channels involved in nerve impulse transmission, the microtubules critical to internal cellular transport, and the mitochondria that provide cellular energy (Bhagra & Rao, 2007; Windebank & Grisold, 2008). In addition, impaired central nervous system mechanisms, although less understood, appear to play a role in sustaining
neuropathy pain well beyond the initial nerve injury (Treede, Meyer, Raja, & Campbell, 1992).

Peripheral neuropathy symptoms arise as a result of damaged sensory, motor, or autonomic nerves, including cranial nerves. Patients most commonly report sensory symptoms such as numbness, tingling, electric shocks, burning, and pain. Individuals with chemotherapy-induced peripheral neuropathy (CIPN) most often report symptoms that initially present in their toes. Loss of foot sensation can lead to impaired balance. As neuropathy worsens, uncomfortable symptoms extend distally to proximally, with numbness, tingling, and pain that will move up the feet to the ankles, legs, and beyond. Symptoms may eventually progress to the fingers, hands, wrists, and arms. Some neurotoxic chemotherapeutic drugs cause unique sensory symptoms. For example, oxaliplatin is associated with cold-induced neuropathy experienced in the posterior pharynx, hands, and feet.

Neuropathic symptoms resulting from surgery, radiation therapy, or direct tumor invasion are experienced in the motor and sensory distribution innervated by the damaged nerve. For example, postmastectomy- or thoracotomy-related neuropathy and associated neuropathic pain may occur when nerves innervating the chest wall are transected. Postherpetic neuralgia occurs in cancer survivors because of herpes zoster infection; symptoms are experienced in the dermatome supplied by the affected nerve. Unlike these examples of surgery or virus-induced nerve injury, paraneoplastic sensory neuropathy may result when certain types of cancer cells release antibodies that target and damage nerves (Corbo & Balmaceda, 2001).

Motor symptoms occur less commonly and are associated mainly with high cumulative, neurotoxic, chemotherapy dosages. Muscle weakness is first noted in foot flexors and extensors. Weakness progresses proximally as neuropathy worsens. Lower extremity muscle weakness may be manifested by frequent tripping, falls, or difficulty with driving because of impaired ankle dorsiflexion. Upper extremity motor neuropathy may be demonstrated by an inability to open jars, manipulate faucets, or grasp and hold objects such as eating or writing utensils. Vocal cord paralysis and subsequent hoarseness can occur as a result of cranial (laryngeal) nerve injury. Autonomic neuropathy can lead to constipation, lack of normal heart rate variability, orthostatic hypotension, urinary retention, and erectile dysfunction.

Risk Factors

A comprehensive description of neuropathy risk factors, as well as differential diagnoses, is beyond the scope of this chapter. However, a few examples of CIPN risk factors are provided, many of which may be included in a predictive model that could guide individualized prevention and treatment approaches in the future.

CIPN occurs in 10%–100% of individuals receiving neurotoxic chemotherapy (Armstrong, Almadrones, & Gilbert, 2005; Sweeney, 2002;
Chemotherapeutic agents that commonly cause peripheral neuropathy include the taxanes, platinums, vinca alkaloids, thalidomide, and bortezomib (Hausheer, Schilsky, Bain, Berghorn, & Lieberman, 2006). The incidence of CIPN is variable based on neurotoxic drug class and dose, treatment frequency (dose density), and a variety of other demographic and comorbid variables. For example, Caucasian race has been linked with worse vincristine-associated neuropathy (Renbarger, McCammack, Rouse, & Hall, 2008). Other risk factors for CIPN include atherosclerosis, HIV infection, and exposure to other neurotoxic drugs or toxins such as alcohol (Hausheer et al., 2006; Ocean & Vahdat, 2004; Verstappen, Heimans, Hoekman, & Postma, 2003; Windebank & Grisold, 2008). The presence of systemic metabolic comorbidities, such as diabetes mellitus, hypothyroidism, and B vitamin deficiency, increases neuropathy risk (Hausheer et al., 2006; Visovsky, Meyer, Roller, & Poppas, 2008). In addition, genetic factors may increase the risk profile. For example, Charcot-Marie-Tooth (CMT) disease is a hereditary condition characterized by sensory and motor neuropathy symptoms and foot deformities (high arches and hammer toes). Cases of severe neuropathy have occurred when neurotoxic chemotherapy has been administered to patients with undiagnosed hereditary peripheral neuropathy.

Scientific advances in pharmacogenetics may enable practitioners to individualize chemotherapy dosage in ways that will minimize CIPN without jeopardizing drug efficacy. Based on their individual genetic expression of the various enzymes responsible for drug metabolism, some cancer survivors may be at increased risk for developing CIPN resulting from impaired metabolic capabilities. For example, Renbarger et al. (2008) identified a correlation between CYP3A5 enzyme expression and vincristine metabolism. Individuals who were CYP3A5 enzyme expressers (70% of African Americans versus 10%–20% of Caucasians) developed less severe neuropathy because of their enhanced ability to metabolize vincristine. Therefore, to avoid severe CIPN in nonexpressers or poor metabolizers, the vincristine dosage may need to be decreased. Other genetic predictors of neurotoxicity are currently being explored.

Assessment

Ongoing comprehensive assessment of subjective and objective neuropathy signs and symptoms is important so that patients and clinicians alike can be cognizant of subtle changes over time. This is most important in cases where patients will be receiving neurotoxic chemotherapy. Prospective neuropathy assessment and ongoing monitoring informs the need to dose-reduce neurotoxic chemotherapy and can raise awareness of advancing toxicity before severe and protracted symptoms develop. The most comprehensive approach includes assessment of subjective numbness, tingling, and neuropathic pain. Severity of symptoms should be based on distal to proximal extension (worse
neuropathy equates to more proximal extension). Vibratory sensibility, pin-prick or cold sensibility, and reflexes should be assessed. The more proximal the level of diminished vibratory or pinprick/cold sensation, the worse the neuropathy. Worsened neuropathy is associated with an increased number of diminished or absent reflexes, again distally to proximally. Therefore, an absent or diminished Achilles reflex is often the first sign, and as other more proximal reflexes become altered, neuropathy is considered to be more severe. Weakness should be evaluated using standardized approaches whereby the practitioner assesses the patient’s ability to overcome resistance in isolated muscle groups. Nurses can learn to perform these assessment approaches with mentored training and, upon doing so, can quickly incorporate assessment into daily clinical practice.

When the pattern of neuropathy cannot be explained based on the patient’s history and clinical findings, referral to a neurologist is recommended. To assess for other etiologies, the neurologist may perform a variety of more complex diagnostic tests, such as nerve conduction studies and electromyography (EMG). These tests can confirm the presence, severity, and type of CIPN. Nerve conduction studies assess the conduction velocity and amplitude of selected motor and sensory nerves in both the upper and lower extremities. When the myelin is affected, the conduction velocity is decreased; if the nerve fiber itself is affected, the amplitude of the response is decreased. EMG can document whether neuropathic muscle weakness is present. It should be noted that nerve conduction studies and EMG assess only the fastest, largest myelinated fibers. In addition, autonomic testing can be used to document the presence of autonomic neuropathy through measurement of heart rate changes to deep breathing and the Valsalva maneuver, as well as sweating changes. To assess for hereditary neuropathy such as CMT disease, a careful family history is required. Specific questions should be asked regarding the presence or history of high arches, curled toes, foot surgery, and foot numbness (Pascuzzi, 2003). Genetic testing is available for some forms of CMT but may be expensive.

During neuropathy assessments, the opportunity presents for one-on-one patient education. For example, nurses can educate patients about the importance of reporting symptoms. Safety-enhancing strategies also should be discussed, such as the importance of wearing hard-soled shoes to prevent injury from stepping on sharp objects that may be undetected because of numbness. Patients should be encouraged to perform frequent visual inspections of the plantar and dorsal foot to assess for otherwise unnoticed injuries experienced because of impaired sensation. Likewise, hot water temperature settings in the home should be reduced to avoid burning. Patients with impaired balance, lower extremity weakness, or foot drop should remove items in the home that increase the likelihood of tripping (throw rugs, toys, etc.). In addition, patients should be encouraged to use assistive devices that enhance stability, such as walkers, canes, and bathroom shower mats and grab bars (Visovsky, Collins, Hart, Abbott, & Aschenbrenner, 2009).
PREVENTION AND TREATMENT

A main goal for patients receiving neurotoxic chemotherapy is to minimize or prevent severe CIPN and pain. Every effort should be taken to prospectively identify those who may be at high risk and to adjust chemotherapy treatment plans accordingly. Before initiating chemotherapy, it is very important to assess whether a baseline subclinical or undiagnosed peripheral neuropathy may be present, as this will exacerbate CIPN. As noted, a history of diabetes, alcohol abuse, and hereditary neuropathy all should be considered.

Agents to prevent or decrease CIPN severity have generated much interest. Rationale for their use is based on mitochondrial (acetyl-L-carnitine), calcium channel (ethosuximide), and antioxidant effects (vitamin E), nerve growth factor enhancement (glutamine), sodium channel modulation (calcium and magnesium), impairment of platinum metabolite accumulation in the dorsal root ganglion (glutathione and N-acetylcysteine), and modulation of voltage-gated channels (oxcarbazepine) (Paice, 2009; Pascuzzi, 2003; Wolf, Barton, Kottschade, Grothey, & Loprinzi, 2008). Because the scientific evidence supporting the efficacy of these treatments is not conclusive, future research is needed to more fully evaluate the effectiveness of these agents.

Although no treatments are currently available that will eliminate symptoms of numbness and tingling, treatment of neuropathy pain is possible. An empirical approach to pain management is recommended using an evidence-based treatment algorithm/practice guideline, such as the one published by Dworkin et al. (2007). For initial symptom management, selected tricyclic antidepressants, gabapentin, pregabalin, or duloxetine may be used. The combination of duloxetine with gabapentin or pregabalin also can be very effective. Although tricyclic antidepressants, such as nortriptyline, have significant anticholinergic side effects, these drugs can alleviate neuropathy pain and provide a beneficial sedative effect when taken at bedtime for patients who have difficulty sleeping. Use of opioids for pain related to CIPN should be carefully considered based on the side effect profile when used alone or in combination with other drugs, patient age and comorbidities, and the risk for drug abuse. Therefore, opioids typically are used in cases of severe pain or when other nonopioid options have been ineffective. Topical analgesics, such as 5% lidocaine transdermal patches, can be helpful for painful foot neuropathy (patches cannot be easily applied to fingers and hands) or for postherpetic neuralgia. Pharmacists may make a compounded cream, including drugs such as baclofen, amitriptyline, and ketamine, for neuropathic pain. An advantage of these topical agents is that they do not cause systemic side effects.

Other treatment or supportive modalities for neuropathy include occupational and physical therapy. These approaches can help to improve strength and balance as well as facilitate the use of adaptive devices to enhance function and safety. Massage, focused imagery, and relaxation exercises also may benefit patients. The use of acupuncture is controversial in the literature, but some patients have found it to relieve pain (Visovsky et al., 2009).
THE INFLUENCE OF NEUROPATHY ON OVERALL SURVivorSHIP

Cancer survival statistics have steadily improved because of ongoing advances in diagnosis and treatment. As such, peripheral neuropathy will have an increasing impact on cancer survivors’ quality of life. An increasing number of patients are living longer and therefore will face new challenges as they attempt to regain an acceptable level of functioning while coping with distressing and sometimes disabling neuropathy. Although the exact prevalence of neuropathy in all cancer survivors is unknown, a recent population-based survey of cancer survivors (N = 548) was conducted to assess the prevalence of cancer-related symptoms (Smith et al., 2010). The survey results revealed that 13% had ongoing symptoms of numbness and tingling. Of those experiencing neuropathy symptoms, 57.5% reported wanting help to overcome the problem. Therefore, these findings suggest that neuropathy has not been adequately addressed. Although survivors participating in this survey were not queried about the specific problems experienced as a result of neuropathy symptoms, we can hypothesize how neuropathy may negatively influence survivors’ quality of life.

Figure 9-1 illustrates an adapted version of Ferrell’s Quality of Life Model based on the theoretical influence of neuropathy (Ferrell, Dow, Leigh, Ly, &
Gulasekaram, 1995). This model incorporates physical, psychological, social, spiritual, and economic well-being as critical domains of a cancer survivor’s quality of life. The following case study illustrates the relationship between the various quality-of-life domains in patients with peripheral neuropathy.

**CASE STUDY**

B.J. is a 55-year-old White female currently receiving paclitaxel for metastatic breast cancer. To date, she has received weekly paclitaxel for 39 doses equating to a high total cumulative dosage of 3,100 mg/m². On neurologic examination at week 25 of paclitaxel treatment, the patient was experiencing a stocking-glove loss of sensation affecting predominantly vibration sensation to the level of the knees in the lower extremities and wrists in the upper extremities. She was unable to walk on her toes or heels. When she stood with her feet together and eyes closed, she lost her balance. Reflexes were absent at the ankles and knees and depressed in the upper extremities. Because of the severity of these findings, B.J. was referred to a neurologist. The neurologist obtained a detailed family history focused on foot deformity and neuropathy. B.J. reported very high arches, curled toes, and the use of canes on her mother’s side of the family. The neurologist noted that B.J. also had high arches and curled toes. Given the nature of B.J.’s history and physical findings, the neurologist performed an EMG and nerve conduction studies. These tests revealed a severe sensorimotor peripheral neuropathy affecting both sensory and motor nerves caused by axonal loss. The neurologist confirmed via history, examination, and nerve conduction studies that B.J.’s neuropathy was due to paclitaxel and the concomitant presence of the preexisting diagnosis of a hereditary peripheral neuropathy (CMT).

At B.J.’s subsequent oncology checkup, the nurse discovered that severe CIPN symptoms were negatively influencing the patient’s quality of life in several ways. B.J. was an avid hiker; during a recent hiking excursion, B.J. reported to the nurse that she tripped and fell several times. After she had brought this to her husband’s attention, they discovered that B.J. had been wearing her hiking boots on the wrong feet. B.J.’s lower extremity numbness was so severe that she did not notice the discomfort of ill-fitting boots. Subsequently, B.J. decided that it was no longer safe to hike. She expressed to the nurse that she was sad to no longer be able to spend time with her husband enjoying her favorite recreational activity.

B.J. also reported to the nurse several other problems that were directly related to her neuropathy. Neuropathy-related pain was keeping her from sleeping at night, which was contributing to worsening fatigue, a depressed mood, and diminished daytime cognitive functioning. In addition, she was extremely anxious regarding the uncertainty of her future with respect to the need to dose-reduce or stop the chemotherapy that was prolonging her life. Would this mean the end of the road for B.J.? Were there alternative
chemotherapy treatments that would be equally effective? Also, what would happen if the neuropathy continued to progress? Would she lose the ability to walk altogether, and how would progressive disability affect her family’s overall well-being? Would her husband need to stop working in order to care for her? How would B.J.’s increasing dependence on her husband affect their relationship? The overall influence of neuropathy on B.J.’s life had become overwhelming.

Based on B.J.’s case, it is evident that peripheral neuropathy can lead to a complex domino effect whereby the symptom can negatively affect every domain of quality of life. If B.J. were to receive neurotoxic chemotherapy in the future, it is possible that her unique profile of demographic, clinical, and genetic factors could be used to customize the type, dose, and schedule of chemotherapy. If she was found to be at high risk for developing severe or protracted neuropathy, chemotherapy drugs and dosages could be adjusted to account for and minimize this risk. In addition, neuroprotective agents or other strategies to be discovered in the future could be initiated at treatment onset. The oncology healthcare team would need to assess and monitor neuropathy and pain prior to each chemotherapy dose. Referrals to physical or occupational therapy could be instrumental in maintaining strength; assistive devices could be recommended that would enhance B.J.’s ability to stay active and to safely enjoy the activities that she loves. Using these personalized approaches, B.J.’s quality of life could be enhanced while optimizing her ability to receive life-prolonging treatments.

**SUMMARY**

Peripheral neuropathy can have devastating consequences for cancer survivors. Until better prevention and treatment approaches are discovered, nurses must play an active role in patient care by assessing neuropathy, suggesting treatments that will minimize pain and optimize function, and educating patients and families regarding the importance of reporting symptoms and implementing safety-enhancing strategies. The hope is that scientific advances toward personalized assessment, prevention, and treatment approaches that will enhance the quality and quantity of life for those experiencing neuropathy are soon to be discovered.

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INTRODUCTION

Improvement in survival rates for many types of adult and pediatric cancers has brought into focus the late effects of cancer treatments on the cardiopulmonary system. These complications can be significant, affecting functional ability and quality of life. In severe cases, late cardiac and pulmonary complications can lead to death. Cardiopulmonary toxicities from treatment are the third leading cause of death in pediatric cancer survivors, second only to cancer recurrence and the development of a second malignancy (Green, Hyland, Chung, Zevon, & Hall, 1999; Mertens et al., 2001). Healthcare professionals and cancer survivors need to know the risks for these complications, be aware of monitoring guidelines for detection, and implement evidence-based interventions to manage their effects on daily life.

CARDIOTOXICITY FROM CANCER TREATMENTS

Chemotherapy, biotherapy, and radiation therapy can adversely affect the cardiovascular system. The type, incidence, and sequelae of cardiotoxicity are dependent on the treatment received and the identified risk factors for development. Long-term cardiac complications from cancer treatments can manifest as cardiomyopathy, pericarditis, congestive heart failure, valvular heart disease, or premature coronary artery disease.

Chemotherapy-Induced Cardiotoxicity

Anthracycline antitumor antibiotics are the most common cause of cardiotoxicity from chemotherapy. However, other chemotherapeutic agents, such as microtubule targeting drugs, antimetabolites, and alkylating agents, also can cause cardiac effects (Carver et al., 2007; Ng, Cunningham, & Norman, 2005; Saif, Szabo, Grem, & Hamilton, 2001).
**Anthracycline antitumor antibiotics:** The anthracycline antitumor antibiotics, such as doxorubicin, daunorubicin, idarubicin, and liposomal doxorubicin, are the most researched group of chemotherapeutic agents associated with cardiotoxicity. Mitoxantrone, a chemotherapeutic agent closely related to the anthracycline antitumor antibiotics, is also associated with cardiotoxicity. The mechanism of action believed to cause cardiac toxicity is myocyte damage by free oxygen radicals, leading to irreversible damage and replacement by fibrous tissue (Singal & Iliskovic, 1998). Damage often is irreversible and sometimes fatal. Cardiomyopathy can occur many years after therapy, even as late as 30 years after treatment has been completed (Carver et al., 2007).

Cardiotoxicity from anthracyclines is related to numerous risk factors, with the individual’s cumulative dose being cited as the most significant risk factor (Carver et al., 2007; Pinarli et al., 2005). Other risk factors for cardiotoxicity include age (higher risk if age 70 or older, or age 5 or younger), prior radiation to the chest, underlying heart disease, sex (female), ethnicity (Black/African American have a higher risk), and administration with other chemotherapeutic and biologic agents (Carver et al., 2007; Children’s Oncology Group [COG], 2008).

Cardiac complications from anthracyclines can be categorized as acute (while the patient is receiving the agent), early (days to months after administration), or late (occurring one year or later after administration) (Carver et al., 2007; Polovich, Whitford, & Olsen, 2009). Acute toxicities are rare, usually resolve within a week, and are manifested by electrocardiographic abnormalities, arrhythmias, ventricle dysfunction, or pericarditis. The relationship between the development of an acute toxicity and its relationship to later development of cardiac toxicity is unclear. Early cardiotoxicity can range from asymptomatic left ventricular dysfunction to congestive heart failure. Late-onset cardiotoxicity is often not reversible and can progress to heart failure.

**Nonanthracycline cardiotoxic agents:** Nonanthracycline cardiotoxic chemotherapeutic agents include antimetabolites, microtubule targeting agents (the taxanes and vinca alkaloids), alkylating agents, and antitumor antibiotics. In contrast to the anthracycline antitumor antibiotics, cardiotoxicity from nonanthracycline antitumor antibiotics is not related to cumulative dose and often is reversible (Carver et al., 2007). After the anthracyclines, the antimetabolite 5-fluorouracil is the second most common cause of chemotherapy-induced cardiotoxicity. Complications can include angina, electrocardiograph changes, and myocardial infarction (Saif et al., 2001). Saif et al. (2001) reviewed 262 cases of 5-fluorouracil cardiotoxic events and found that 76% of problems occurred within 72 hours of the first treatment cycle. The mechanism of the cardiac event is believed to be coronary artery vasospasm.

Risk factors that have been cited include the practice of the IV push route of administration, presence of coronary artery disease, and concurrent radiation therapy. Capecitabine, an oral chemotherapeutic agent that is metabolized to 5-fluorouracil, can cause a similar type of cardiotoxicity.
Other antimetabolites that have been associated with cardiotoxicity include fludarabine, pentostatin, cladribine, and cytarabine (Floyd, Morgan, & Perry, 2010).

Microtubule targeting agents also can cause cardiotoxicity, including paclitaxel, which is associated with asymptomatic bradycardia in about 30% of patients and, rarely, cardiac ischemia or complete heart block (Arbuck et al., 1992). Nanoparticle albumin-bound paclitaxel has similar cardiotoxic properties. Conduction abnormalities and angina have been reported in patients receiving docetaxel. The taxanes, when combined with anthracycline antitumor antibiotics, can significantly increase a patient’s risk for cardiotoxicity (Gehl, Boesgaard, Paaske, Jensen, & Dombernowsky, 1996).

The alkylating agents cyclophosphamide and ifosfamide can both cause cardiac changes. Cyclophosphamide cardiotoxicity is more likely to occur in patients receiving high-dose therapy as part of an autologous stem cell transplantation and has been reported as cardiomyopathy and pericardial effusions (Floyd et al., 2010). Ifosfamide cardiotoxicity is also related to high-dose therapy and includes arrhythmias and heart failure. Although occurrence is rare, other chemotherapeutic agents, including cisplatin and busulfan, can cause cardiotoxicity (Floyd et al., 2010).

Antitumor antibiotics are associated with cardiotoxicity, including mitomycin and bleomycin (Floyd et al., 2010). Heart failure has occurred in survivors who received cumulative doses of mitomycin greater than 30 mg/m² (Verweij, Funke-Küpper, Teule, & Pinedo, 1988). Bleomycin has been reported to cause pericarditis and myocardial infarction (Floyd et al., 2010).

**Biologic Agent–Induced Cardiomyopathy**

Biologic agents are all associated with cardiotoxicity. Trastuzumab is the monoclonal antibody with the highest incidence of cardiotoxicity. It can cause decreased left ventricular function that may progress to cardiomyopathy and heart failure. In contrast to cardiotoxicity from the anthracyclines, trastuzumab-induced cardiotoxicity is not related to cumulative dose and is often reversible (Perez & Morgan, 2010). The incidence of trastuzumab-induced cardiotoxicity is increased in survivors who were previously treated with anthracyclines (Perez & Morgan, 2010). Other agents, such as interferon alfa-2a, aldesleukin, and denileukin diftitox, have been reported to cause myocardial infarction, angina, and congestive heart failure (Al-Zahrani, Gupta, Minden, Messner, & Lipton, 2003).

Sunitinib and sorafenib are oral multitargeted kinase inhibitors that have been identified as having cardiotoxic properties. Sunitinib has been found to cause decreased left ventricular function in up to 28% of patients and congestive heart failure in 3%–15% (Polovich et al., 2009). Sorafenib has been found to be associated with myocardial ischemia and myocardial infarction in 2.9% of patients (Polovich et al., 2009). Imatinib, lapatinib, nilotinib, and dasatinib have been found to be cardiotoxic (Polovich et al., 2009).
Radiation-Induced Cardiomyopathy

Thoracic radiation involving the heart causes injury by the generation of free radicals that destroy DNA. Damage can cause inflammation, which can lead to fibrosis. Pericarditis, coronary artery disease, congestive heart failure, arrhythmias, valvular disease, and carotid artery stenosis also can occur (Adams, Hardenbergh, Constine, & Lipshultz, 2003; Marks, Constine, & Adams, 2010). Clinical symptoms may not appear for 20 years or more (Carver et al., 2007; Shankar et al., 2008).

Radiation to the mediastinum and the neck is the most common cause of radiation-induced cardiomyopathy. Mantle field radiation (radiation delivered to a large area of the neck, chest, and axilla) was standard treatment for Hodgkin lymphoma 10–20 years ago and is associated with radiation-induced cardiomyopathy in cancer survivors today (Carver et al., 2007). The incidence of radiation-induced cardiomyopathy is estimated to be 10%–30%, occurring 5–10 years after treatment has been completed (Carver et al., 2007). Radiation-induced cardiotoxicity has declined significantly since 1985 because of improvements in radiation techniques (Marks et al., 2010).

Both patient factors and factors related to the radiation therapy treatment plan can increase the patient’s risk for radiation-induced cardiotoxicity. Patient risk factors include age younger than 18 years at the time of treatment, past treatment with anthracycline antitumor antibiotics, greater than 10 years since treatment, location of tumor close to the cardiac border, and preexisting cardiac disease (Carver et al., 2007; Marks et al., 2010). Additionally, long-term survivors of pediatric cancers with a history of mediastinal radiation therapy have an increased risk for coronary artery disease and myocardial infarction (Shankar et al., 2008). Risk factors related to the radiation treatment plan include (a) the amount of heart radiated, (b) greater than 30 Gy total dose directly to the heart, and (c) daily dose fractions of greater than 2 Gy per day (Carver et al., 2007; Shankar et al., 2008).

PREVENTION OF TREATMENT-INDUCED CARDIOTOXICITY

Various strategies have been tried to prevent anthracycline-induced cardiotoxicity. Some studies have indicated a decreased incidence of doxorubicin cardiotoxicity when the infusion method was changed from IV push to a continuous infusion over 48–96 hours (van Dalen, van der Pal, Caron, & Kremer, 2009). However, drawbacks to this method are continued concerns about efficacy, the need for a central line to administer the continuous infusion of the vesicant doxorubicin, and the need for hospitalization. Two structural analogs of doxorubicin, epirubicin and mitoxantrone, were developed with the goal of reduced cardiotoxicity; however, their efficacy and degree of cardiotoxicity are yet to be determined (van Dalen et al., 2009). Encapsulating doxorubicin and daunorubicin in liposomes has demonstrated a protective mechanism in some studies, allowing for a higher
dose of chemotherapy to be administered with less toxicity (O’Brien et al., 2004). Dexrazoxane, an iron chelating agent, inhibits the formation of free radicals and can thus prevent damage to cardiac myocytes (Bryant et al., 2007).

MONITORING FOR CARDIOTOXICITY

A variety of diagnostic tests have been used to evaluate cardiotoxicity, including multigated acquisition (MUGA) scans, cardiac echocardiograms, electrocardiography (ECG), endocardial biopsies, brain natriuretic peptide (BNP) levels, and troponin levels. Of these diagnostic tests, MUGA scans and echocardiograms are the most common types used to measure left ventricular ejection fraction (LVEF). Serial endocardial biopsies have been cited to be the most effective method to diagnose cardiotoxicity from anthracycline antitumor antibiotics; however, the procedure is not available at all institutions, is invasive, and has risks (Ewer & Lenihan, 2008). Serum troponin levels can detect early cardiac damage from anthracycline antitumor antibiotics (Ewer & Lenihan, 2008), and BNP levels can be used to detect left ventricular heart failure (Mavinkurve-Groothuis, Kapusta, Nir, & Groot-Loonen, 2008).

Few clinical trials have been published evaluating the effectiveness and impact of screening guidelines for cardiotoxicity on morbidity and mortality of survivors. The American Society of Clinical Oncology (ASCO) and the National Comprehensive Cancer Network (NCCN) do not have published recommendations for monitoring for cardiotoxicity.

COG (2008) developed guidelines for cardiac monitoring for survivors of childhood, adolescent, and young adult cancers who have received anthracycline antitumor antibiotics. Recommended monitoring includes baseline history and physical, ECG, and echocardiogram or MUGA scan. A yearly history and physical, along with a repeat echocardiogram or MUGA scan every one to two years, is encouraged. Follow-up ECGs are recommended based on the survivor’s clinical condition (COG, 2008). In addition to diagnostic tests, findings from the patient’s history and physical examination can help aid in the detection and diagnosis of complications. Symptoms such as shortness of breath, dyspnea on exertion, angina, palpitations, and exercise intolerance can be indicative of potential problems. Physical examination findings of cardiac toxicity can include murmurs, S3, S4, and P2 sounds, pericardial rubs, peripheral edema, weight gain, jugular venous distention, wheezes, and rales (Polovich et al., 2009). Investigation of these findings is pertinent to the early detection and treatment of possible cancer treatment–induced toxicities or treatment of an unrelated comorbidity.

MANAGEMENT OF TREATMENT-INDUCED CARDIOTOXICITY

Survivors who exhibit signs and symptoms of cardiac disease should be referred to a cardiologist for evaluation and treatment. Survivors with conges-
tive heart failure should have medications prescribed to treat the disease and support cardiac output. Examples of medications used to treat this population include diuretics and inotropic cardiac medications. Oxygen supplementation also may be indicated. Because underlying cardiac disease is a risk factor for cancer treatment–induced cardiotoxicity, lifestyle choices may help prevent or modulate it. Attention to habits such as smoking, alcohol intake, exercise patterns, dietary habits, and body weight merit future study to determine their overall benefit to risk reduction. Cardiac rehabilitation programs can provide survivors with information and assistance with physical therapy and exercise programs, nutrition counseling, smoking cessation, and psychosocial resources.

### PULMONARY TOXICITY FROM CANCER TREATMENTS

Pulmonary toxicities can be caused by chemotherapy, biologics, radiation therapy, and bone marrow transplantation. Early and late treatment-related toxicities can include radiation pneumonitis, pulmonary fibrosis, and decreased pulmonary function.

#### Chemotherapy-Induced Pulmonary Toxicity

Pulmonary toxicity can be manifested as acute reactions, such as pulmonary edema and allergic reactions, and late reactions, such as interstitial pneumonitis progressing to pulmonary fibrosis. Bleomycin is the most common cause of late pulmonary toxicity from chemotherapy; however, numerous other agents have been cited to cause long-term pulmonary complications, including busulfan, carmustine, chlorambucil, cyclophosphamide, cytosine arabinoside, docetaxel, etoposide, fludarabine, gemcitabine, ifosfamide, lomustine, methotrexate, mitomycin, paclitaxel, procarbazine, and the vinca alkaloids (Carver et al., 2007; Polovich et al., 2009).

Bleomycin is the chemotherapeutic agent most commonly associated with pulmonary toxicity with an incidence rate of 0%–46% (Sleijfer, 2001). Potential late effects include interstitial pneumonitis, pulmonary fibrosis, and acute respiratory distress syndrome. Numerous pathologic mechanisms are believed to be involved with bleomycin-induced pulmonary toxicity, including inflammation, release of interleukins, and activation of fibroblasts, which can lead to fibrosis (Polovich et al., 2009).

Risk factors for bleomycin-induced pulmonary toxicity include cumulative dose; younger age at the time of treatment; older than 70 years of age; smoking history; renal dysfunction; concurrent administration of busulfan, carmustine, or lomustine; and thoracic radiation (COG, 2008; O’Sullivan et al., 2003; Sleijfer, 2001). The survivor’s cumulative dose is the most significant risk factor; cumulative doses of bleomycin greater than 400 units total dose are associated with a high risk (Carver et al., 2007; COG, 2008). High-dose
oxygen support, such as that during general anesthesia and scuba diving, can rapidly cause progression to acute respiratory distress syndrome. Symptoms of bleomycin-induced pulmonary toxicity include cough, shortness of breath, dyspnea on exertion, and wheezing. Rales may be heard on auscultation. Chest x-ray findings can include patchy opacities. Decreased carbon monoxide diffusion capacity levels, as evidenced by pulmonary function testing, also can be an early indicator of toxicity (Polovich et al., 2009).

### Radiation-Induced Pulmonary Toxicity

Chest radiation can cause interstitial pneumonitis, pulmonary fibrosis, restrictive lung disease, and obstructive lung disease. Radiation therapy to the chest, whole lung, mediastinum, axilla, mini-mantle, mantle, and extended mantle and total body irradiation all can lead to pulmonary toxicity. Survivor risk factors include younger age at the time of treatment and smoking. Treatment-related risk factors include (a) radiation dosages greater than or equal to 10 Gy, (b) chest radiation combined with total body irradiation, and (c) radiation combined with bleomycin, busulfan, carmustine, lomustine, or anthracycline antitumor antibiotics (Carver et al., 2007; COG, 2008). Symptoms, physical findings, and results of diagnostic tests of radiation-induced pulmonary toxicity can be similar to those found in bleomycin-induced pulmonary toxicity, as discussed previously.

### Monitoring of Pulmonary Toxicity

Similar to cardiotoxicity from cancer treatments, few clinical trials have been conducted or published evaluating the effectiveness and impact of different screening guidelines for pulmonary toxicity on morbidity and mortality of cancer survivors. ASCO and NCCN currently do not have published recommendations for monitoring for pulmonary toxicity. COG (2008) has developed follow-up guidelines for treatment with bleomycin and thoracic radiation. Recommendations for both bleomycin and thoracic radiation include a baseline (at the time of entry into long-term follow-up) history, physical examination, chest x-ray, and pulmonary function studies that include spirometry and diffusing capacity of the lung for carbon monoxide. Follow-up chest x-rays and pulmonary function studies are based on risk factors and clinical findings.

### Prevention and Management of Pulmonary Toxicity

Management of interstitial pneumonitis and pulmonary fibrosis caused by cancer treatments is similar to that associated with other etiologies
(Polovich et al., 2009). Helpful medications include corticosteroids, bronchodilators, and expectorants. Oxygen may be indicated; however, caution should be used with patients who have received bleomycin. High rates of oxygen, such as that delivered during general anesthesia, can precipitate acute respiratory distress syndrome in patients who have received bleomycin. Prior to any planned surgeries, patients should be evaluated for this risk. To prevent further compromise of pulmonary status, routine influenza and pneumococcal pneumonia vaccines may be indicated. Pulmonary rehabilitation programs can provide survivors with pulmonary disease resources and information regarding breathing exercises and retraining, exercise programs, anxiety interventions, stress management, and smoking cessation.

**CASE STUDY**

M.J. was a 52-year-old woman with breast cancer admitted to the outpatient infusion clinic for adjuvant therapy, dose # 10 of trastuzumab 6 mg/kg every week. Her temperature was 98.6°F (37°C) orally, respirations 20 and labored, heart rate 100, and blood pressure 120/68. Her oxygen saturation on pulse oximetry was 95%. Her weight was 80 kg, which was 5 kg more than her weight two weeks ago. She complained of fatigue, shortness of breath, and exercise intolerance. Abnormal findings in her physical examination included decreased breath sounds bilaterally in both bases and bilateral peripheral edema in her ankles and feet. Her complete blood count, serum creatinine, and liver function tests were within normal limits. Her history revealed that she had received a total cumulative dose of 400 mg/m² of doxorubicin in the past. At the start of the initiation of her trastuzumab, her LVEF measured by an echocardiogram was 48%. Based on her subjective reports, physical findings, and treatment history, the trastuzumab was held and the oncologist notified. He ordered an echocardiogram and chest x-ray. The patient’s LVEF came back as 31% and chest x-ray showed small bilateral pleural effusions. Because of the patient’s symptoms, physical findings, and decrease in LVEF by more than 16%, the oncologist’s plan included holding the trastuzumab for four weeks, administering furosemide, and then repeating the echocardiogram to determine if treatment could be resumed. Nursing interventions included teaching the patient energy conservation strategies and indications to notify the physician.

**SUMMARY**

With the number of cancer survivors increasing every day, the late effects of cancer treatment, including cardiopulmonary complications, are receiving more attention. Knowledge of risk factors, signs and symptoms, and ongo-
ing monitoring for detection and management are imperative for survivors. Table 10-1 outlines implications for survivors as related to treatment-induced cardiopulmonary complications.

<table>
<thead>
<tr>
<th>Prevention</th>
<th>Monitoring</th>
<th>Management</th>
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<tbody>
<tr>
<td><strong>Cardiotoxicity From Cancer Treatments</strong></td>
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<tr>
<td>Educate the survivor about the risks of cardiac toxicity from cancer treatments, including the delay in onset of symptoms.</td>
<td>Educate the survivor that monitoring for cardiotoxicity may be required for years after treatment is finished.</td>
<td>–</td>
</tr>
<tr>
<td>Educate the survivor to report signs and symptoms of cardiotoxicity, including</td>
<td>Examples of follow-up monitoring:</td>
<td>–</td>
</tr>
<tr>
<td>• Weight gain</td>
<td>• Yearly history and physical</td>
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<tr>
<td>• Peripheral edema</td>
<td>• Multigated acquisition scan or echocardiogram, and/or electrocardiogram, depending on risk factors</td>
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<tr>
<td>• Shortness of breath</td>
<td></td>
<td></td>
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<tr>
<td>• Dyspnea on exertion</td>
<td></td>
<td></td>
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<tr>
<td>• Decreased activity tolerance</td>
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<tr>
<td>• Extreme fatigue</td>
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<tr>
<td>• Rapid or irregular heart beat or palpitations</td>
<td></td>
<td></td>
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<tr>
<td>• Wheezes.</td>
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<td></td>
</tr>
<tr>
<td>Educate the survivor to modify risk factors that can increase the risk for cardiotoxicity, including</td>
<td></td>
<td></td>
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<tr>
<td>• Avoid alcohol.</td>
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<td>• Avoid tobacco.</td>
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<td>• Exercise regularly.</td>
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<td>• Maintain appropriate weight.</td>
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<tr>
<td>• Eat a healthy diet.</td>
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<thead>
<tr>
<th>Pulmonary Toxicity From Cancer Treatments</th>
<th>Examples of medications:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educate the survivor about the risks of pulmonary toxicity from cancer treatments, including the delay in onset of symptoms.</td>
<td>• Corticosteroids</td>
</tr>
<tr>
<td>Educate the survivor that monitoring for pulmonary toxicity may be required for years after treatment is finished.</td>
<td>• Bronchodilators</td>
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<td></td>
<td>• Expectorants</td>
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<td></td>
<td>• Antibiotics</td>
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</tbody>
</table>

(Continued on next page)
## Table 10-1. Cardiac and Pulmonary Complications: Implications for Survivors (Continued)

<table>
<thead>
<tr>
<th>Prevention</th>
<th>Monitoring</th>
<th>Management</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pulmonary Toxicity From Cancer Treatments (Cont.)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educate the survivor to report signs and symptoms of pulmonary toxicity from treatments, including</td>
<td>Examples of follow-up monitoring:</td>
<td>Oxygen, as indicated. However, high rates of oxygen, such as that delivered during general anesthesia, can precipitate acute respiratory distress syndrome in patients who have received bleomycin.</td>
</tr>
<tr>
<td>• Shortness of breath</td>
<td>• Annual history and physical with respiratory examination</td>
<td></td>
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<tr>
<td>• Dyspnea on exertion</td>
<td>• Pulmonary function studies with carbon monoxide lung diffusion; frequency depends on the patient’s risk factors and treatment received.</td>
<td></td>
</tr>
<tr>
<td>• Wheezing.</td>
<td>• Chest x-ray; frequency depends on the patient’s risk factors and treatment received.</td>
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<tr>
<td>Educate the survivor to modify risk factors that can increase the risk for pulmonary toxicity, including</td>
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<td>–</td>
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<tr>
<td>• Avoid tobacco.</td>
<td>Administer the influenza vaccine and pneumococcal pneumonia vaccine, as indicated, to prevent further pulmonary compromise.</td>
<td>–</td>
</tr>
<tr>
<td>• Exercise regularly.</td>
<td></td>
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</tr>
<tr>
<td>Educate survivors who have received bleomycin regarding the risk of pulmonary complications with high levels of oxygen, such as during general anesthesia or scuba diving. Instruct survivors to notify their surgeon and anesthesiologist if general surgery is planned regarding this potential complication.</td>
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</table>

### REFERENCES


INTRODUCTION

The phase that begins upon completion of initial cancer treatment usually is characterized by gradual recovery; however, many survivors experience persistent symptoms and delayed effects of treatment. Cancer-related fatigue (CRF) and sleep-wake disturbances are among the most common symptoms in cancer survivors (Bower, 2008). These symptoms can result in lower physical, social, cognitive, and vocational functioning, adverse mood changes, emotional distress, amplification of concurrent symptoms, and treatment noncompliance that affect recurrence-free and overall survival. Screening, evaluation, and management of CRF and sleep disturbances are suboptimal in cancer survivors, and an evidence-based approach is needed to modify these and related symptoms.

Several explanatory models of the psychophysiology of CRF and disturbed sleep have been proposed (Miller, Ancoli-Israel, Bower, Capuron, & Irwin, 2008; Otte & Carpenter, 2009). Models help guide the evaluation of cancer survivors who are at risk for experiencing CRF and sleep disturbances and promote the translation into practice of interventions to manage these symptoms. A framework developed by the authors depicts the factors most frequently identified as contributing to CRF in cancer survivors (see Appendix E). These factors are associated with decrements in health-related quality of life and an increased risk for adverse illness outcomes. This chapter will provide assistance to clinicians in improving survivors’ CRF and sleep-wake disturbances. The defining features, incidence, etiology, risk factors, screening, and diagnosis will be described for these common problems in cancer survivors. Evidence-based interventions, including both pharmacologic and nonpharmacologic measures, will be discussed in detail as well.
FATIGUE

Defining Features

The National Comprehensive Cancer Network (NCCN) defines CRF as a distressing, persistent, and subjective sense of tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning (NCCN, 2010b). The 10th International Classification of Diseases criteria for the diagnosis of CRF identify it as being of markedly different quality and severity from ordinary fatigue, adversely affecting function, and being unrelieved by rest or sleep (Cella, Lai, Chang, Peterman, & Slavin, 2002).

The clinical expression of CRF is multidimensional, making evaluation challenging. An inherently subjective condition, CRF may be experienced and reported differently by individuals. Personality and coping style also may influence the experience of CRF. Some survivors identify the main features of their CRF as a loss of efficiency, mental fogginess, inertia, and sleep that is not restorative, while others describe an excessive need to rest, an inability to recover promptly from exertion, or muscle heaviness and weakness. Researchers have attempted to distinguish CRF from depression, cognitive dysfunction, or asthenia, and to understand possible shared neurophysiologic mechanisms (Bower, 2008; Lee et al., 2004).

Incidence, Etiology, and Risk Factors

Prevalence rates for CRF have been reported from 30% to 76% in cancer survivors (Ng, Alt, & Gore, 2007). The etiology of CRF likely involves the interaction of several physiologic and psychobehavioral mechanisms. The relationships between CRF and types of cancer treatment have been explored, but few consistent relationships have been observed (Prue, Rankin, Allen, Gracey, & Cramp, 2006). Associations between CRF and demographic variables have not been identified consistently. Evidence links CRF with several mechanisms, including gene polymorphisms, circadian rhythm disruption, immune dysregulation, abnormal cortisol secretion, and proinflammatory cytokine activity (Miller et al., 2008).

Screening

Screening patients for CRF is fundamental to improving management and is a key component of quality care. Brief screening measures for CRF are sensitive and can be efficiently applied in clinical settings to identify patients who could benefit from further evaluation. The NCCN (2010b) guidelines recommend that every patient be screened for the presence of fatigue (i.e., a yes/no question). If present, CRF should be assessed quantitatively on a 0–10 scale (0 = no fatigue and 10 = worst fatigue imaginable). Patients with
a score of 4 or higher should be further evaluated by a history and physical examination. Routine screening should occur at regular intervals during and after cancer treatment.

**Evaluation and Diagnosis**

A detailed history should be taken in patients with moderate or severe CRF (NCCN, 2010b). CRF may have several different causes in any one patient, and causes may change over time. Clinicians can obtain information by exploring the effects of CRF on the patient’s self-esteem, mood, and ability to perform activities of daily living and usual roles. Inquiring about the self-management interventions the patient has tried for CRF and their effectiveness can be helpful in tailoring recommendations for managing CRF. Consideration needs to be given to etiologic factors or comorbidities that may amplify CRF. Evaluation should include whether disease progression or recurrence could be among the causes of CRF. Reviewing the medication profile will identify medications with a side effect profile likely to intensify CRF.

**Interventions**

Clinicians, survivors, and their families must work together to identify appropriate and acceptable management strategies. Open communication will facilitate discussion about the experience of CRF and its effects on daily life. The follow-up phase is an important time to provide anticipatory guidance about the pace at which CRF may improve. Moderate to severe CRF may take several months to a year to resolve, and a subset of patients may continue to experience CRF that interferes with function for a longer time. Development of the survivorship care plan provides clinicians an opportunity to suggest strategies for each patient that are most likely to be effective in managing persistent CRF (see Appendix F).

More than 170 empiric studies of pharmacologic and nonpharmacologic interventions to manage CRF and several recent meta-analyses or systematic reviews have been completed. Some interventions have demonstrated strong and consistent evidence to support effectiveness, whereas others have only preliminary data available. Some interventions have had only limited study in particular groups or have been studied only in mixed samples of survivors (i.e., some receiving treatment and some who have completed treatment). Guidelines for the management of CRF have been disseminated by NCCN (2010b) and the Oncology Nursing Society Putting Evidence Into Practice (ONS PEP) project team (Mitchell, Beck, Hood, Moore, & Tanner, 2009). Research-tested pharmacologic and nonpharmacologic interventions that have shown positive effects on CRF are listed in Figure 11-1.

Patients should be encouraged to develop their own care plan for CRF self-management based on the research currently supporting the effectiveness of these interventions, including the following.
Screening and management of contributing etiologies and comorbidities: Expert consensus is that patients with CRF should be evaluated for potentially treatable etiologic factors (NCCN, 2010b) and managed as indicated.

**Exercise:** The importance of remaining active and participating in a consistent program of gentle exercise, individualized to the patient’s age,
condition, and physical fitness level, should be communicated to survivors. Meta-analyses and systematic reviews of randomized controlled trials (RCTs) (Cramp & Daniel, 2008; Speck, Courneya, Mâsse, Duval, & Schmitz, 2010; Spence, Heesch, & Brown, 2010) support the benefits of exercise following cancer treatment for patients with breast cancer, solid tumors, or hematopoietic stem cell transplant. Exercise improves aerobic capacity, reduces muscle loss and deconditioning, and may produce favorable effects on sleep, mood, self-efficacy, body composition, immune system, cytokine milieu, and long-term disease outcomes (Irwin, 2009).

Patients require practical guidance about how to begin, maintain, and advance an exercise program. Referral to a rehabilitation professional can provide specific and detailed recommendations about the type, intensity, and frequency of exercise and should be considered for patients in whom CRF is accompanied by significant comorbidities and deconditioning. Ongoing follow-up by rehabilitation professionals strengthens motivation and adherence and allows for the exercise program to be advanced as functional capacity improves.

**Psychoeducational and psychosocial interventions:** A growing body of evidence that includes several adequately powered RCTs suggests that educational interventions and psychological support strengthen positive coping in patients with CRF (Goedendorp, Gielissen, Verhagen, & Bleijenberg, 2009; Jacobsen, Donovan, Vadaparampil, & Small, 2007). Common elements in psychoeducational and psychosocial interventions include anticipatory guidance about CRF patterns, tailored recommendations for self-management of CRF that include energy conservation strategies, increasing activity and exercise, implementing strategies to address sleep disturbances, coaching to enhance motivation, self-care and active coping, and praise and encouragement to promote self-efficacy and augment feelings of control. Other elements of effective psychoeducational interventions for CRF include supportive counseling, the use of a diary to record the affective consequences of CRF, and cognitive restructuring to help normalize CRF and adjust catastrophizing thought patterns that diminish mood and interfere with self-efficacy and incremental goal attainment. Studies have indicated that cognitive-behavioral interventions designed specifically to improve sleep quality also have a beneficial effect on CRF during and following treatment (Kangas, Bovbjerg, & Montgomery, 2008).

**Structured rehabilitation:** A recent systematic review suggested that structured multicomponent rehabilitation programs result in statistically significant and sustained improvements in CRF in patients who have completed treatment and are in the survivorship phase (van Weert et al., 2008).

**Pharmacologic interventions:** Several pharmacologic agents have been evaluated for their effects on fatigue in cancer survivors during or following cancer treatment (Minton, Richardson, Sharpe, Hotopf, & Stone, 2008). Two small trials have shown a trend for either paroxetine or venlafaxine in treating CRF in survivors experiencing hot flashes. Potential drug-drug interactions
may reduce the effectiveness of tamoxifen when taken with selective serotonin
reuptake inhibitors or serotonin-norepinephrine reuptake inhibitors (Sateia &
Lang, 2008). Survivors reported less CRF after treatment with methylphenidate
in single-arm trials and in a recent RCT (Lower et al., 2009). Small trials
have suggested that donepezil, bupropion, and modafinil may limit CRF and
improve daytime function in survivors (Kohli et al., 2009; Minton et al., 2008;
Spathis et al., 2009).

Correction of anemia: Patients with CRF and concurrent anemia should
be evaluated to determine the cause of the anemia and managed according
to national practice guidelines (NCCN, 2010a).

Complementary therapies: Preliminary evidence exists in mixed samples of
survivors across the treatment trajectory to support the use of complementary
therapies in managing CRF. Complementary therapies include yoga,
relaxation, medical Qigong, biofield therapies (healing touch and Reiki),
massage, mindfulness-based stress reduction, and acupuncture (Kwekkeboom,
Cherwin, Lee, & Wanta, 2010).

SLEEP-WAKE DISTURBANCES

Defining Features

Sleep-wake disturbance is the term used to describe the symptom when a
specific diagnosis of a sleep disorder has not been made. Common complaints
include difficulty in one or more of these areas: falling asleep, staying asleep,
early morning awakenings with inability to resume sleep, nonrefreshing or
nonrestorative sleep, and daytime sleepiness. Recognized categories of sleep
and arousal disorders include insomnia, hypersomnia, sleep-related breathing
disorders, circadian rhythm sleep disorders, parasomnias, and sleep-related
movement disorders. New-onset insomnia in patients with cancer is coded as
adjustment insomnia (acute insomnia) or insomnia due to medical condition
(comorbid insomnia). The timing of insomnia is categorized as acute, transient
(less than one month), or chronic (one month or longer) (American Academy
of Sleep Medicine, 2005).

Incidence, Etiology, and Risk Factors

Several studies have documented the prevalence of sleep problems among
patients with cancer with up to 50% of newly diagnosed patients experiencing
sleep disturbances, mostly insomnia (Palesh et al., 2010). The common pathway to
insomnia in the general population is heightened arousal (Buysse, 2003). Cancer
processes may alter physiology and play a prominent role in disrupting sleep,
circadian rhythms, and hypothalamus-pituitary-adrenal (HPA) axis regulatory
processes (Bower, 2007). Conversely, disrupted HPA axis and circadian rhythms
may lead to disturbed sleep and increased risk for cancer (Hrushesky et al., 2009).
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Screening

The Insomnia Severity Index (Savard, Savard, Simard, & Ivers, 2005) and the Clinical Sleep Assessment for adults and children (Lee & Ward, 2005) have been recommended as screening tools. Within the Patient-Reported Outcomes Measurement Information System, or PROMIS (Cella et al., 2007), brief, precise self-report measures for sleep disturbance and sleep-related impairment are also available. When screens are positive, interventions and referrals may be indicated. Survivors with positive screens should be taught behavioral techniques in a survivorship care plan to promote sleep (see Appendix G).

Evaluation and Diagnosis

The first step in evaluation is to recognize that, just as with CRF and pain, sleep quality is a perception. A daily diary can be used to evaluate patients’ perceptions of their sleep-wake patterns (Morin & Espie, 2003), or patients can rate their sleep quality during the past month using the Pittsburgh Sleep Quality Index (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989). When a patient is referred to a sleep center, professionals will make a diagnosis after considering the most common sleep disorders.

Interventions

If evaluation confirms a diagnosis of insomnia of moderate to severe intensity, clinicians need to consider a multidisciplinary approach and make referrals to advanced practice registered nurses (APRNs), primary care or internal medicine providers, or an accredited sleep center. APRNs are ideally suited to coordinate and lead the process. The patient and clinician can mutually decide to initiate a referral to a behavioral or psychological therapist. Interventions for sleep-wake disturbances, as categorized by the ONS PEP criteria (Page, Berger, & Johnson, 2009), are listed in Figure 11-2 and include the following.

Cognitive-behavioral therapy/behavioral therapy (CBT/BT): The goal of treatment is to reduce perpetuating factors below the insomnia threshold and to decondition the hyperarousal response (Perlis, Jungquist, Smith, & Posner, 2008). The evidence is strongest that CBT/BT interventions are likely to be effective in improving sleep in patients with cancer (Page et al., 2009). CBT interventions have varied in content, length, delivery, and measured sleep-wake outcomes in patients with varied cancer diagnoses. Despite these limitations, evidence is increasing that CBT improves sleep in cancer survivors.

Complementary therapies: These interventions reduce stress and promote relaxation and have improved sleep in patients with cancer. The ONS PEP project team (Page et al., 2009) rated these therapies as Effectiveness Not Established because of a lack of large RCT studies. The variety of studies have
been organized according to the type of complementary intervention; most common include mindfulness-based stress reduction, autogenic training, supportive-expressive group or individual therapy, expressive writing, progressive muscle relaxation, hypnosis, healing touch, and massage therapy. Evidence is increasing that complementary therapies improve sleep in cancer survivors, but results from RCT studies are needed.

**Education and information:** Few interventions have been tested to improve sleep disturbances in patients with cancer by teaching them about the treatment being received (Page et al., 2009). More evidence is needed to evaluate the effects of education and information interventions on sleep in cancer survivors.

**Exercise:** A few small studies have tested aerobic and strength training programs and have shown favorable effects on sleep outcomes. Evidence to date shows a positive trend for exercise interventions to improve sleep in cancer survivors, but results from larger studies are needed (Page et al., 2009).

<table>
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<th>Strong and Consistent Evidence Supporting Effectiveness</th>
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<tr>
<th>Preliminary Evidence to Support Effectiveness</th>
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<tr>
<td>• Cognitive-behavioral therapy (during and after active treatment)</td>
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<th>Evidence Supporting Effectiveness but With Risk for Harm</th>
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<td>• Pharmacologic treatment</td>
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<th>Effectiveness Not Established</th>
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<td>• Education and information</td>
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<td>- Herbal supplements</td>
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<td>- Mindfulness-based stress reduction</td>
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<td>- Muscle relaxation</td>
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<td>- Music therapy</td>
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<td>- Yoga</td>
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<th>Supported by Expert Opinion</th>
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<tr>
<td>• Referral to an accredited sleep center</td>
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*Note.* Based on information from Page et al., 2009.
Pharmacologic: Prescription pharmacologic agents have not been tested to improve sleep in patients with cancer. Clinicians must evaluate the efficacy, side effects, and potential interactions of sleep-promoting medications with other medications patients are taking. The National Cancer Institute’s Physician Data Query (PDQ®) on sleep disorders lists drugs from the benzodiazepine class and new sleep agents as the most widely prescribed (National Cancer Institute, 2010). Survivors are encouraged to check with their provider before taking herbal agents because potential interactions may occur between herbal agents and other common drugs.

CASE STUDY

G.A. was a married, 56-year-old African American female who received a matched unrelated donor hematopoietic stem cell transplantation for acute lymphocytic leukemia two and a half years ago. Her post-transplant course had been complicated by chronic graft-versus-host disease (GVHD) requiring treatment with immunosuppressants, including prednisone 40 mg daily. Comorbidities include neuropathic pain, depression, weight gain, and osteoporosis. She had been postmenopausal since her remission induction chemotherapy. G.A. returned to part-time work, with adjusted responsibilities because of her physical and cognitive fatigue and to allow her to keep frequent medical appointments. However, G.A. was worried these accommodations would not be offered to her indefinitely. Although she was prepared to feel fatigued for at least a year after transplant, she had become very discouraged by its persistence, and she was tearful as she discussed her concerns.

Because of the multiple psychological stresses as well as neuropathy, she had difficulty falling asleep most nights, and often lay awake in pain. Although she had experienced trouble sleeping for several years, it had worsened with the initiation of prednisone. She rated her fatigue severity as 6 or 8 on a 0–10 scale and was fatigued on most days. Her muscles felt weak, and she frequently experienced daytime sleepiness, difficulty concentrating, and short-term memory problems. These all caused her to limit her social interaction and recreational pursuits. She often went straight to bed after work, spending the evenings napping and watching television. On examination, she was obese with a body mass index of 32; complete blood count and basic metabolic panel were normal.

As an initial step in the management of this patient with moderate to severe fatigue, the nurse conducted a comprehensive assessment of her fatigue and sleep-wake patterns and coordinated the care team. Evaluating the contributing factors, the nurse noted that G.A. had an elevated thyroid-stimulating hormone and reduced free T4, consistent with hypothyroidism. The nurse also noted depression, sarcopenia, and suboptimal management of neuropathic pain. The patient was not engaged in a program of regular exercise. An initial plan included pharmacotherapy to address pain,
depression, and hypothyroidism, as well as referral to physical therapy to improve strength, aerobic conditioning, and muscle mass. Amitriptyline at bedtime was selected for painful neuropathy, and its sedating side effects also may have a beneficial impact on sleep. To improve G.A.’s sleep quality, the nurse recommended progressive muscle relaxation with imagery and behavioral measures including maintaining regular bedtime and get-up times, using the bedroom only for sleep and sexual activity, and initiating a calming presleep routine. The nurse discussed with G.A. several causes of her fatigue during survivorship and how chronic GVHD and its treatment may amplify her fatigue and sleep problems through an altered cytokine milieu and disrupted immune-neuroendocrine stress response. The nurse also provided coaching to encourage goal setting and self-management. At the weekly team conference, the nurse suggested administering prednisone in the morning to limit the effects on sleep and/or moving to an every-other-day steroid dosing, as tapering proceeds. At her follow-up appointment eight weeks later, G.A. rated her fatigue as a 3 out of 10 and reported that her sleep and daytime functioning were gradually improving. The team encouraged her to continue the positive steps she has taken to reduce her symptom distress and recommended follow-up assessments every month to modify the care plan and consider referrals.

SUMMARY

Progress delineating the pathophysiology and etiology of CRF and sleep disturbances has led to gains in identifying effective interventions. However, treatment approaches are largely symptom oriented and must be individualized and regularly revised. A substantial body of evidence indicates that selected pharmacologic, rehabilitative, and supportive care interventions are effective for these symptoms, but follow-up is needed to evaluate the effect of the prescribed therapies in individual survivors. Future work is needed in the areas of research, practice development (education and training), and health policy. Questions remain about the effectiveness of these interventions for specific groups of cancer survivors, about best practices to disseminate these research-tested interventions, and how best to educate and support providers for widespread delivery of interventions to survivors.

REFERENCES


INTRODUCTION

Gastrointestinal (GI) cancers include a variety of malignant conditions that affect the esophagus, stomach, liver, biliary system, pancreas, small and large bowels, rectum, and anus. GI cancers are common among males and females; colorectal cancer (CRC) is the third most common cancer in the United States (Edwards et al., 2010). The treatment plan for nonmetastatic CRC includes surgical intervention resulting in the excision of a portion of the colon (colectomy), the entire colon (subtotal colectomy), the rectum (low anterior resection or abdominoperineal resection), or the entire colon and rectum (total proctocolectomy), resulting in decreased anatomic function. As a result, patients who have undergone a major surgical resection for CRC may experience a variety of chronic symptoms, including constipation, diarrhea, or fecal incontinence, that persist during their survivorship and result in a negative impact on quality of life (Arndt, Merx, Stegmaier, Ziegler, & Brenner, 2006; Ramsey, Berry, Moinpour, Giedzinska, & Anderson, 2002).

Genitourinary (GU) cancers also are common and include the female cancers (cervical, uterine, ovarian, and genital) and prostate cancer; both genders are at risk for bladder cancers. Treatment interventions, specifically surgery and radiation therapy, can significantly alter the GU anatomy with a negative effect on quality of life. GI and GU cancer survivors commonly experience multiple GI and GU symptoms. Additionally, survivors with all types of malignancies can experience GI or GU symptoms throughout the cancer trajectory. GI symptoms are frequent and can be devastating in advanced cancer (Potter & Higginson, 2002).

GI symptoms often are interrelated and are a source of physiologic and emotional morbidity to survivors and their families. These symptoms can in-
Altered gastrointestinal motility

Constipation

Constipation, either acute or chronic, is the irregular, infrequent, or difficult evacuation of the bowels (Enck, 2009). Multiple etiologies are related to constipation, including organic factors such as pharmacologic agents, metabolic disturbances, and neurologic disorders, as well as structural abnormalities and functional factors. Functional factors include diet, environment, lack of exercise, and advanced age (Enck, 2009). Treatment of constipation includes laxatives, enemas, and increased dietary fiber and fluid intake.

Constipation commonly occurs in cancer survivors as a result of mechanical malfunction or as a side effect of opioid use or other pharmaceutical agents. Opioids affect the elimination tract, causing a decrease in motility or peristalsis and an increase in intestinal fluid absorption (Chamberlain et al., 2009). Sykes (1998) proposed that patients taking opioids do not develop a tolerance to constipation over time, as often observed with other symptoms such as sedation, nausea, and vomiting. Constipation may occur in 90% of patients on opioid therapy, persisting for the duration of use (Chamberlain et al., 2009).

Opioid-induced constipation can negatively affect quality of life because of the chronic nature of the symptom as related to ongoing opioid pain management. In an effort to improve laxation, patients may minimize their opioid treatment with a resulting negative effect on pain control. Opioids can increase gut fluid reabsorption and inhibit gastric emptying, with a concomitant decrease in intestinal transit. These mechanisms lead to abdominal distention, bloating, pain, and oozing of liquid stool. The novel use of opioid antagonists may reverse the slowing of the gut without reversing the analgesic effects of the opioids. Laxation can be predictable, and reduction in the
use of laxatives and enemas will improve quality of life and restore a sense of dignity for the patient (Chamberlain et al., 2009; Healey, 2009).

Diarrhea

Diarrhea can be categorized according to its underlying mechanism, such as osmotic, secretory, exudative, or motility disturbances (Richardson & Dobish, 2007), although the etiology of diarrhea often is difficult to discern, especially in cancer survivors with multiple comorbidities. An assessment of medications, chemotherapeutic agents, laxative treatment, magnesium-containing antacids, constipation, and recent antibiotic therapy is necessary. Other contributing factors of diarrhea include diet, infection, inflammatory factors, malabsorption, neuroendocrine factors, and psychological factors (Richardson & Dobish, 2007).

Treatment typically is empiric in nature regardless of the etiology, with fluid supplementation and dietary modifications. Loperamide treatment often is effective; in some situations, the addition of octreotide acetate, budesonide, or atropine may reduce the severity of symptoms. If diarrhea is severe with concomitant dehydration, hospitalization may be required to avoid debilitating dehydration, renal insufficiency, or electrolyte imbalances (Asnacios, Naveau, & Perlemuter, 2009; Richardson & Dobish, 2007).

Diarrhea is a common side effect of chemotherapeutic agents. Regimens containing 5-fluorouracil or irinotecan are associated with high rates (80%) of diarrhea (Richardson & Dobish, 2007). Diarrhea is somewhat common (20%–28%) in patients receiving anti–epidermal growth factor receptor (anti-EGFR) monoclonal antibody therapy, although it is seldom severe. In patients receiving EGFR–tyrosine kinase inhibitors, diarrhea can be more severe with an incidence of 50%–60% (Richardson & Dobish, 2007). Treatment is focused on conventional interventions, and dose modifications may be necessary. Symptom management is necessary to avoid adherence issues, decreased drug intake, or treatment discontinuation (Asnacios et al., 2009).

Chronic diarrhea can have a negative impact on lifestyle and be a source of psychosocial issues. Cancer survivors who experience frequent bouts of diarrhea with or without fecal incontinence tend to stay at home, monitor their diet, avoid other people, and, when they socialize, must ascertain available restroom facilities. Control of diarrhea is imperative to improve quality of life and well-being.

Nausea and Vomiting

Nausea and vomiting (N/V) are two of the most feared adverse events associated with a cancer diagnosis (Trigg & Higa, 2010). Nausea is an uncomfortable feeling with the need to vomit, with associated autonomic symptoms such as pallor, cold sweats, and tachycardia, and with diarrhea. Vomiting is described as the forceful expulsion of gastric contents, whereas retching is spas-
modic contractions without expulsion (Ang, Shoemaker, & Davis, 2010). The incidence of chemotherapy-induced N/V is a significant problem despite the efficacy of pharmaceutical interventions. In advanced cancer survivors, 60% reported vomiting and 30% reported nausea, with a 75% overall incidence of N/V (Ang et al., 2010). Advanced cancer survivors may experience N/V as a result of impaired gastric emptying or gastric stasis, metabolic or chemical factors, central nervous system metastases, and vestibular effects.

Treatment for N/V can be empiric with the use of one or more interventions, or etiologic with clinical assessment of the cause (Ang et al., 2010). Healthcare professionals may underestimate the incidence and severity of N/V because of the lack of effective assessment and communication with survivors (Grunberg, Clark-Snow, & Koeller, 2010). The failure to control N/V can inadvertently increase utilization of healthcare resources, but more importantly, it can negatively affect survivors’ functional activity and quality of life (Trigg & Higa, 2010).

In order to deliver effective antiemetic therapy, the clinician should undertake a comprehensive health assessment of the patient. Grunberg et al. (2010) described multiple factors to consider as part of a thorough assessment. Conditions such as arthritis can interfere with dexterity and administration of medications, and cognitive issues can impede the understanding of complex medication regimens. Polypharmacy may be confusing to patients, affect adherence, and potentially increase drug-drug interactions. The costs of drugs may be prohibitive, leading to decisions to eliminate or decrease prophylactic regimens. Mucositis, a complication from both chemotherapy and radiation therapy, may also affect adherence. Anticipatory N/V can make effective control difficult. Depression can negatively affect compliance; language and cultural barriers may inhibit effective communication; and some patients may just “accept” that N/V is an expected side effect or a reflection of treatment efficacy.

Healthcare professionals may contribute to ineffective management of N/V. Time, a precious commodity, is a barrier for most healthcare providers. As a result, education, support, and ongoing conversation with the patient often do not occur. Reinforcement of the mantra that N/V is easier to prevent than treat is essential. Additionally, the patient’s literacy level, ability to read, severity of illness, and ethnicity are important variables to consider. Empathy with the ability to “connect” can reduce anxiety and increase satisfaction and adherence. Furthermore, effective communication among members of the healthcare team is essential (Grunberg et al., 2010). Administration issues are associated with effective control of N/V and adherence to medication regimens.

Evidence-based practice guidelines, such as those recommended by the Multinational Association of Supportive Care in Cancer, the National Comprehensive Cancer Network, or the American Society of Clinical Oncology, are key to the effective management of N/V but often are not used. Methods to improve follow-up care, such as online communication, should be explored. The estimated costs of controlled or uncontrolled N/V can be as high
as $1,300/month and may require detailed discussion in order to remove barriers to delivery systems.

Effective management of chronic N/V in survivors with advanced cancer may center on novel drug delivery systems such as long-acting formulations, nasal sprays, ambulatory pumps, or transdermal patches (Grunberg et al., 2010).

The advent of the 5-HT$_3$ receptor antagonists (ondansetron, granisetron, dolasetron, and palonosetron) has been revolutionary in providing effective management of N/V. Other effective agents, either singular or in combination, include aprepitant, dexamethasone, olanzapine, metoclopramide, and haloperidol. The notion of zero tolerance of N/V is important to enhance available treatments, avoid delays in cancer treatment, and provide effective symptom management for the long-term or metastatic cancer survivor.

**ALTERED GENITOURINARY FUNCTION**

The primary treatment regimen for abdominal cancers in the Western hemisphere is a multimodality approach consisting of chemotherapy, radiation, and/or surgery. The collective and cumulative effects of these treatment modalities often result in impaired urinary dysfunction and sexual dysfunction, or both, because of damage of the autonomic nerves in the pelvis (Donovan, Thompson, & Hoffe, 2010; Lindsey & Mortensen, 2002). Surgical interventions, whether laparoscopic or open (Jayne et al., 2005; Morino et al., 2009), are highly correlated with impaired sexual and urinary function (Hendren et al., 2005) resulting from direct nerve injury at the time of surgery or from potential surgical complications such as an anastomotic leak or blood loss (Lange et al., 2009; Moriya, 2006).

**Urinary Incontinence**

Urinary stress incontinence is a distressing side effect related to childbirth and menopause, as well as anatomic alterations as a result of gynecologic and colorectal surgical procedures. Postmenopausal women with and without breast cancer (62%) reported symptoms related to stress and urge incontinence; 91% of pre- and postmenopausal women reported nocturnal urination (Lester & Bernhard, 2009). Kegel exercises, lifestyle changes, and nonpharmacologic and pharmacologic interventions may reduce or improve symptoms. Surgical interventions to repair anatomic defects are sometimes necessary.

Men, likewise, can suffer from urinary incontinence related to aging, prostatic hypertrophy, or as a result of colorectal or prostate surgery. The incidence of post-prostatectomy urinary incontinence is variable (3%–74%) depending on the type of surgical procedure. At six weeks after a radical prostatectomy, 59% of men were incontinent, compared to 22% at 58 weeks after surgery (Wolin, Luly, Sutcliffe, Andriole, & Kibel, 2010). The nerve-sparing radical prostatectomy used to treat localized prostate cancer can reduce the
risk of long-term urinary incontinence (Loughlin & Prasad, 2010), but the patient must be informed that urinary incontinence can occur regardless of surgical expertise and technique.

Factors such as obesity and sedentary lifestyle may contribute to increased symptoms of incontinence in prostate cancer survivors (Wolin et al., 2010). Obesity may cause additional strain on the bladder and, thus, a higher incidence of incontinence. Decreased physical activity may increase the risk of incontinence because of a lack of overall muscle tone and a lack of motivation to do Kegel exercises. Therefore, lifestyle changes may have a positive impact on this debilitating symptom.

### Urogenital Atrophy

Urogenital atrophy is the presence of subjective or objective symptoms related to the urologic, genital, and sexual domains and anatomy of the lower genital tract (see Figure 12-1). The subjective complaint of vaginal dryness is the most common symptom related to urogenital atrophy in women (Lester & Bernhard, 2009).

The pathophysiology of urogenital atrophy is related to estrogen receptors found in the structures of the lower urinary and genital tracts. Degeneration of tissues occurs with decreases in size and blood flow, vaginal secretions, loss of elasticity, thinning of tissues, increase in pH, and overall structure atrophy (Kelley, 2007). In cancer survivors, these changes typically occur as a result of surgical- or chemotherapy-induced menopause and can be exacerbated by ongoing antiestrogen therapy. The atrophic and dry vaginal epithelium, thinned endometrium, and increased vaginal pH predispose the woman to infection and mechanical weakness, with symptoms of vaginal dryness, loss of pelvic support, decreased tissue elasticity, dyspareunia, voiding changes, and overall urogenital discomfort.

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<tr>
<th>Urologic</th>
<th>Genital</th>
<th>Sexual</th>
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<tr>
<td>• Urinary urgency</td>
<td>• Vaginal bleeding</td>
<td>• Dyspareunia</td>
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<td>• Urinary urge incontinence</td>
<td>• Burning</td>
<td>• Decreased sexual satisfaction</td>
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<td>• Urinary stress incontinence</td>
<td>• Discharge</td>
<td>• Difficulty in sexual arousal</td>
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<td>• Vaginitis</td>
<td>• Loss of interest in sexual activity/decreased libido</td>
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<td>• Itching</td>
<td>• Discharge</td>
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<td>• Recurrent urinary tract infections</td>
<td>• Irritation</td>
<td>• Decreased closeness with partner</td>
</tr>
<tr>
<td>• Dryness</td>
<td>• Soreness/tenderness</td>
<td>• Dryness</td>
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*Note. Based on information from Lester & Bernhard, 2009.*
Sexual Functioning in Men

Impairment of sexual functioning in men is manifested as erectile dysfunction and ejaculatory disorders such as retrograde ejaculation (Donovan et al., 2010; Hendren et al., 2005). The reported prevalence of sexual dysfunction varies widely (Donovan et al., 2010; Hendren et al., 2005) but has been reported to be as high as 76% up to 24 months after therapy (Lange et al., 2009). Prostate cancer survivors undergoing androgen deprivation therapy can suffer from severe hypogonadism with a significant drop in serum testosterone and accompanying physiologic changes (Saylor, Keating, & Smith, 2009).

Rectal cancer survivors report a lower quality of life in relation to these dysfunctions, particularly sexual impairment, as a result of diminished self-esteem and body image (da Silva et al., 2008). This is notably true for patients who have undergone surgical excision of the rectum resulting in a permanent ostomy due to an abdominoperineal resection or total proctocolectomy (Donovan et al., 2010; Guren et al., 2005). Survivors of CRC with stomas have a diminished body image and sexual function in comparison to other CRC survivors, especially if they are less educated and young (da Silva et al., 2008; Morino et al., 2009). See Chapter 13 for more information about sexuality and cancer survivors.

CASE STUDY

A 47-year-old recently divorced female presented to her primary care physician with a one-month history of bright red blood per rectum with stools, alternating diarrhea and constipation, and fatigue. Upon physical examination, she had a palpable mass 3 cm from the anal verge. A subsequent colonoscopy with biopsy was indicative of a moderately differentiated adenocarcinoma. She underwent neoadjuvant chemotherapy (capecitabine) with concurrent radiation followed by a low anterior resection with a low coloanal anastomosis. She was pathologically staged at T3N1Mx. After the surgery, she developed an anastomotic leak requiring an ileostomy for the duration of her FOLFOX (leucovorin, fluorouracil, and oxaliplatin) chemotherapy regimen. She underwent an ileostomy reversal eight months after it was placed. She has returned to the outpatient oncology clinic for routine surveillance as recommended by the American Society of Clinical Oncology. At two years since her initial surgery, she showed no evidence of disease.

Since her ileostomy reversal, she reported frequent (2–5) loose stools per day with occasional fecal incontinence. She was currently on a regimen of two tablets of over-the-counter loperamide four times per day, fiber powder daily, and cholestyramine powder 4 g daily. (Cholestyramine is used as an antidiarrheal for patients with severe diarrhea or fecal incontinence after colectomy; it absorbs the bile salts [Remes-Troche, Ozturk, Philips, Stessman, & Rao, 2008].) She was unable to afford octreotide injections. During her most recent visit, she expressed concern and anxiety because she felt emotional-
ly prepared to begin dating but was reluctant to do so because of a negative body image. Her medical history included anxiety treated by her primary care provider with a selective serotonin reuptake inhibitor and diabetes mellitus type 2 treated with metformin. Additionally, she was active in counseling for six months with a licensed social worker affiliated with a local comprehensive cancer center.

**SUMMARY**

Patients with GI and GU cancers undergo complex treatment regimens with multiple treatment modalities that are responsible for transient, semi-permanent, and sometimes permanent symptoms. Additionally, GI and GU symptoms can occur in any cancer survivor at any point in the cancer trajectory. The early recognition of symptoms with appropriate interventions may reduce the negative impact, severity, and permanence of symptoms. Members of the oncology healthcare team should become familiar with the assessment of these GI and GU symptoms, especially the more common symptoms of constipation, diarrhea, N/V, urinary incontinence, and urogenital atrophy. As we continue to strive for extended disease-free intervals, we also must strive for improved quality of care with symptom-free survival.

**REFERENCES**


INTRODUCTION

Cancer survivors report that insufficient information is provided to them about sexual functioning and that the information provided is often not shared in a timely fashion (Gallo-Silver & Parsonnet, 2001; Katz, 2005; Melby, 2009). Cancer survivors clearly indicate that returning to a sense of self as a sexual person is part of their expectations of thriving after cancer and the post-treatment reentry process (Hawkins et al., 2009; Katz, 2007). Unfortunately, patients and survivors often are desexualized by healthcare professionals’ belief that they are too ill, impaired, or weak for sexual activity. Barriers for healthcare professionals, patients, and partners to addressing sexual concerns and issues can be seen as rooted in a rigid understanding of the expression of human sexuality (Gallo-Silver, 2006). Therefore, it is more helpful and accurate to define human sexuality as inclusive of all aspects of connecting and communicating pleasurable touch that includes soothing, affection, sensuality, and eroticism, rather than seeing sexual issues as only functioning of genitals (De Villers, 2002; Esmail, Yashima, & Munro, 2001). This chapter will address current reentry process options, described as a series of steps, for cancer survivors and their partners (see Figure 13-1).

REBUILDING ROMANTIC RELATIONSHIPS

Romantic partners often provide both practical and personal care to the partner with cancer (Hawkins et al., 2009). Becoming involved with a partner’s appetite, personal hygiene, and toileting lends itself to a parent’s protective and loving approach to a child. When the cancer survivor gradually resumes these responsibilities, romantic partners have difficulty addressing
sexual intimacy without proactive interventions. Sexual intimacy requires a return to the basic emotional intimacy of the couple. Emotional intimacy can be addressed by having couples reminisce about the history of their relationship by describing memories of how they met, when and why they became a couple, and the various milestones they have experienced as a couple, such as the birth of children (Hazan & Shaver, 1987; Maltz, 2001). Creating a story board using photos that represent the different points in their history together can help this process. Listening to “their song,” visiting their favorite restaurant from when they were dating, and renting movies they saw together are additional ways of reminiscing. Couples are encouraged to return to the foundation of their romantic relationship by holding hands rather than steadying their partner, to engage in caresses rather than supportive hugs, and kisses on the lips rather than the cheek or forehead. As the care partner also has been desexualized, both need to help each other rebuild the romance in their relationship and diminish the parent-child dyad that may have been formed (McCabe, 1994).

RECLAIMING PLEASURABLE SENSATIONS

Cancer survivors experience intrusive touching, loss of privacy, loss of weight and muscle mass that causes a general achiness, and a variety of distressing and painful sensations that make them wince, shudder, or generally dread another person’s approach (Gallo-Silver, 2000; Gallo-Silver & Parsonnet, 2001). Touch has been rendered toxic by negative reinforcement, thus becoming an intractable obstacle to a return of sexual intimacy. The care partner also can experience a loss of sensitivity to pleasurable touch because of anxiety, sadness, inadequate nutrition, sleep disturbance, lack of exercise, and fatigue (Schover, 1997). Exercises can help cancer survivors and their partners reclaim the sensation of pleasurable touch. For example, finger writing is an exercise that asks the receiver to close his or her eyes while the giver traces the letters of a three- or four-letter word on the palm of the receiver’s hand.
using a finger. The receiver has to concentrate in order to sense and identify the word being traced (Maltz, 2001, 2003).

REESTABLISHING BODY SELF-ESTEEM AND REDISCOVERING RELAXATION

Cancer survivors who have rejected and disconnected from their body are unlikely to want to participate in touching exercises or to even contemplate sexual intimacy. Bathing presents opportunities for improving the connection between survivors and their bodies. Using liquid soaps rather than bars and soft artificial bathing sponges instead of washcloths can promote gentle notice and exploration of the body because of the soothing nature of these bathing interventions. Additional opportunities to improve the survivor’s connection to his or her body are in changing bedtime rituals. Chief among these is suggesting to the survivor to get rid of old, worn bed clothes such as socks, T-shirts, bed shirts, pajamas, and nightgowns, especially any item that was worn during hospital stays or at home during convalescence. These should be replaced with new bed clothes in bright, pleasing colors made of natural fabrics (Gallo-Silver & Parsonnet, 2001). A helpful morning exercise to introduce is self-talk. The survivor stands before a mirror, looks at his face, and then lists the things—physical, emotional, spiritual, or intellectual—that he likes, admires, or values (Golden, Gersh, & Robbins, 1992). This exercise helps in the survivor’s ownership of his abilities, skills, and attributes.

Stress diminishes a person’s responsiveness to desire, touch, and arousal, thus causing a sense of separation from the body. These feelings close off the survivor’s body sensations and emotional accessibility to his or her partner. Relaxation of one’s thoughts, images, and muscles can sometimes help the survivor to remain open to emotional, physical, and sexual experiences while still feeling safe and secure. Most of these exercises are based on diaphragmatic breathing (deep breathing) mixed with visualizing the word peace or love, calming memories, or pleasing images of favorite settings (Benson, 2000).

REINTRODUCING EROTICISM

Eroticism needs to be slowly and gradually reintroduced to the cancer survivor and partner. It is important that the cancer survivor feel in control of this process so that it is paced in a way that modulates the possibility of pain. Body mapping can help couples by having the cancer survivors indicate on a blank outline of a body through color (using crayons or pencils) the areas of their body that feel pleasurable when touched, feel neutral, or feel distressing or painful (Maltz, 2003).

Massage can enliven and identify pleasurable areas described by the survivor as “neutral.” Massage often is more successful if the focus is on a body part
that is not considered traditionally erogenous, such as the hands, face, back, or neck (De Villers, 2002). Sensate focus is a structured group of nongenital sensuous massage that gradually helps couples to reawaken their sexual interest and responsiveness (Kaplan, 1987). Masturbation is the initial foundation of eroticism. Cancer survivors often find it easier to return to masturbation before having sexual contact with partners because it is a way to experience changes in body sensations and functioning (Gallo-Silver, 2000). Sex toys are common interventions that can be helpful in increasing eroticism and include vibrators, clitoral stimulators, masturbation pumps, suction devices, and anal plugs (Kaufman, Silverberg, & Odette, 2007). Regardless of the steps the cancer survivor takes to reintroduce eroticism, it is helpful to use lubricants that enhance the experience and protect sensitive body tissues. Using these concepts, survivors can recover sexual enjoyment.

CASE STUDY ONE

Jerry (age 68) was treated for prostate cancer with surgery, and Adelaide (age 59) was treated for recurrent breast cancer using multiple treatments. They have been married for 30 years and have three children together. Following the removal of his post-prostatectomy urinary catheter, Jerry’s erectile dysfunction urologist started him on a low dose of oral erectile dysfunction medication. Taken before bed, this medication serves to potentiate blood engorgement of the penis that men experience during the dream phase of sleep. The urologist also suggested that Jerry use a vacuum pump two to three times a week to both force blood into the penis and to address the potential shortening of his penis. Jerry and Adelaide used reminiscing to help them regain a level of emotional intimacy. Jerry was given permission to masturbate by rubbing the glans of his penis when well lubricated; he experienced orgasm. Because he was unable to achieve an erection, he was prescribed an injected erectile dysfunction medication that resulted in a strong erection.

When Adelaide was diagnosed with recurrent breast cancer, the change in her body, her feelings about having breast cancer again, physical changes due to estrogen deprivation, and diminished desire generally made her less interested and accessible to sexual intimacy. Sensate focus exercises gave Adelaide more comfort and control when she was physically intimate with Jerry. Their kisses deepened, and they enjoyed cuddling in bed again. The use of small dilators with a lubricant gently stretched Adelaide’s estrogen-deprived vaginal vault and enabled her to use a small vibrator, providing sensual pleasure.

RECOVERING THE POSSIBILITY OF BIOLOGIC PARENTHOOD

The previous steps in sexual recovery can increase couples’ emotional intimacy and therefore prepare them psychosocially for the challenge of bio-
logic parenthood. Problems with fertility experienced by cancer survivors are related not only to the damage caused by the uncontrolled growth and invasion of malignant cells but also to the designated treatment regimen. Chemotherapy, especially alkylating agents, and radiation therapy may affect the ability to naturally conceive. The destruction of sperm production or the inability to ejaculate adequately may prevent sperm from reaching the fallopian tubes. These same treatments are toxic to ovaries (Jeruss & Woodruff, 2009) and can damage the surface of a woman’s uterus so that implantation of an embryo may be virtually impossible. In some instances, although implantation takes place, the woman’s uterus may not be capable of carrying a pregnancy to term. Radiation directed at the pelvic region can damage reproductive organs responsible for the development of sperm and eggs. In cancers that affect the brain, surgery or radiation therapy may alter fertility because brain tissue is involved in hormonal regulation and can be damaged, thus negatively affecting menstruation, ovulation, and sperm production (Kelvin, 2009).

**Sperm Banking**

Small vials are used to store amounts of sperm (1 ml or less), which are maintained at extremely low temperatures (–320°F [–190°C]) in tanks containing liquid nitrogen (Cryochoice, n.d.). Prior to this freezing process, the sperm is specially processed for intracervical insemination, intrauterine insemination, or for assisted reproductive technology (ART) procedures such as in vitro fertilization (IVF), gamete intrafallopian transfer, or zygote intrafallopian transfer and intracytoplasmic sperm injection (Cryobank, n.d.). According to the University of Michigan Comprehensive Cancer Center (2009), the average pregnancy requires four to five ovulatory cycles with intrauterine insemination. However, the intracytoplasmic sperm injection, an innovative ART technique, can be successful using only a very small number of sperm (University of Michigan Comprehensive Cancer Center, 2009). Although these techniques offer viable options to survivors with infertility issues, the costs often can be problematic and typically are not covered by insurance. Expenses for these services can range from several hundred to thousands of dollars to test and process the sperm, with additional substantial costs per year to store it (Sperm Bank Inc. dba Fertility Center of California, n.d.).

Men experiencing cancer at a young age often are just as concerned about their risk for infertility as women are and may undergo emotional mood swings and indecisiveness upon first hearing their diagnosis (Lance Armstrong Foundation, n.d.). Lack of privacy, embarrassment, fear, and anxiety can prevent a man from providing an adequate deposit of sperm.

**Ovum Banking**

Similar to men’s option of sperm banking, women have the option to bank ovum (see Appendix H). According to Licciardi (2008), to ensure successful
oocyte retrieval and IVF, and increase the chances of recovering several mature, healthy ova, the woman has to harvest as many as 18 eggs. The preparation includes up to two weeks of intensive hormonal treatment with fertility drugs, blood tests, and ultrasound scans to establish the most favorable time to retrieve the eggs when they are ready for fertilization. Transvaginal oocyte retrieval can be done in an outpatient setting under local anesthesia, resulting in only mild discomfort after the procedure (Georgia Reproductive Specialists, 2007).

Fertility preservation by creating cryogenically stored eggs, sperm, or embryos leads to questions regarding the disposition of remaining eggs, sperm, or embryos. Quinn et al. (2010) pointed out that some patients and families consider “posthumous parenting,” allowing the embryos to be used even if the patient dies. They suggested that patients should outline the procedures for future disposition of the stored embryos. Legal and ethical issues often arise if the remaining partner does not want to use the embryos or if the couple separate or divorce. Medenwald (2001) cited cases that resulted in Supreme Court decisions where there was no agreement regarding the disposition by both parties. In these cases, joint control was presumed, and the courts upheld that “the right of procreational autonomy is composed of two rights of equal significance—the right to procreate and the right to avoid procreation” (p. 508). Without consensual agreement regarding disposition, the court decision resulted in continual storage of the embryos until they would no longer be viable for implantation, or simply thawing and discarding the embryos. Interestingly, although significant ethical controversy exists as to whether an embryo should be considered “property” or a “person,” Upchurch (2005) referred to Louisiana’s legislation that deemed frozen embryos to be “persons” mainly because it would result in making IVF clinics impractical and possibly illegal.

CASE STUDY TWO

A young woman of African American descent, Ayesha (age 32), was in her first trimester of pregnancy when she was diagnosed with breast cancer. It is rare for women to be diagnosed with cancer during pregnancy, although as women are waiting longer to have children and the risk for breast cancer increases with age, more cases are occurring than in previous years. It is anticipated that the number of cases of breast cancer diagnosed during pregnancy will escalate if this trend continues. According to the American Cancer Society (ACS), the present rate for pregnant women diagnosed with breast cancer is approximately 1 out of 3,000 (ACS, n.d.). During pregnancy, hormonal shifts occur and the breasts increase in size and become tender and lumpy, making it more difficult to perform an accurate breast examination. For this reason, women who are diagnosed with breast cancer during pregnancy may be more likely to be diagnosed with a more advanced stage of the disease (ACS, n.d.).
Although some physicians continue to encourage terminating the pregnancy to help slow the advancement of breast cancer, generally no proven studies exist demonstrating that terminating pregnancy improves survival outcomes (ACS, n.d.). However, most physicians agree that the sooner any type of appropriate treatment is begun with any illness or disease, the more rapidly healing will occur. Because many of the diagnostic tools that establish the best therapy, as well as the actual chemical, radiologic, or surgical treatments, could place the fetus in jeopardy, it is very difficult for an expectant mother to make a decision such as this. It is distressing for a person to cope with a life-threatening diagnosis of cancer that requires immediate treatment and the natural desire to protect her unborn baby.

Ayesha was determined to have her baby, even if it meant delaying her own therapy. After researching her options with her primary practitioners, Ayesha realized that the safest option was to proceed with surgical intervention, her primary cancer treatment. Although adjuvant radiation is sometimes done following surgical intervention, this was not an option for Ayesha because the radiation could negatively affect the fetus. However, studies demonstrate that adjuvant chemotherapy treatment using CA (cyclophosphamide and doxorubicin) or CAF (cyclophosphamide, doxorubicin, and 5-fluorouracil) can be administered during the second trimester with little risk of neonatal harm. CMF (cyclophosphamide, methotrexate, and 5-fluorouracil) is not typically chosen for adjuvant breast cancer chemotherapy, as methotrexate must be avoided because of its folic-inhibiting qualities, which would negatively affect the neural tube development of the growing fetus, even into the third trimester (Visco, Meyer, Xi, & Brown, 2009). In one of the studies cited by Visco et al. (2009), it was noted that a fetus may be at risk for teratogenic effects from cytotoxic drug therapy even into the second trimester. The only pregnancies that appeared unaffected by treatment in the study were those treated in the final trimester, which all resulted in the birth of healthy babies. The lack of prospective data for decisions related to cancer treatment during pregnancy can create anxiety and frustration.

Ayesha’s mother and sister supported her decision to maintain the pregnancy, to undergo surgery (modified radical mastectomy) during her second trimester, and to wait to begin chemotherapy until the third trimester of her pregnancy. Ultimately, Ayesha delivered a healthy baby boy by cesarean section.

**CASE STUDY THREE**

Angel, a single Hispanic man, was diagnosed at the age of 22 with a rare form of stage II non-Hodgkin sporadic Burkitt lymphoma. Although Burkitt lymphoma is a fast-growing non-Hodgkin lymphoma, it is curable with rigorous chemotherapy (Pagano, Caira, Valentini, & Fianchi, 2009). Initially, Angel did not want to accept the diagnosis and proceed with treatment. However, after a short time, he adjusted to his situation and agreed to therapy. Additionally, he decided to store his sperm in a cryobank for future use.
At the age of 23, Angel decided that he was unable to continue maintaining the storage charges for his sperm, yet he wanted to have a child. After discussing the situation with his girlfriend, who also wanted to have a child, he decided to use his stored sperm to impregnate her. The sperm count was sufficient to utilize the simplest method, intrauterine insemination, and she delivered a full-term baby boy through a normal spontaneous vaginal delivery. Angel became a father at age 24. The couple never married but shared custody of their son and went on to other relationships.

**SUMMARY**

Sexuality need not be sacrificed as the price of surviving cancer. Cancer survivorship includes the right to express sexual feelings in the most optimal way possible, given physical changes and constraints. The ongoing sensitivity of the skin, the ability to reignite sensuous feelings, and the gradual addition of eroticism contribute to making sexual enjoyment possible for cancer survivors and their partners. The wish to conceive a biologic child as a living testament to one’s health, vigor, and hope in the future is a privilege that no cancer survivor needs to immediately surrender.

**REFERENCES**


of partners in a sexual relationship with a person with cancer. Cancer Nursing, 32, 271–280. doi:10.1097/NCC.0b13e31819b5a93


CHAPTER 14

Lymphedema Following Cancer Treatment

Jane M. Armer, PhD, RN, FAAN, CDT/MLT, Bob R. Stewart, EdD, Kandis M. Smith, PhD, and Janice N. Cormier, MD, MPH

INTRODUCTION

The leading cause of secondary lymphedema (LE) in developed countries is cancer treatment (Rockson & Rivera, 2008). LE may have a significant impact on psychological and physical well-being and overall quality of life, with the onset of symptoms ranging from immediately after to more than 30 years after treatment (Rockson & Rivera, 2008). More than 11.4 million cancer survivors in the United States are at risk for developing LE over their lifetime (American Cancer Society [ACS], n.d.). “Oncology nurses caring for patients throughout the cancer trajectory have a critical role to play in early assessment of risk, prompt identification of LE, and implementation of evidence-based, individualized treatment plans in collaboration with therapists” (Poage, Singer, Armer, Poundall, & Shellabarger, 2008, p. 951).

BACKGROUND

LE is the accumulation of protein-rich fluid within interstitial spaces, often leading to chronic inflammation and reactive fibrosis in the affected tissues (Földi, Földi, & Kubik, 2003). In the early stages of LE, symptoms may include “heaviness, tightness, aching, burning, swelling, hardness, stabbing, pins and needles, pain, and numbness” (Ridner, 2009a, p. 30). LE is a lifelong condition, and although there is no cure for secondary (or primary) LE, treatments are available that help individuals effectively manage the physical and psychosocial impact of living with LE.

Secondary LE may occur following any cancer treatment (Földi et al., 2003). Although some studies report that up to 70% of breast cancer survivors may
develop LE (Armer & Stewart, 2005, 2010; Armer, Stewart, & Shook, 2009), a leading oncology textbook reported that 15%–20% of breast cancer survivors may develop LE over their lifetime (Disa & Petrek, 2001). The wide ranges reported are mainly a result of discrepancies in diagnostic criteria, measurement modalities, and length of follow-up (Armer, 2005; Armer, Stewart, Shook, & Cormier, 2009; Bernas, Cormier, Askew, & Armer, 2010). Further variation is seen in LE occurrence across different cancer diagnoses (Cormier et al., 2010) (see Table 14-1). In a systematic review of the literature, Cormier et al. (2010) found that the overall incidence of LE for survivors of melanoma, gynecologic malignancies, genitourinary cancers, head and neck cancers, and sarcomas was 15.4%.

A constellation of treatment and lifestyle risk factors exists for secondary LE following cancer treatment. Treatment risk factors include extent of surgery and lymph node dissection; chemotherapy; radiation therapy; and occurrence of postoperative seroma, swelling, and infection (Armer, Shook, et al., 2009; Cormier et al., 2010; Mahamaneerat, Shyu, Stewart, & Armer, 2008). Several studies have indicated that new surgical techniques may minimize the occur-

<table>
<thead>
<tr>
<th>Group</th>
<th>Number of Articles</th>
<th>Total Sample Size</th>
<th>Range of LE (%)</th>
<th>Mean LE Incidence Estimates (%)</th>
<th>U.S. Cancer Prevalence</th>
<th>U.S. LE Incidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast cancer</td>
<td>44</td>
<td>17,292</td>
<td>0–70</td>
<td>18.7</td>
<td>2,533,193</td>
<td>473,707</td>
</tr>
<tr>
<td>Melanoma</td>
<td></td>
<td></td>
<td></td>
<td>758,688</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Upper extremity</td>
<td>9</td>
<td>2,147</td>
<td>1–59</td>
<td>11.8</td>
<td>–</td>
<td>89,525</td>
</tr>
<tr>
<td>Lower extremity</td>
<td>14</td>
<td>1,549</td>
<td>6–67</td>
<td>30.5</td>
<td>–</td>
<td>231,400</td>
</tr>
<tr>
<td>Genitourinary malignancies (e.g., prostate,</td>
<td>7</td>
<td>826</td>
<td>1–23</td>
<td>12.9</td>
<td>2,705,471</td>
<td>349,005</td>
</tr>
<tr>
<td>bladder, penile)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gynecologic malignancies (e.g., uterine,</td>
<td>25</td>
<td>3,085</td>
<td>0–73</td>
<td>23.9</td>
<td>996,776</td>
<td>238,229</td>
</tr>
<tr>
<td>cervical, vulvar)</td>
<td></td>
<td></td>
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</table>

Total U.S. LE incidence = 1,381,866

ence of swelling and other morbidities that result from breast cancer surgery. Early studies examining LE occurrence following sentinel lymph node biopsy (SLNB) as compared to axillary lymph node dissection in breast cancer survivors showed a decrease in incidence (6%–8%) and severity of LE, although still clinically significant, following SLNB (Purushotham et al., 2005).

Modifiable lifestyle risk factors may affect the incidence of LE, including body mass index (BMI) greater than 25 (or increasing BMI greater than 25), hand dominance and level of arm use, and infection (Armer, Shook, et al., 2009; Mahamaneerat et al., 2008). The combination of high BMI and early postoperative swelling is reported to be a significant risk for the future development of LE (Mahamaneerat et al., 2008).

Diagnosis and Assessment

A patient history and physical examination are routinely used to determine whether an individual has cancer-related LE. The most commonly used radiographic modality for evaluation of the lymphatic system is lymphoscintigraphy. Additional radiologic imaging techniques, such as computed tomography, magnetic resonance imaging, or ultrasound, can be used to rule out other causes of edema during the diagnostic evaluation of a patient. Radiologic imaging also can be used to evaluate anatomy and function of the lymphatic system (Williams, Witte, Witte, & McNeill, 2000).

Historically, the gold standard of measurement in clinical evaluation of an individual with extremity swelling was water displacement volumetry. Water displacement, however, is cumbersome, presents hygienic issues, and is limited to patients with no skin lesions (Petlund, 1991). Today, in most clinical settings, serial circumferential limb measurements are used as an inexpensive and simple measurement approach for patients with extremity swelling. In this evaluation, the clinician uses a flexible, nonstretch tape measure to take a series of measurements along the limb with comparison of measurements to baseline or to the contralateral limb by girth or formula-derived volume (Armer, 2005; Callaway et al., 1988; Casley-Smith, 1994; Mayrovitz, 2003). Other measurements include perometry, an optoelectronic device designed for enhancing the fit of compression garments. Using arrays of infrared light with optoelectronic sensors, a three-dimensional silhouette is created (Armer, 2005; Petlund, 1991; Stanton, Northfield, Holroyd, Mortimer, & Levick, 1997). Bioelectrical impedance spectroscopy and tissue tonometry also are used to measure and evaluate LE (Armer, 2005; Bagheri, Ohlin, Olsson, & Brorson, 2005; Moseley & Piller, 2009; Petlund, 1991; Ward, 2009).

The International Society of Lymphology (2009) currently recognizes four stages of LE (see Table 14-2). The term latent or subclinical LE has recently been introduced to represent the at-risk stage (stage 0) experienced by patients undergoing diagnostic or treatment interventions that affect the lymphatic system (Gergich et al., 2008; International Society of Lymphology, 2009). Progressive swelling severity and skin changes define stages I through III.
Treatments and Interventions

Complete decongestive therapy (CDT)/complex physical therapy is the standard of care for the treatment of cancer survivors who develop LE (Földi et al., 2003; Moseley, Carati, & Piller, 2007; National Lymphedema Network [NLN], 2006). The key components of CDT treatment include (a) compression using low-stretch compression bandaging and compression garments, (b) manual lymph drainage (MLD), (c) movement therapies, including remedial exercise, (d) skin care, (e) nutrition, and (f) education for self-management. Administered by a specialty-trained therapist, CDT aims to reduce swelling and prepare patients for self-management and maintenance (Földi et al., 2003; NLN, 2005, 2006; Zuther, 2009). This therapy also may improve shoulder range of motion and decrease pain, as well as decrease limb volume. Intensive CDT typically lasts 10–20 days or 4–6 weeks, routinely beginning when LE is moderate to severe. Modified CDT may be used for mild to moderate LE (Poage, Armer, Singer, Shellabarger, & Poundall, 2009).

Compression bandaging is used to reduce swelling and prepare the limb for compression garments. Short-stretch, multilayer bandages are used either alone or in combination with other therapies to reduce limb volume during intensive treatment by a specialty-trained clinical therapist (NLN, 2005, 2006). Intensive therapy is followed by the maintenance phase of self-management, which includes self-MLD, daytime compression garments, and nighttime bandaging or adjunct compression wear. Properly sized and fitted compression garments, worn on a regular basis for daytime management of swelling, operate on the same principle as compression bandaging but also protect the limb against wounds (Devoogdt, Van Kampen, Geraerts, Coremans, & Christiaens, 2010).

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Subclinical or pre-lymphedema. Typically includes all patients who have had lymph node dissection. Swelling is not evident although impaired lymphatic flow is present. This stage may last for many years.</td>
</tr>
<tr>
<td>I</td>
<td>Accumulation of fluid and protein in tissue is present; an increase in proliferating cells may be seen. Elevation may influence the limb; pitting may be present.</td>
</tr>
<tr>
<td>II</td>
<td>Includes swelling that does not reduce with elevation alone; pitting is present with fibrosis. Excess fat and fibrosis supervene late in stage.</td>
</tr>
<tr>
<td>III</td>
<td>Fibrotic tissue has indiscernible pitting; includes skin thickening and large limb volume known as elephantiasis, a morbid condition where lymphstasis and chronic inflammation develop into fibrosclerosis and additional tissue swelling (Földi et al., 2003). Warty overgrowths may develop.</td>
</tr>
</tbody>
</table>

Note. Based on information from International Society of Lymphology, 2009.
MLD, a light, specialized lymphatic massage, moves lymph fluid from the affected body part to another more central (proximal) area of the body. Although treatment is initially done in the intensive phase by a specialty-trained LE therapist, the patient or caregiver also can be trained to perform the massage for long-term management (Moseley et al., 2007; NLN, 2006). Although not considered a component of CDT or a stand-alone therapy, pressotherapy, in which a person inserts the affected limb into a garment that sequentially inflates and deflates with a pneumatic compression device, may be used as an adjunct therapy to MLD and compression bandaging (NLN, 2006).

Exercise or nonfatiguing movement therapy as a central component of CDT is based on the premise that muscle contractions increase lymph flow throughout the body, thereby reducing fluid stasis and decreasing LE symptoms (Földi et al., 2005; Irdesel & Celikatas, 2007). Contrary to previous beliefs, recent research demonstrates that supervised exercise including weight training can be beneficial and not harmful to breast cancer survivors with LE (Schmitz et al., 2009). Based on each individual cancer survivor’s needs and conditioning, a supervised exercise program can be developed to support cardiovascular health, muscle strength, and functional capacity without increasing risk of LE progression (NLN, 2008; Schmitz et al., 2009).

Proper skin care is essential for LE risk reduction and prevention of infection. Patients must keep the skin clean and moisturized and avoid skin breaks, sunburn, and constriction (e.g., tight clothing and use of blood pressure cuffs or tourniquets for blood draws in the affected area) (NLN, 2006; Ridner, 2009b). Some other simple and effective ways to protect the skin are to wear protective gloves when doing housework or gardening and to use insect repellent to decrease insect bites (NLN, 2006).

According to the ACS (n.d.), excess weight is a risk factor for the development of LE in cancer survivors. Additional tissue increases lymphatic load in the affected limb, which increases the potential for development and progression of LE (ACS, n.d.; Thiadens, 2008). LE risk-reduction guidelines call for maintenance of optimal weight for maximal protection and management. Because LE and LE risk are lifelong conditions, individuals with LE need to know the specifics of how to cope with LE-related changes in their lifestyle and how to optimize their self-care management (Armer, Brooks, & Stewart, 2011; Armer, Shook, et al., 2009). Survivors who have not developed LE need to know what they can do to reduce their risk of developing LE, for example as related to weight maintenance (Armer et al., 2011; Armer, Shook, et al., 2009; Fu, Ridner, & Armer, 2009b).

Following an extensive literature review for the Oncology Nursing Society (ONS) Putting Evidence Into Practice (PEP) initiative, Poage et al. (2008) applied a guide for assessing the evidence for and effectiveness of various LE treatments. As a result, the PEP schema (see Appendix I) for LE management was created, which delineates interventions for the management of secondary LE following cancer treatment (Armer, 2009; ONS, n.d.; Poage et al., 2008, 2009).
QUALITY OF LIFE

Breast cancer survivors are most fearful of a recurrence of cancer, but the second greatest fear is the development of LE (Bernas et al., 2010; Disa & Petrek, 2001). In addition to swelling, individuals often experience pain, fatigue, and a decrease in physical activity. This decrease in physical activity may contribute to an increase in BMI in individuals with LE (Ridner, 2005).

In addition to physical concerns, cancer survivors with LE face financial concerns as well. More than 80% of individuals diagnosed with LE have lost time at work; 9% experience a negative effect on job status (Moffatt et al., 2003). Many individuals also experience issues with insurance coverage for ongoing treatments. Most insurance companies view LE not as a chronic condition but rather as an episodic event that requires rehabilitation instead of ongoing care (Ridner, 2009b). Shih et al. (2009) reported that the two-year medical costs for breast cancer survivors with LE were approximately 25% higher ($14,877–$23,167 higher) than for those breast cancer survivors without LE.

Ridner (2009b) reported several recurring psychosocial concerns for individuals trying to manage their lives with LE. In addition to physical and financial issues, breast cancer survivors with LE often experience psychological distress, have a poor physical self-image, and withdraw from social activities. Fu, Ridner, and Armer (2009a, 2009b) reported that daily lives and expectations of breast cancer survivors with LE lead to psychological distress. In a study by Fu and Rosedale (2009), individuals indicated that they lived with constant discomfort or pain, felt handicapped in daily living, and felt they had lost “who they were” before LE. Nurses caring for patients with cancer should be knowledgeable about LE risk assessment, identification, and multidisciplinary management to ensure appropriate referral and enhance overall function and quality of life throughout survivorship (see Figure 14-1 for resources).

CASE STUDY

Rebecca, an 88-year-old breast cancer survivor, participated in a qualitative research study examining the experience of post-breast cancer LE in 2000 (Armer, 2002). She reported she had a radical mastectomy (without radiation therapy or chemotherapy) in 1958. Two years later, she developed LE in her affected arm (see Figure 14-2). According to Rebecca, her first episode of abnormal swelling occurred as a result of a pinprick to her arm combined with overuse of the limb. In subsequent years, she had a number of serious infections in the arm, each of which was treated with antibiotics.

Over the years, Rebecca had to contend daily with sensations of “tenderness, swelling (with pitting), firmness/tightness, and stiffness” in the affected arm. In the year prior to the study, she had also begun to experience “aching, numbness, and elevated temperature due to infection.” At the time of the
Figure 14-1. Lymphedema Resources for Survivors and Health Professionals

- BreastCancer.org: www.breastcancer.org/tips/lymphedema/
- National Cancer Institute's Lymphedema PDQ® for health professionals: www.cancer.gov/cancertopics/pdq/supportivecare/lymphedema/healthprofessional/allpages
- National Cancer Institute's Lymphedema PDQ® for patients: www.cancer.gov/cancertopics/pdq/supportivecare/lymphedema/patient
- National Lymphedema Network position papers: http://lymphnet.org/lymphedemaFAQs/positionPapers.htm
  - Air Travel: http://lymphnet.org/pdfDocs/nlnairtravel.pdf
- Oncology Nursing Society's Putting Evidence Into Practice lymphedema resources: www.ons.org/Research/PEP/Lymphedema

Figure 14-2. Lymphedema Following Breast Cancer Treatment

interviews, Rebecca reported that the affected limb was painful and weak, with loss of wrist, hand, and thumb mobility.

The year Rebecca was diagnosed with LE, she had to retire from her government clerical position with disability and a pension. Although she remained emotionally close to her son, she reported that her relationship with her husband became distant as she became less able to continue their previous lifestyle of entertaining and related social activities. Her doctor, while kind and concerned, was not able to provide any further medical help. She said she would decline invitations because of the “hassle” of getting dressed with her compression sleeve and the difficulties of how clothes fit. Rebecca said she always wore long sleeves to cover the compression bandage and had to have dress sleeves altered for the affected arm. Because LE had no known cure, Rebecca reported she had been generally depressed for many years, but that she had moved to acceptance of her condition. Overall, she said that the breast cancer treatment was “nothing” compared to living with LE these many years.

During the day, Rebecca wore a compression garment. At night, she used a sequential pump for many years and sometimes used compression bandaging. In entering into the qualitative study about post-breast cancer LE, she learned about an educational seminar where she became aware of additional options available to manage her LE. She experienced for the first time the intensive phase of CDT, including MLD, compression bandaging, skin care, nutrition, exercise, and education, which helped to alleviate the distressing symptoms and led her to obtain a well-fitted garment to manage daytime swelling and a directional foam garment for nighttime wear (see Appendix I). With this appropriate management, Rebecca’s comfort increased and her willingness to go out in public returned.

Rebecca represents a significant case of LE. Considering the radical nature of the surgical treatment for breast cancer in 1958, she reported that the LE experience was more distressing than the surgery itself. Also significant to note is the reduction of LE-related symptoms with the first course of intensive CDT in 1999, after 39 years of chronic secondary LE. This case illustrates the distress reported by a cancer survivor successfully treated for cancer and left to cope with this lifelong disease, the symptom experience of a cancer survivor living with LE, and the symptom management and volume reduction provided by CDT.

**SUMMARY**

Although advances in current cancer therapy are believed to lower the risks of developing post-treatment LE, more than a million remain at risk for LE over their lifetime, and millions more are living with this distressing chronic condition. Oncology nurses have a central role to play in education, assessment, referral for diagnosis, and treatment management as part of the effort to improve survivors’ function and quality of life.
REFERENCES


CHAPTER 14. LYMPHEDEMA FOLLOWING CANCER TREATMENT


INTRODUCTION

Reproductive hormonal imbalances are common in cancer survivors and most commonly occur as a result of gonadotoxic chemotherapies, hormonal antineoplastic therapies, and surgery or radiation therapy involving the reproductive organs. Reproductive hormonal imbalances may result in clinical manifestations such as vasomotor symptoms (hot flashes), genitourinary and sexual dysfunction, infertility or subfertility, abnormalities of bone metabolism, and cardiovascular and metabolic derangements. This chapter will discuss hot flashes and cardiovascular and metabolic implications.

PATHOPHYSIOLOGY AND RISK FACTORS

Chemotherapy and Gonadal Toxicity

Chemotherapy causes direct gonadal toxicity resulting in hormonal imbalances. In women, chemotherapy may induce or accelerate progress toward menopause by prematurely reducing or abolishing viable ovarian follicles, leading to chemotherapy-related amenorrhea (cessation of menses due to chemotherapy), dramatic declines in circulating estrogen, and onset of menopausal symptoms (Oktay & Sönmez, 2008). In men, chemotherapy-related damage to testicular Leydig cells causes declines in serum testosterone
levels that may persist for years after treatment, the effects of which are just beginning to be appreciated (Greenfield et al., 2007; Meinardi et al., 2000; Romerius et al., 2009).

A number of risk factors exist for chemotherapy-related gonadal toxicity (see Table 15-1), including disease, treatment, and advancing age (Simon, Lee, Partridge, & Runowicz, 2005). Alkylating agents pose the greatest risk to gonadal function in women and men. Cisplatin is associated with prolonged Leydig cell dysfunction. Risk corresponds to greater cumulative chemotherapy doses and longer durations of therapy. Advancing age is a significant risk factor in women. Both prepubertal and postpubertal males are at risk for Leydig cell dysfunction and testosterone deficiency from chemotherapy, although the former group may not manifest symptoms until natural declines in testosterone occur years later (Romerius et al., 2009; Simon et al., 2005).

**Radiation Therapy and Gonadal Toxicity**

Radiation therapy to male and female reproductive organs also leads to reproductive hormone imbalances (Simon et al., 2005). Ovarian follicles of older women are more sensitive to radiation therapy because of natural declines in follicle reserves. Ovarian failure occurs at relatively low doses of radiation therapy (5–6 Gy) in women older than age 40, whereas much higher doses (approximately 20 Gy) are required to induce ovarian failure in younger women (Simon et al., 2005). Conversely, Leydig cells of the testes are more sensitive to the effects of radiation therapy in prepubertal life than in adulthood, with radiation doses of 20 Gy being associated with Leydig cell dysfunction in prepubertal boys, and Leydig cell function preservation with radiation doses as high as 30 Gy in sexually mature males. Total body irradiation causes profound gonadal failure in both men and women (Simon et al., 2005).

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Advancing age, especially in women</td>
</tr>
<tr>
<td>Cumulative dose</td>
<td>Higher cumulative dose confers higher risk. High-dose chemotherapy and stem cell transplant confers high risk.</td>
</tr>
<tr>
<td>Disease</td>
<td>Testicular cancer (hypogonadism is often present at diagnosis)</td>
</tr>
<tr>
<td>Type of chemotherapy</td>
<td>High risk: Alkylating agents (e.g., cyclophosphamide, busulfan, melphalan, procarbazine, nitrogen mustard)</td>
</tr>
<tr>
<td></td>
<td>Moderate risk: Cisplatin, doxorubicin, paclitaxel, docetaxel</td>
</tr>
<tr>
<td></td>
<td>Low or no risk: Methotrexate, 5-fluorouracil, bleomycin, vinca alkaloids</td>
</tr>
</tbody>
</table>

*Note. Based on information from Oktay & Sönmezer, 2008; Simon et al., 2005; Stricker, 2007.*
Hormonal Therapy

Hormonal treatments for cancer cause hormonal imbalances in cancer survivors. This is especially true for women who are breast cancer survivors. Tamoxifen, a selective estrogen receptor antagonist, has both estrogen agonist and antagonist properties (Sverrisdóttir, Fornander, Jacobsson, von Schoultz, & Rutqvist, 2004). Both medical (as achieved with gonadotropin-releasing hormone [GnRH] agonists) and surgical bilateral oophorectomy cause rapid and substantial declines in estrogen (Sverrisdóttir et al., 2004). Aromatase inhibitors (AIs) cause dramatic reductions in circulating estrogen levels by blocking the peripheral conversion of androgens to estrogens by more than 95% (Kendall, Dowsett, Folkerd, & Smith, 2006).

In men, decreasing testosterone to castrate levels with androgen deprivation therapy (ADT) is a mainstay for the treatment of metastatic prostate cancer and is increasingly used for treatment of locally advanced and recurrent prostate cancer (Saigal et al., 2007). Medical castration is primarily accomplished with GnRH agonists and leads to markedly decreased production of testosterone by the Leydig cells of the testes. Testosterone recovery after medical castration is delayed, especially with older age and longer duration of therapy (Yoon et al., 2008).

Surgery

In pre- and perimenopausal women, gynecologic surgeries that include bilateral oophorectomy result in reproductive hormonal imbalances with marked and immediate declines in estrogen and rises in follicle-stimulating hormone (Dørum et al., 2008). In men, bilateral orchiectomy results in marked and irreversible testosterone deprivation but is rarely used as ADT, given its psychological impact (Engstrom & Kasper, 2007). Testosterone levels decrease after unilateral orchiectomy for testicular cancer, although not as markedly as expected, suggesting that the remaining testicle compensates by increasing its production of testosterone (Nuver et al., 2005).

Hot Flashes

Hot flashes are one of the most common menopausal symptoms in cancer survivors, especially women (Hickey et al., 2008). Vasomotor symptoms have a substantial negative impact on the quality of life of cancer survivors and their partners and may adversely affect treatment adherence (Barron, Connolly, Bennett, Feely, & Kennedy, 2007; Gupta et al., 2006). Hot flashes and night sweats are characterized by a sudden and fleeting sense of flushing and heat in the upper chest, neck, and face and are characterized by peripheral vaso-dilation resulting in increased skin temperature and blood flow (Freedman, 2005). They typically are more severe, distressing, and persistent in cancer survivors than in women undergoing natural menopause (Carpenter, John-
son, Wagner, & Andrykowski, 2002). In men, hot flashes are most common during the treatment of prostate cancer with ADT, occurring in up to 80% of patients (Higano, 2003). Risk factors for hot flashes in cancer survivors include lower education, younger age, prior chemotherapy and chemotherapy-related amenorrhea, and current use of hormonal therapies, such as tamoxifen and AIs in women and GnRH analogs in men and women (Carpenter et al., 1998; Ganz, 1997; Kouriefs, Georgiou, & Ravi, 2002).

**ASSESSMENT AND MANAGEMENT**

Nurses should routinely screen for the presence of hot flashes in individuals at risk. If hot flashes are present, the nurse should assess their frequency, severity, impact on quality of life and adherence to anticancer therapy, and the individual’s desire for and expectations from interventions to manage hot flashes (Hickey et al., 2008). Published clinical guidelines for assessing and managing menopausal symptoms after breast cancer (Hickey et al., 2008) could be easily adapted to other cancer populations and provide practical advice and a systematic approach, as summarized in Figure 15-1. All individuals experiencing hot flashes should be given lifestyle advice, including avoiding or limiting triggers (Hickey et al., 2008).

**Nonpharmacologic Strategies**

Relaxation training with or without cognitive-behavioral therapy, acupuncture, hypnosis, and mindfulness-based stress reduction are the most promis-

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**Figure 15-1. Summary of Practical Guidelines for Assessing and Managing Hot Flash Symptoms After Breast Cancer**

1. Assess the likely cause for hot flashes.
2. Establish the frequency and severity of hot flashes and their impact on quality of life.
3. Establish what the patient wishes for and expects from intervention for hot flashes.
4. Provide information about hot flashes and possible treatments.
5. Assess lifestyle and environmental factors that may be exacerbating hot flashes, such as spicy food, alcohol, anxiety, and use of hair dryers. Encourage the use of a hot flash diary to identify triggers.
6. Provide lifestyle advice to all cancer survivors experiencing hot flashes.
7. Prescribe nonhormonal pharmacologic interventions for individuals with severe hot flashes.
8. Evaluate the effectiveness of interventions, and consider changing to another if ineffective or if the individual is intolerant.
9. Consider changing endocrine therapy (if applicable) or prescribing hormonal therapies for refractory hot flashes after thorough discussion with a well-informed patient.

*Note. Based on information from Hickey et al., 2008.*
ing complementary and alternative therapies for hot flashes; however, more clinical trials are needed, and results to date are mixed (Hickey et al., 2008; Stricker, 2007; Thurston, Joffe, Soares, & Harlow, 2006; Tremblay, Sheeran, & Aranda, 2008). Controlled clinical trials of exercise, magnet therapy, and homeopathy have found no consistent evidence of benefit (Tremblay et al., 2008). Neither black cohosh nor phytoestrogens (plant compounds that have weak estrogenic effects, including soy isoflavones) reduce hot flashes in either healthy postmenopausal women or cancer survivors (Jacobson et al., 2001; Lethaby et al., 2007; Newton et al., 2006; Sharma et al., 2009).

Pharmacologic Strategies

For cancer survivors with hormone-dependent tumors, nonhormonal strategies generally are recommended. The most widely used nonhormonal pharmacologic agents for hot flash management (see Table 15-2) are selective serotonin reuptake inhibitors (SSRIs), serotonin norepinephrine reuptake inhibitors (SNRIs), and gabapentin (Hickey et al., 2008). In individuals receiving tamoxifen, SSRIs and SNRIs that are moderate or strong inhibitors of cytochrome P450 enzyme CYP2D6 (see Table 15-3) should be avoided or used with caution because CYP2D6 metabolizes tamoxifen to its active metabolite endoxifen (Hickey et al., 2008). Gabapentin or SSRIs/SNRIs are both reasonable first-line pharmacologic agents in cancer survivors, and recommended doses are noted in Table 15-2. Vitamin E 400 or 800 IU (international units) daily also may decrease hot flashes but should be used with caution in prostate cancer survivors because of its association with increased prostate cancer risk (Lippman et al., 2009). Clonidine is rarely used because of its high withdrawal rates due to side effects, but doses of 0.1–0.4 mg/day result in hot flash reductions that are greater than with placebo (Hickey et al., 2008). Men on ADT do not appear to benefit from clonidine (Loprinzi et al., 1994).

<table>
<thead>
<tr>
<th>Drug Type</th>
<th>Dose Recommended</th>
<th>Efficacy</th>
<th>Side Effects/Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Progestins</td>
<td>• Depot medroxyprogesterone acetate 400 mg intramuscular as a one-time injection</td>
<td>Reduce hot flashes (HFs) better than venlafaxine, and remained effective for 6 months in many women</td>
<td>• Vaginal bleeding, appetite stimulation, weight gain</td>
</tr>
<tr>
<td></td>
<td>• Megestrol acetate 40 mg/day</td>
<td>Reduces HFs better than placebo</td>
<td>• Theoretical concern: increased risk of breast cancer recurrence</td>
</tr>
</tbody>
</table>

(Continued on next page)
Table 15-2. Pharmacologic Therapies for Hot Flashes (Continued)

<table>
<thead>
<tr>
<th>Drug Type</th>
<th>Dose Recommended</th>
<th>Efficacy</th>
<th>Side Effects/ Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selective serotonin reuptake inhibitors</td>
<td>• Venlafaxine 37.5 mg/day for 1 week, then 75 mg/day</td>
<td>Reduce HFs better than placebo</td>
<td>• Nausea, dry mouth, and gastrointestinal side effects tend to decrease over time.</td>
</tr>
<tr>
<td></td>
<td>• Paroxetine 10 mg/day</td>
<td></td>
<td>• Long-term efficacy is uncertain.</td>
</tr>
<tr>
<td></td>
<td>• Fluoxetine 20 mg/day</td>
<td></td>
<td>• Moderate to severe CYP2D6 inhibitors should not be taken with tamoxifen (see Table 15-3).</td>
</tr>
<tr>
<td></td>
<td>• Desvenlafaxine 100 mg/day</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Sertraline 50–100 mg/day</td>
<td></td>
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<tr>
<td></td>
<td>• Mirtazapine 30 mg/day</td>
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</tr>
<tr>
<td>Gabapentin</td>
<td>• 900 mg/day (300 mg three times a day), titrate up to 2,700 mg/day</td>
<td>Reduces HFs better than placebo</td>
<td>• Dizziness, somnolence, and fluid retention are reported, but decrease over time.</td>
</tr>
<tr>
<td></td>
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</tr>
<tr>
<td>Clonidine</td>
<td>• 0.1 mg/day (oral or transdermal)</td>
<td>Reduces HFs better than placebo</td>
<td>• Drowsiness, dizziness, sleeping difficulty, dry mouth; withdrawal rates as high as 40%</td>
</tr>
</tbody>
</table>

Note. Based on information from Stricker, 2007.

Table 15-3. Selective Serotonin and Serotonin Norepinephrine Reuptake Inhibitors

<table>
<thead>
<tr>
<th>Degree of CYP2D6 Inhibition</th>
<th>Drug</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strong inhibitor</td>
<td>Fluoxetine</td>
</tr>
<tr>
<td></td>
<td>Paroxetine</td>
</tr>
<tr>
<td></td>
<td>Bupropion</td>
</tr>
<tr>
<td>Moderate inhibitor</td>
<td>Duloxetine</td>
</tr>
<tr>
<td>Not inhibitors</td>
<td>Citalopram</td>
</tr>
<tr>
<td></td>
<td>Escitalopram</td>
</tr>
<tr>
<td></td>
<td>Sertraline</td>
</tr>
<tr>
<td></td>
<td>Venlafaxine</td>
</tr>
</tbody>
</table>

Note. Based on information from Hickey et al., 2008.
CARDIOVASCULAR DISEASE AND RISKS AFTER CANCER TREATMENT

Incidence

Both estrogen and testosterone play an important role in maintaining cardiovascular health and are frequently referred to as cardioprotective. As will be discussed in this section, growing data support that, as a result of cancer therapies, many cancer survivors experience reproductive hormonal imbalances that directly and indirectly increase their risk for developing cardiovascular disease (CVD).

Perhaps nowhere is the association more apparent than among patients with prostate cancer receiving ADT with GnRH agonists. A significantly increased incidence of coronary heart disease, myocardial infarction (MI), and sudden cardiac death has been noted within 4–12 months of initiating therapy (D’Amico et al., 2007; Keating, O’Malley, & Smith, 2006; Saigal et al., 2007). The incidence of CVD is less compelling in patients treated with bilateral orchiectomy, which is at least in part due to the relatively few patients who undergo this form of therapy (Keating et al., 2006).

Testicular cancer survivors who received cisplatin-based chemotherapy regimens demonstrate significantly increased incidences of angina, MI, and sudden cardiac death, beginning within four to five years of completing therapy and increasing over time (Meinardi et al., 2000; Zoltick, Jacobs, & Vaughn, 2005). Although nonhormonally-mediated mechanisms (e.g., cisplatin-mediated vascular endothelial damage) likely contribute to CVD (Zoltick et al., 2005), testosterone deficiency also may play an important role. Testicular cancer survivors treated with cisplatin have significantly lower (p = 0.023) testosterone levels and slightly higher luteinizing hormone levels compared to patients treated with orchiectomy alone, reflecting a prolonged effect of cisplatin on Leydig cell function (Meinardi et al., 2000). Such hormonal imbalances have been linked to increased risk of CVD in other populations, including men on ADT (Saigal et al., 2007).

In women, premature ovarian failure and consequent estrogen deprivation has been associated with an increased risk for CVD (Atsma, Bartelink, Grobbe, & van der Schouw, 2006; Lobo, 2007; Løkkegaard et al., 2005). This risk is particularly increased in women who have undergone bilateral oophorectomy before the ages of 40–50 (Atsma et al., 2006; Løkkegaard et al., 2005).

Hormonal therapies for women also influence the risk for CVD. Tamoxifen has positive and negative effects on CVD in female cancer survivors (Braithwaite et al., 2003). Most likely because of its estrogen-agonist effects, tamoxifen is associated with decreased rates of MI and cardiovascular-related deaths, and yet increased thromboembolic disease. AIs do not appear to have a net negative effect on CVD risk. When compared to tamoxifen, AIs are associated with slightly higher rates of angina and MI, but not when compared to placebo, suggesting that the difference in CVD incidence is likely due to tamoxifen’s cardioprotective effects (Ewer & Glück, 2009).
Pathophysiology

An understanding of the physiologic association between reproductive hormonal imbalances and CVD is evolving. Estrogen and testosterone deficiencies exert a detrimental effect directly on vasculature through myriad mechanisms (Allison et al., 2008; Traish, Guay, Feeley, & Saad, 2009). However, deleterious effects of reproductive hormonal deficiencies on metabolic risk factors for CVD likely play a greater causative role in the development of CVD events in cancer survivors. Although not consistent across all studies, myriad detrimental changes in well-established metabolic risk factors for CVD have been observed in cancer survivors with reproductive hormonal imbalances (Alibhai et al., 2009; Braga-Basaria et al., 2006; Dørum et al., 2008; Meinardi et al., 2000; Saarto, Blomqvist, Ehnholm, Taskinen, & Elomaa, 1996; Smith, 2004; Yannucci, Manola, Garnick, Bhat, & Bubley, 2006). These findings are summarized in Table 15-4, with data on subpopulations of survivors not yet identified as being at greater risk for CVD events but who experience an increased incidence of adverse metabolic risk factors for CVD that may be hormonally mediated (Greenfield et al., 2007; Saarto et al., 1996; Vehmanen, Saarto, Blomqvist, Taskinen, & Elomaa, 2004).

Assessment and Management

Clearly, increased risk for CVD represents a serious actual and potential threat to health for a significant number of cancer survivors who experience treatment-related reproductive hormone imbalances. Clinicians should be vigilant about identifying patients who are at high risk and initiating appropriate interventions. Given the paucity of intervention studies in this area, strategies for screening, prevention, monitoring, and treatment of CVD and cardiovascular risk factors for cancer survivors experiencing reproductive hormone imbalances generally are the same as the guidelines for the general adult population (American Diabetes Association, 2010; Chobanian et al., 2003; Expert Panel on Detection, Evaluation, and Treatment of High Blood Cholesterol in Adults, 2001; Grundy et al., 2004). Expert opinion and consensus-based recommendations for specific subpopulations of cancer survivors are summarized in Table 15-5 and briefly reviewed next.

Screening and Prevention

Women and men at increased risk for CVD because of reproductive hormonal imbalances should undergo regular screening for metabolic risk factors for CVD (Lenihan & Esteva, 2008; Levine et al., 2010). Although obtaining baseline screening tests prior to initiating therapy is generally recommended, a lack of consensus exists as to what specifically should be obtained and with what frequency (see Table 15-5). Cancer specialists should work with primary care providers to individualize care.
Table 15-4. Cancer Therapies Associated With Changes in Incidence of Cardiovascular Disease and Risk Factors

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Prostate Cancer and ADT</th>
<th>Testicular Cancer and Cisplatin</th>
<th>Women &lt; 45–50 Years, Bilateral Oophorectomy</th>
<th>Breast Cancer and Tamoxifen</th>
<th>Premenopausal Breast Cancer and Amenorrhea After Chemotherapy</th>
<th>Young Adult Males and Chemotherapy +/- Radiation</th>
</tr>
</thead>
<tbody>
<tr>
<td>CVD</td>
<td>↑ CHD</td>
<td>↑ Angina</td>
<td>↑ CHD</td>
<td>↓ MI</td>
<td>↓ CV deaths</td>
<td>−</td>
</tr>
<tr>
<td></td>
<td>↑ MI</td>
<td></td>
<td></td>
<td></td>
<td>↑ Thromboembolic events</td>
<td>−</td>
</tr>
<tr>
<td></td>
<td>↑ Sudden cardiac death</td>
<td>(D’Amico et al., 2007; Keating et al., 2006)</td>
<td>↑ Sudden cardiac death</td>
<td>(Meinardi et al., 2000)</td>
<td>(Atsma et al., 2006; Løkkegaard et al., 2006)</td>
<td>−</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(D’Amico et al., 2007; Keating et al., 2006)</td>
<td>↑ BMI</td>
<td>−</td>
<td>−</td>
<td>↑ Fat mass (Greenfield et al., 2007)</td>
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<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>↑ Weight</td>
<td>↑ BMI</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td></td>
</tr>
<tr>
<td></td>
<td>↑ Fat mass</td>
<td>(Nuver et al., 2005)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>↓ Lean muscle mass</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>(Smith, 2004)</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>↑ Fasting insulin⁷</td>
<td>↑ Fasting insulin⁷</td>
<td>−</td>
<td>−</td>
<td>−</td>
<td>↑ Fasting glucose (Greenfield et al., 2007)</td>
</tr>
<tr>
<td></td>
<td>↑ Fasting glucose</td>
<td>(Meinardi et al., 2000; Nuver et al., 2005)</td>
<td>↑ Fasting glucose</td>
<td>−</td>
<td>−</td>
<td></td>
</tr>
<tr>
<td></td>
<td>↑ HbA1c⁶</td>
<td>(Alibhai et al., 2009; Basaria et al., 2006; Braga-Basaria et al., 2006; Keating et al., 2006)</td>
<td>↑ HbA1c⁶</td>
<td>−</td>
<td>−</td>
<td></td>
</tr>
<tr>
<td></td>
<td>↑ Diabetes⁶</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

(Continued on next page)
Table 15-4. Cancer Therapies Associated With Changes in Incidence of Cardiovascular Disease and Risk Factors (Continued)

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Prostate Cancer and ADT</th>
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<th>Women &lt; 45–50 Years, Bilateral Oophorectomy</th>
<th>Breast Cancer and Tamoxifen</th>
<th>Premenopausal Breast Cancer and Amenorrhea After Chemotherapy</th>
<th>Young Adult Males and Chemotherapy +/- Radiation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lipids</td>
<td>↑ Total cholesterol&lt;sup&gt;a&lt;/sup&gt; ↑ Triglycerides&lt;sup&gt;a&lt;/sup&gt; ↑ TC/Colesterol ratio&lt;sup&gt;a&lt;/sup&gt;</td>
<td>↑ TC</td>
<td>–</td>
<td>↓ Total cholesterol ↓ LDL ↓ HDL ↑ Triglycerides (Meinardi et al., 2000; Nuver et al., 2005)</td>
<td>↑ TC ↓ LDL, ↑ HDL ↑ Triglycerides ↑ TC/HDL ratio (Vehmanen et al., 2004)</td>
<td>–</td>
</tr>
<tr>
<td>Metabolic syndrome&lt;sup&gt;b&lt;/sup&gt;</td>
<td>↑ Incidence (Braga-Basar-&lt;sup&gt;a&lt;/sup&gt;ia et al., 2006)</td>
<td>↑ Incidence (Nuver et al., 2005)</td>
<td>↑ Incidence (Dørum et al., 2008)</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Framingham risk score&lt;sup&gt;c&lt;/sup&gt;</td>
<td>–</td>
<td>–</td>
<td>↑ Score (Dørum et al., 2008)</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
</tbody>
</table>

<sup>a</sup> Manifest within 3–6 months of ADT initiation

<sup>b</sup> Metabolic syndrome is the clustering of distinct but related metabolic and physical variables (increased waist circumference, hypertension, elevated fasting blood glucose, dyslipidemia) that have been associated with a significantly increased risk of diabetes mellitus and CVD.

<sup>c</sup> Framingham risk score: tool that estimates the risk for MI or coronary death in the next 10 years (Expert Panel on Detection, Evaluation, and Treatment of High Blood Cholesterol in Adults, 2001)

↑ = increased; ↓ = decreased; ADT—androgen deprivation therapy; BMI—body mass index; CHD—coronary heart disease; CV—cardiovascular; CVD—cardiovascular disease; HDL—high-density lipoprotein; LDL—low-density lipoprotein; MI—myocardial infarction; TC—total cholesterol
Table 15-5. Recommendations for Assessment and Management of Cardiovascular Risk Factors in Cancer Survivors Experiencing Reproductive Hormonal Imbalances

<table>
<thead>
<tr>
<th>Time Frame</th>
<th>All Cancer Survivors Experiencing Reproductive Hormone Imbalances</th>
<th>Specific Recommendations for Patients Receiving Androgen Deprivation Therapy</th>
</tr>
</thead>
</table>
| Screening prior to initiating therapy | • Assess for preexisting CVD and CV risk factors.  
• Relay escalating risk for CVD and CV risks to primary care provider and coordinate appropriate screening, monitoring, and treatment.  
• Obtain baseline measures of CV health (blood pressure, weight, BMI, fasting glucose and lipids, HbA1c). | Initial blood pressure, lipid profile, and glucose level be obtained within 3–6 months after ADT (Levine et al., 2010). |
| Prevention                  | • Clearly relay escalating risk for CVD and CV risks to patient.  
• Address modifiable risk factors such as low-fat/high-fiber diet, regular aerobic and muscle resistance exercise, and smoking cessation. |                                                                                                                                            |
| Monitoring                  | • Monitor for the development or progression of CVD.  
• Patient should be aware of reportable signs of CVD.  
• Monitor for CV risk factors at least yearly while on therapy, then as clinically indicated (blood pressure, weight, BMI, fasting glucose and lipids, HbA1c). | Patients receiving ADT  
• Obtain fasting glucose, lipids, HbA1c at baseline, every 3 months for first year and thereafter as indicated (Basaria, 2008; Kintzel et al., 2008).  
• Testosterone recovery can be delayed for many months after receiving last injection of GnRH agonist, necessitating long-term monitoring (Kintzel et al., 2008). |
| Treatment                   | As per relevant national guidelines                                                                                              |                                                                                                                                            |

ADT—androgen deprivation therapy; BMI—body mass index; CV—cardiovascular; CVD—cardiovascular disease; GnRH—gonadotropin-releasing hormone; HbA1c—glycosylated hemoglobin

Note. Unless otherwise noted, recommendations for cancer survivors are the same as advised by national hypertension, dyslipidemia, and diabetes guidelines (Chobanian et al., 2003; Expert Panel on Detection, Evaluation, and Treatment of High Blood Cholesterol in Adults, 2001; Grundy et al., 2004).
Concerted effort should be made to address modifiable cardiovascular risk factors. In the absence of contraindications, cancer survivors should participate in regular exercise with the goal of CVD prevention, as both resistance and aerobic exercise improve CVD risk factors in cancer survivors (Lenihan & Esteva, 2008; Levine et al., 2010; Schmitz et al., 2010). Dietary guidelines are the same as for the general population.

Monitoring and Treatment

Monitoring should be tailored to the expected onset and trajectory of CVD and related risk factors of the target population. Given the early onset and prolonged duration of CVD and metabolic risk factors with ADT, frequent early testing and prolonged monitoring are both prudent. Prolonged monitoring also is advisable in patients with testicular cancer treated with cisplatin, considering the late manifestation of CVD years after treatment. With respect to treatment, targets for metabolic cardiovascular risk factors (e.g., lipids) should be the same as for the general population. In male survivors of non–hormonally mediated cancers, testosterone replacement therapy has been suggested as an intervention to address hormone imbalance and its associated consequences, but this is not the standard of care (Greenfield et al., 2007).

SUMMARY

Both estrogen and testosterone deprivation in cancer survivors may lead to deleterious effects on vasculature, body composition, insulin sensitivity, lipid profiles, and development of metabolic syndrome. Taken together, these effects appear to contribute to the increased incidence of CVD seen in male and female cancer survivors. Heightened awareness of these associations by oncology, primary care, and specialist providers is crucial. Unfortunately, little empirical evidence exists to guide clinical practice. Long-term prevention, monitoring, and treatment should be guided by general population guidelines, contemporary expert opinions, and consensus guidelines for cancer survivors.

REFERENCES


The incidence of suicide in cancer survivors is almost twice that in the general population in the United States, and the risk is highest during the first five years following cancer diagnosis (Misono, Weiss, Fann, Redman, & Yueh, 2008). These conclusions are based on data from more than 3.5 million cancer survivors from the National Cancer Institute Surveillance, Epidemiology, and End Results (2009) program for the years 1973–2007. In adults age 65 and older, the risk of suicide is higher for patients who had cancer than for age- and sex-matched patients with other illnesses even after accounting for psychiatric illness and the risk of dying within a year (Miller, Mogun, Azrael, Hempstead, & Solomon, 2008). These findings demonstrate clearly that cancer survivors face significant psychosocial challenges, and management of these challenges should be a central focus of cancer care.

Although physical sequelae tend to be specific to the type of cancer and treatment, many psychosocial challenges are common regardless of cancer type. Anxiety about an uncertain future and fear of recurrence are examples; because they are reality-based fears, they tend to be widespread and particularly difficult to mitigate. A minority of cancer survivors experience anxiety severe enough to be diagnosed as post-traumatic stress disorder (PTSD) characterized by re-experiencing, avoidance of reminders, and hyperarousal (Cordova, Studts, Hann, Jacobsen, & Andrykowski, 2000). Most of the research in this area has focused on PTSD in breast cancer survivors, but it also has been seen in mothers of pediatric cancer survivors (Pelcovitz et al., 1996).
Some psychological and physical sequelae are interrelated in such a manner that they form a constellation of synergistic symptoms. In these cases, interventions need to address the entire constellation of symptoms to increase the likelihood of successful outcomes. For example, depression, fatigue, and pain have been identified as symptoms that commonly cluster together (Misaskowski, Dodd, & Lee, 2004) and negatively affect quality of life in cancer survivors (Fox & Lyon, 2006). Even adult survivors of childhood cancer have been found to experience clusters of symptoms. For these survivors, Finnegan et al. (2009) generated unique subgroups based on a cluster of eight symptoms: depression, anxiety, irritability, nervousness, difficulty with concentration, fatigue, difficulty sleeping, and pain. Quality of life differed significantly among the subgroups, demonstrating that the symptoms had a negative impact on life.

Similarly, Meeske, Siegel, Globe, Mack, and Bernstein (2005) found depression, neurocognitive symptoms, sleep disturbance, fatigue, and pain clustered together in adult survivors of childhood cancer. The combination of depression and fatigue had a greater negative impact on quality of life than either symptom alone. However, this work is in its infancy, and more studies are needed to identify clusters in various subgroups of cancer survivors and the causal relationships among symptoms in a cluster. This information can then be used to guide evaluation and treatment in clinical practice. For example, Continuum Cancer Centers of New York currently use the National Comprehensive Cancer Network distress thermometer (Holland & Bultz, 2007) as part of routine, standardized screening throughout the trajectory of care to identify patients needing management of pain, depression, and fatigue (Fleishman, 2004).

Finally, we need to keep in mind that many survivors report that, on balance, their lives changed for the better as a result of their experience with cancer. Some of the earliest studies of cancer survivors reported changes in priorities, an increased focus on things they sincerely valued, decreased concern for trivial matters, and increased appreciation of family and friends (Ferrans, 1994). They reported that they understood life better, had become better people, were more positive in outlook, and had grown in their faith in God and other people. When patients with breast cancer were asked, “All things considered, do you think that all you have gone through to treat the cancer was worth it?”, 95% answered yes (Ferrans, 1994). By providing comprehensive care through active symptom management for psychosocial challenges, we can increase the likelihood of an improved quality of life for cancer survivors, as well as length of life.

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Co-Director, UIC Center of Excellence in Eliminating Health Disparities
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REFERENCES


INTRODUCTION

Anxiety is a common problem in people coping with a cancer diagnosis. The experience of anxiety has been defined as feelings of distress or tension from known or unknown stimuli (Lehman & Rabins, 1999). Although the word anxiety is commonly used, the National Comprehensive Cancer Network (NCCN) recommends clinicians use the term distress because it has less social stigma attached to it and may make it easier for people with cancer to discuss their concerns. Distress has been defined as a multifactorial experience that can interfere with one’s ability to effectively cope with cancer. The experience of distress extends along a continuum from normal feelings of vulnerability and fear to disabling problems such as depression, anxiety, panic, social isolation, and existential and spiritual crisis (NCCN, 2010). For the purposes of this chapter, the terms anxiety and distress will be used to describe the experience of survivors.

The experience of anxiety may vary at different time points from diagnosis and through survivorship. At certain points, survivors may be more vulnerable to increased anxiety (see Figure 16-1). Anxiety and distress after the initial diagnosis are expected reactions to a sudden change in health. During cancer treatment, individuals have frequent and supportive contact with their healthcare team. Once treatment is completed, survivors move through longer periods of time without contact with their team and may worry about the cancer recurring.

In cancer survivors, the incidence of chronic anxiety may be as high as 30% (Marrs, 2006). The actual incidence of anxiety has often been combined with depression in studies that evaluate psychiatric disorders in patients with cancer. According to the landmark study by the Psychosocial Collaborative Oncology Group, 47% of patients with cancer had psychiatric disorders, 68% of whom had reactive or situational anxiety and depression (Derogatis et al., 1983). Further examination revealed that 90% of these disorders were reactions to the cancer or manifestations of the cancer itself. Unfortunately,
less than 10% of people with cancer and anxiety were identified as needing psychosocial interventions (Derogatis et al., 1983).

Anxiety is a subjective experience characterized by emotional discomfort and apprehension that stimulates a physiologic adaptation to stress. Symptoms of anxiety arise from both emotional and physical responses (see Figure 16-2). The presentation of anxiety in cancer survivors is variable and depends not only on the stage of disease and treatment but also on personality factors. People with a history of adjustment disorders with anxiety, depression, panic attacks, sexual abuse, and other psychiatric disorders are at increased risk for maladjustment (Derogatis et al., 1983). Although some level of distress is expected after a diagnosis of cancer, when concerns develop into significant anxiety that affects functioning and quality of life, further assessment and intervention are needed.

Uncertainty in patients with cancer has been defined as ambiguity, unpredictability, fluctuating courses of remissions and exacerbations, incomplete information and explanations, and vague feedback about prognosis (Mishel, 1981). It may influence coping, quality of life, and appraisal of danger and opportunity, and cause emotional distress. Although the most common times for uncertainty to arise are during diagnosis and at follow-up, one study found that triggers for uncertainty occurred long after treatment and included hearing about someone else’s cancer, hearing about controversy in the media, and environmental factors (Gil et al., 2004).

Mishel (1990) has conceptualized uncertainty as the experience of living with continual, constant uncertainty. This may become a state of being for many cancer survivors because of the fear of recurrence. Several studies have

---

**Figure 16-1. Periods of Increased Vulnerability to Anxiety**

- Upon finding a suspicious symptom
- During workup
- At the time of diagnosis
- While awaiting treatment
- During arduous treatment cycles
- With a change in treatment modality
- At the end of treatment and when encountering survivorship issues
- Upon discharge from hospital
- Before medical follow-up visits and surveillance
- When experiencing minor symptoms that could represent recurrence of disease
- After treatment failure with recurrence or progression
- With advanced cancer or worsening symptoms
- During transition to hospice or palliative care
- With awareness of the end of life

*Note.* Based on information from Dahlin, 2006; National Comprehensive Cancer Network, 2010.

explored the role of uncertainty in affecting multiple patient outcomes, including coping and quality of life (Bailey, Wallace, & Mishel, 2007; Gil et al., 2006). Uncertainty also plays a factor in the transition from patient to cancer survivor for childhood cancer survivors (Parry, 2003) and adults (Garofalo, Choppala, Hamann, & Gjerde, 2009). One study of breast cancer survivors associated more uncertainty with decreased quality of life (Sanmarco, 2001). The experience of uncertainty is individual to each survivor and is based on many factors, including the person’s diagnosis, prognosis, overall health, personality factors, and social supports.

### DIAGNOSIS AND ASSESSMENT

The use of diagnostic criteria (as discussed later) for the evaluation of anxiety is complicated in regard to cancer survivors, as many survivors live with a very real threat of their disease returning. Even after definitive cure, levels of anxiety in survivors may not return to population norms (Stark & House, 2000). A wide spectrum of anxiety disorders can be experienced by cancer survivors as described in the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2000), but a distinct diagnosis for cancer-related anxiety is not available in the literature.

Several tools are available to assess anxiety and distress in the general population (Spielberger, 1983). For people with cancer, NCCN recommends using the distress thermometer (DT) as the preferred tool to assess distress (NCCN, 2010). The DT asks patients to indicate their level of distress from any cause on a visual analog scale from 0 (no distress) to 10 (extreme distress) in addition to optionally identifying any of 38 problems on a list covering physical conditions and emotional symptoms.

#### Figure 16-2. Physical and Emotional Symptoms of Anxiety in Patients With Cancer

<table>
<thead>
<tr>
<th>Physical Symptoms</th>
<th>Emotional Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tachycardia or palpitations</td>
<td>Recurrent thoughts about diagnosis and treatment</td>
</tr>
<tr>
<td>Sweating</td>
<td>Fears about the future or sense of dread</td>
</tr>
<tr>
<td>Perception of dyspnea or shortness of breath</td>
<td>Concerns about possible disability and pain</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>Changes in body image and functioning</td>
</tr>
<tr>
<td>Headaches</td>
<td>Inability to sleep</td>
</tr>
<tr>
<td>Restlessness or fidgeting</td>
<td>Difficulty concentrating</td>
</tr>
<tr>
<td>Abdominal distress</td>
<td>Hypervigilance and scanning</td>
</tr>
<tr>
<td></td>
<td>Irritability and impatience</td>
</tr>
<tr>
<td></td>
<td>Worries about death</td>
</tr>
</tbody>
</table>

and psychosocial domains. The DT has been validated in several studies with different cancer populations and demonstrated good concordance with the well-accepted Hospital Anxiety and Depression Scale (Bjelland, Dahl, Haug, & Neckelmann, 2002; Zigmund & Snaith, 1983).

**INTERVENTIONS**

Treatments for distress and anxiety range from nonpharmacologic interventions, such as individual counseling, to medications or complementary and alternative medicine (CAM), such as relaxation exercises (see Sheldon, Swanson, Dolce, Marsh, & Summers, 2008, for a review of the literature). Decisions regarding the appropriate treatment rely on accurate assessment and diagnosis of the problem and identification of the sources of anxiety and distress at specific points during the survivorship trajectory. Assessment of the physical and psychological symptoms of distress should be a part of every patient-provider interaction. The development of an open, trusting relationship between the survivor, the survivor’s family, and the oncology team is an essential component of quality cancer care. Addressing distress, anxiety, and uncertainty at the time of the first encounter sets the stage for ongoing communication between the survivor and the team throughout survivorship.

The relationship between a patient and survivor is based on the Rogerian principle of unconditional positive regard (Rogers, 1951), where providers accept another person’s beliefs despite their own feelings. By fostering acceptance, providers can help patients feel comfortable disclosing their concerns, which may be sources of anxiety and distress. Revelation of concerns may be therapeutic in itself (Stiles, Shuster, & Harrigan, 1992) or can identify the need for further assessment or interventions. The NURSE mnemonic has proved useful in delineating steps that providers can use in acknowledging and normalizing patient concerns and providing necessary support and assistance (Smith, 2002).

- **N** = Name the feeling: “I can see that you are worried about this new pain.”
- **U** = Understand the patient’s experience: “Many cancer survivors become concerned when something changes, such as a new pain.”
- **R** = Respect the patient’s coping: “You are handling this well and your family is supporting you, but you all want to know why you have this pain.”
- **S** = Support the patient: “I am here to help you and to find out what is causing this pain.”
- **E** = Explore the patient’s concerns: “What do you think this pain means?”

Most survivors worry that a new pain means recurrence or the spread of disease. By specifically naming the concern and the feelings that it creates, the provider can then offer to support the survivor and address the specific concerns. Detailed assessment tools provide more information about the presence and extent of anxiety, uncertainty, and distress (see Table 16-1).
When increased levels of anxiety, distress, and uncertainty are discovered on routine assessment, the provider needs to pursue further assessment, treatment, or referral.

<table>
<thead>
<tr>
<th>Table 16-1. Examples of Tools to Measure Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tool</strong></td>
</tr>
<tr>
<td>Beck Anxiety Inventory</td>
</tr>
<tr>
<td>Brief Symptom Inventory</td>
</tr>
<tr>
<td>Distress Inventory Scale (0–10)</td>
</tr>
<tr>
<td>Hospital Anxiety and Depression Scale</td>
</tr>
<tr>
<td>Spielberger State Trait Anxiety Inventory</td>
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<tr>
<td>Visual Analog Scale</td>
</tr>
</tbody>
</table>


**Psychosocial and Psychoeducational Interventions**

Research findings demonstrate that psychosocial interventions have been effective in decreasing anxiety in people with cancer. Studied psychosocial interventions include cognitive-behavioral therapy (CBT), behavioral therapies, and support groups. In CBT, identifying and altering maladaptive thoughts and behaviors may reduce symptoms of anxiety in people with cancer. CBT can be offered in counseling sessions by trained therapists in either individual or group settings or via a telephone or videoconference format (Badger, Segrin, Dorros, Meek, & Lopez, 2007). Evidence supports the use of CBT as an intervention for patients with cancer who have anxiety (Antoni et al., 2006; Arving et al., 2007; Kissane et al., 2003; Osborn, Demoncada, & Feuerstein, 2006). Support groups have been shown to be useful in providing anxiety management techniques, coping skills, and therapeutic social support (Chujo et al., 2005; Manne et al., 2005). This evidence provides additional support for use of the NCCN (2010) guidelines, which recommend psychotherapy with or without an anxiolytic and/or an antidepressant medication for patients with cancer who are experiencing anxiety or distress.
Evidence suggests that psychoeducational interventions provide some benefit to patients experiencing anxiety related to their cancer diagnosis (Deshler et al., 2006; Jones et al., 2006). Psychoeducational interventions for the treatment of anxiety in people with cancer can be categorized into three areas: (a) education regarding the cancer diagnosis and treatment, (b) information about the treatment facility, staff, and contacts, and (c) guidance and education about self-care and symptom management.

**Pharmacologic Interventions**

If conservative treatment for anxiety fails, medication may be the appropriate next step. Benzodiazepines are a popular class of medications for anxiety treatment in the general population; however, few randomized, placebo-controlled trials of benzodiazepines have been performed in people with cancer. In the early 1990s, two trials using benzodiazepines in patients with cancer were published. One study of 147 patients with cancer and anxiety or depression compared alprazolam to a behavioral muscle relaxation technique and found both to be effective, although alprazolam had a stronger and more rapid effect (Holland et al., 1991). Another trial of alprazolam in people with cancer showed no difference between placebo and alprazolam for the reduction of anxiety (Wald, Kathol, Noyes, Carroll, & Clamon, 1993). Scant evidence exists to guide the duration of benzodiazepine therapy; a common best practice strategy is to use benzodiazepines as a bridge to long-term antidepressant therapy, then taper off the benzodiazepine dose after two to three weeks (Tyrer & Baldwin, 2006).

Several classes of antidepressants are used routinely in the treatment of anxiety. The most commonly prescribed are the selective serotonin reuptake inhibitors (SSRIs). In patients diagnosed with generalized anxiety disorder (GAD), two eight-week, randomized, placebo-controlled trials demonstrated that paroxetine was more effective than placebo in reducing anxiety (72% versus 56%) and improving rates of remission (42% versus 26%) (Pollack et al., 2001; Rickels et al., 2003). Few studies have addressed the use of SSRIs for alleviation of anxiety in patients with cancer as an independent symptom from depression. A review of seven studies spanning three decades concluded that antidepressants probably improve symptoms of depression in patients with cancer, but additional research is warranted to evaluate whether the side effects and risks of treatment outweigh the benefits in this special population (Fisch, 2004).

One medication from the serotonin norepinephrine reuptake inhibitor family, extended-release venlafaxine, is approved by the U.S. Food and Drug Administration for the treatment of GAD and depression. In the general population, randomized controlled trials have demonstrated efficacy of venlafaxine, but response to the medication could take more than eight weeks (Montgomery, Sheehan, Meoni, Haudiquet, & Hackett, 2002). A recent search of the PubMed database found no trials of venlafaxine for isolated anxiety.
or depression in patients with cancer. Additionally, it can be very difficult to distinguish chronic anxiety from depression in people with cancer, making management of these unique diagnoses more difficult. When both diagnoses are evident, antidepressants are preferable to benzodiazepines (Greenberg, 2004).

**Complementary and Alternative Medicine**

CAM spans a wide breadth of herbal remedies, ancient medical practices, physical techniques, and many other areas outside of Western medicine. Some existing CAM therapies may be effective for the treatment of anxiety in people with cancer. Kava is an herbal medicine originating from the Pacific Islands that gained popularity in the United States in the late 1990s. Several randomized, placebo-controlled trials have evaluated the efficacy of kava in treating various anxiety disorders in the general population, with sample sizes ranging from 20 to 141. Some of these trials demonstrated a significant improvement in anxiety symptoms when comparing kava to placebo but were limited by the heterogeneity of the populations in the studies, short treatment duration, and lack of rigorous diagnostic criteria (Mischoulon & Rosenbaum, 2008). Adequate evidence is not available to recommend kava for the treatment of anxiety, specifically in the cancer population.

Exercise (defined here as aerobic or strength-focused exercise) has frequently been studied as a potential treatment for anxiety in patients with cancer. Two of four studies investigating the effect of exercise demonstrated a reduction in anxiety, but sample sizes were small (Badger et al., 2007; Burnham & Wilcox, 2002; Midtgaard et al., 2005; Segar et al., 1998). Although the overall health benefits of exercise are well established, evidence is lacking to evaluate its effectiveness for the treatment of anxiety in patients with cancer.

Music and art therapy are appealing options for alternative treatments and have been studied specifically for the treatment of anxiety in cancer. A trial studying the effect of art therapy with a registered art therapist showed significant decreases in anxiety scores; however, a control group was not included in the design of the study (Nainis et al., 2005). One trial examined the effects of music, distraction, and usual treatment on anxiety in patients with cancer but failed to demonstrate benefits (Kwekkeboom, 2003). Meditation is a frequently studied mind-body intervention and has been evaluated in two studies with statistically significant reductions in anxiety (Hidderley & Holt, 2004; Targ & Levine, 2002).

**SUMMARY**

Working with survivors requires that healthcare providers carefully assess psychosocial functioning. Interventions are tailored for the specific experience of each survivor and incorporate an individualized approach. Most survivors
experience anxiety at certain time points, such as during follow-up testing. Mild anxiety can be a normal reaction and can heighten awareness, whereas severe anxiety can be incapacitating, impairing the survivor’s ability to focus, make decisions, and function. Timely assessment at these points may provide early relief of anxiety or direct further interventions, including referral. Whatever the survivor’s experience, healthcare providers can promote self-management through support and education. When working with cancer survivors, providers can build on individual coping strategies to manage uncertainty and anxiety, promote early detection through targeted assessments, and treat disabling distress and anxiety to improve quality of life in survivorship.

REFERENCES


INTRODUCTION

Advances in cancer screening and treatment for cancer have resulted in an increasing population of cancer survivors in the United States (Rowland & Bellizzi, 2008). Many cancers once thought of as acute diseases are now considered chronic. The potential for long-term consequences and treatment decisions exists for individuals for years or even decades after their initial cancer diagnosis. The psychosocial sequelae can be both negative and positive and are shaped by health and disease factors, available resources and support, and intrapersonal factors. A greater need exists for a more thorough and comprehensive understanding of the long-term impact of cancer on individuals.

The most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) has been revised to include the diagnosis of a life-threatening illness (e.g., cancer) as an example of a potentially traumatic event. As a result, the literature on post-traumatic stress disorder (PTSD) among this population has expanded (Jim & Jacobsen, 2008; Kangas, Henry, & Bryant, 2002; Mundy & Baum, 2004; Palmer, Kagee, Coyne, & DiMichele, 2004) despite existing debate about the application of DSM-IV PTSD criteria to cancer survivors. Although critically important, PTSD appears to be low in incidence and prevalence in this population.

PTSD is only one potential consequence of a traumatic life event such as cancer. Subclinical levels of distress are more common, especially soon after diagnosis (Holland, 2000; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Furthermore, the negative effects of cancer are clearly
only part of the picture. Evidence has been accumulating that demonstrates that individuals with cancer often report positive changes in their life as a result of their experience (Bellizzi, Miller, Arora, & Rowland, 2007; Calhoun & Tedeschi, 2006; Tedeschi & Calhoun, 1995). Separate but related theoretical perspectives assert that both PTSD and post-traumatic growth (PTG) are precipitated by trauma, and both of these potential outcomes result from the struggle to reconcile a breakdown in world assumptions or individual core beliefs (Calhoun & Tedeschi, 2006; Janoff-Bulman, 1992). A diagnosis of PTSD is more likely when assimilation does not occur and intrusive thoughts and avoidance persist (Horowitz, 1997). Conversely, PTG appears to occur when individuals are able to change the meaning of the traumatic event, integrate the cancer experience into their lives, and reconstruct their worldview in a positive manner.

This chapter examines the relationship between cancer, PTSD, and PTG. Although PTSD and PTG will be examined separately, positive and negative outcomes often coexist in cancer survivors. Indeed, to some degree, PTG requires that the event (i.e., cancer diagnosis and treatment) has been perceived as traumatic (Tedeschi & Calhoun, 1996). Thus, negative and positive effects are interwoven in varying, individualistic trajectories of the cancer experience. Understanding the nature of these trajectories is complicated because of the often extended periods of treatment and disease-free survival or recurrence, the ambiguity of the stressor embedded in other life events, and the degree and nature of symptoms experienced. Moving toward a more comprehensive understanding of the potential impacts that cancer can have on an individual has important implications for both assessment and intervention, as will be discussed later in the chapter.

**POST-TRAUMATIC STRESS DISORDER**

Cancer is a very personal psychological experience. Responses to cancer are as diverse as the people who are diagnosed with the disease. Dealing with the interrelated web of medical, family, economic, and psychosocial issues associated with cancer can cause significant stress. Stress is a condition caused by uncertainty or unpredictability about obtaining positive outcomes or avoiding negative outcomes (Levin & Ursin, 1991). Once regarded as an acute condition, cancer is now becoming chronic. While this is beneficial because it allows for a long life with many positive elements, it also has the potential to increase the number, intensity, and duration of stressors. Persistent stress can lead to a variety of psychiatric conditions, including mood disorders, acute stress disorder, and PTSD (Desaive & Ronson, 2008).

The DSM-IV diagnostic criteria for PTSD are summarized in Figure 17-1. If multiple symptoms from each criterion are present, a diagnosis of PTSD may be warranted.
Although cancer would appear to be an exemplary example of a traumatic life event that can precipitate a clinical diagnosis of PTSD, the prevalence rates are relatively low, ranging from 2% to 35%. This wide range is due to definitional issues and specific subpopulations. Summarily, the majority of studies have been cross-sectional with reported rates around 5% (Andrykowski, Cordova, McGrath, Sloan, & Kenady, 2000; Gandubert et al., 2009; Kangas et al., 2002; Mehnert, Lehmann, Graefen, Huland, & Koch, 2010; Palmer et al., 2004; Pitman et al., 2001; Smith, Redd, Peyser, & Vogl, 1999), and most studies have been focused on breast cancer and early-stage disease. Studies that have found higher rates have tended to focus on people with advanced cancers and poor prognoses. Despite the relatively low incidence and prevalence rates of PTSD in the cancer population, several studies have identified moderate levels of PTSD-related symptoms in this group.

A review of the literature suggested that the rates of PTSD-related symptoms, including intrusive and avoidance symptoms, in cancer survivors within a year of diagnosis are somewhat higher than confirmed PTSD diagnoses. These symptoms tend to decline the further away people are from their diagnosis and treatment (Kangas et al., 2002). Once the initial threat of cancer and its treatment is removed, thoughts often turn to fear of the cancer returning, which is reported as the most prevalent concern among cancer survivors (Bellizzi, Latini, Cowan, DuChane, & Carroll, 2008; Lebel, Rosberger, Edgar, & Devins, 2007). Several studies suggest some fluctuation in PTSD symptoms, with increased rates 12 months after treatment. This could reflect the heightened anxiety and fear that often accompany follow-up care visits.

### Risk Factors for Post-Traumatic Stress Disorder

Although a diagnosis of cancer in and of itself is not a sufficient cause of PTSD, certain factors seem to place some people at risk for developing...
PTSD. For instance, younger age and low socioeconomic status have been found to increase the risk of PTSD in cancer survivors (Shalev, Peri, Canetti, & Schreiber, 1996). Medical and health characteristics, including advanced disease, aggressive treatment (e.g., bone marrow transplant), disease recurrence, and competing comorbid conditions seem to increase the risk of PTSD (Dadić-Hero, Torić, Ruzić, Medved, & Graovac, 2009). The latter is troubling because cancer disproportionately affects older men and women, a population expected to double in the United States by 2050, many of whom have coexisting comorbidities (Blank & Bellizzi, 2008; Smith, Smith, Hurria, Hortobagyi, & Buchholz, 2009). Additional psychosocial and biologic factors associated with PTSD include avoidant coping, low levels of social support, previous history of trauma and psychiatric disorders, and biologic and genetic factors that affect memory and learning.

Assessment and Interventions for Post-Traumatic Stress Disorder

The Institute of Medicine’s (2007) report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, discussed the need for a thorough assessment of cancer survivors’ psychological status. Measures of PTSD should be included in the patient assessments, particularly for those who may meet criteria for being at risk for PTSD. Several instruments exist, including the Structured Clinical Interview for DSM-IV, the PTSD Checklist–Civilian Version, and the Clinician-Administered PTSD Scale–Structured Interview. Other PTSD self-report symptom tools are available, such as the Impact of Event Scale and the Post-Traumatic Stress Reaction Index. Although these tools are frequently used in research and practice and have demonstrated sound psychometric properties in trauma victims, none were specifically designed to measure or assess trauma associated with cancer or any other life-threatening illness. Psychometric validation of these measures in the cancer population is needed. Nevertheless, Smith et al. (1999) suggested “a multimodal approach in which a variety of different types of data (e.g., social, cognitive, emotional, familial, and vocational functioning), collected both from different sources (e.g., self-report, clinician, collateral) and by different methods (e.g., interviews, behavioral observation, physiological and psychological tests), is gathered and evaluated” (p. 522).

A diagnosis of PTSD can be long-lasting and seriously affect an individual’s everyday life, including family, work, and social activities. Several different therapies have been successful in the treatment of PTSD in trauma victims, including behavior therapy, coping and stress management techniques, relaxation training, professionally facilitated support groups, and certain medications, such as antidepressants and antianxiety medicine in severe cases. Behavioral methods are geared toward helping the individual to identify upsetting triggers and to reframe distressing thoughts, perhaps leading to a different understanding of the cancer experience that may, in turn, be indicative of PTG.
POST-TRAUMATIC GROWTH

Many researchers have noted the presence of what is often termed post-traumatic growth (Calhoun & Tedeschi, 2006). A number of theorists in the 1990s focused on what has been well known for centuries concerning the impact of even the most adverse, traumatic situations: that they not only engender distress, but, in fact, may serve as entrée events into a realm of heightened positive cognitions and emotions as one creates a new sense of self and relationship to the world and to others (Park, Cohen, & Murch, 1996; Tedeschi & Calhoun, 1995). Although continuing concerns exist about the degree to which what is reported is “real” or “subjectively experienced,” what is important is that positive reactions to one’s cancer experience have been found to be common across many populations and studies. As reviewed in multiple studies, more than 80% of people diagnosed with cancer reported at least some benefit and growth from their cancer experience (Algoe & Stanton, 2009; Jim & Jacobsen, 2008; Sears, Stanton, & Danoff-Burg, 2003). These reports ranged from the very personal experience (such as discovery of one’s strengths), to the very social (relationships with others), and even to existential experiences (closer relationship to God or nature). It is important to note that most of the research has been conducted with women diagnosed with early-stage breast cancer. Although gender differences are likely, studies using other cancers, including prostate cancer (Blank & Bellizzi, 2006; Kinsinger et al., 2006), have shown similarly high rates. However, in many cases, the reported levels are modest in both breadth (range of domains) and depth (strength of change indicated).

Post-Traumatic Growth and Trauma

Although PTG is obviously parallel to PTSD, the meaning and designation of the term are not as crisp and precise, nor does the usage follow strict DSM-IV terminology (Tedeschi & Calhoun, 1995, 2009). Tedeschi and Calhoun (1995) specifically asserted that PTG would occur only when the initial event was perceived as traumatic; however, traumatic is explicitly not defined as analogous to DSM-IV criteria. Whether the diagnosis of cancer attains this level of trauma for many is not clear and would likely vary by site, intensity of treatment, and prognosis, among other intraindividual factors. Many eschew the specific terminology (Park, 2009, p. 12), preferring stress-related growth (Park et al., 1996) or benefit-finding (Algoe & Stanton, 2009), which usually are considered synonymous. The linchpin of the approach to PTG, however labeled, is that the root experience of cancer has been sufficiently traumatic (or dramatic) that it has instigated a search for meaning and a need for reconstruction of one’s sense of self and relationship to the world (Park, 2009; Tedeschi & Calhoun, 2009).

Measurement and Assessment of Post-Traumatic Growth

Issues exist related to the appropriate measurement and assessment of PTG, similar to those related to labeling. The most commonly used measure
is the Post-Traumatic Growth Inventory (PTGI) (Tedeschi & Calhoun, 1996), followed by the measure of benefit-finding (Tomich & Helgeson, 2004) and stress-related growth (Park et al., 1996). Each taps into a similar realm but with quite distinct sets of dimensions; the PTGI is framed specifically within the trauma model of Tedeschi and Calhoun (1996). In each case, the major aspects of growth or benefit include a new sense of importance of and commitment to relationships with others, religious or spiritual awareness, an appreciation for nature, and a sense of one’s own value and openness to the world. Underlying much of the positive nature of the changes is the ability to make meaning from the event, a view of the world and oneself that takes into account the reality of the cancer experience (Park, 2009). An important methodologic limitation of existing measures is the inherent self-enhancing bias in measuring simply the positive aspects of cancer’s impact. Because positive and negative consequences can and do occur, future research should consider concurrently assessing both aspects (Bellizzi et al., 2007).

**Post-Traumatic Growth and Positive and Negative Health Outcomes**

Whether labeled PTG or not, and regardless of whether one can trace the development of reported growth after cancer to a specific formulation of cancer as a traumatic event, the reality is clear. Many, if not most, cancer survivors report relatively significant levels of positive impacts (Bellizzi & Blank, 2006; Jim & Jacobsen, 2008; Sears et al., 2003; Stanton, Bower, & Low, 2006; Tomich & Helgeson, 2004). Less clear is whether psychological growth and benefit-finding after cancer are related to what we would consider standard positive or negative outcomes. As reviewed by Algoe and Stanton (2009), the impact on both negative outcomes, such as depression and negative affect, and positive outcomes, such as positive affect, is very unclear. Some studies showed beneficial effects of benefit-finding, whereas others show little. Lechner, Carver, Antoni, Weaver, and Phillips (2006) provided evidence that the relationship of benefit-finding and outcomes in cancer survivors may be a curvilinear, complex one. Lechner et al. (2006) and others (e.g., Bower et al., 2005) also showed that effects can endure over a number of years into survivorship. The only clear finding seems to be that it has not been associated with lower positive affect or quality of life.

Likewise, the relationship of PTG to demographic factors is unclear. It does appear that younger cancer survivors are more likely to report psychological growth than older ones (Aldwin, Levenson, & Kelly, 2009; Stanton et al., 2006). The roles of competing personal demands and varying personal resources with age are important but very underattended. Much work needs to be done to disentangle the array of influences that present such a complicated picture of both the realities and the personal value of psychological growth.

A final, critically important point is that PTSD, or distress, and PTG are not independent. Indeed, the model that sets the tone for much of the research on positive life changes begins with cancer being a traumatic, life-altering event.
It is very likely that the mixed findings of the effects of positive change on outcomes are at least partially explained by competing influences of coexisting distress and growth. Unfortunately, relatively few studies have included both outcome measures. When both measures are included, there appear to be coexisting effects, such that some people report both relatively high negative and relatively high positive impacts, and others report little to no impact in either direction (Bellizzi et al., 2007; Blank & Bellizzi, 2006; Bower et al., 2005). An important next step in both research and practice is to incorporate the ways in which cancer survivors integrate these seemingly contradictory forces.

**SUMMARY**

With more people living longer with cancer, the need to recognize and attend to the wide range and variety of consequences on individuals is critical. Nurses who deal regularly with cancer survivors bear a great responsibility to address and integrate the effects of their cancer experience into their lives. A diagnosis of PTSD is possible in certain segments of the prevalent cancer population, and we have identified factors associated with that increased risk. More common are the normative risks of both initial and ongoing distress and, in many cases, the opportunity for initial and ongoing growth and benefit-finding. Attention to both the negative and positive aspects of cancer represents a paradigm shift away from only considering the negative spiral of a cancer diagnosis. New measures need to be developed that capture the spectrum of responses in order to develop a more complete understanding of the disease’s impact on the individual. Of course, attenuating the negative, such as PTSD or PTSD-related symptoms, is vital, but building on the strengths of individuals and tactfully guiding the individual to recognize the positive in a seemingly negative experience can be transforming and lead to other adaptive behaviors and outcomes. The challenge is to develop the infrastructure and capacity to both integrate brief psychosocial assessments into everyday practice and to identify and have access to appropriate resources and support services for the patients in our care.

**REFERENCES**


INTRODUCTION

Recent trends show that most types of cancers have been associated with a greater increase in overall survival time (Horner et al., 2009). While this is overwhelmingly positive, increased attention must be directed toward the needs of survivors. A portion of these survivors will ultimately have chronic pain and be categorized as chronic opioid therapy users. The question becomes, do these patients differ from other patients who experience pain not from cancer or a cancer treatment–related origin?

It has been commonly believed that patients with cancer were fundamentally different from patients with chronic, nonmalignant pain and therefore were less prone to issues such as abuse, misuse, and addiction. However, it is becoming evident that a cancer diagnosis does not necessarily bestow protection against the risk of addiction or substance abuse. The long-term survivorship period is a significant time frame of exposure for patients with preexisting or unknown risk factors to develop problematic behaviors. Some reports of substance abuse, and even diversion, have been observed (Blot, 1992; Bruera et al., 1995; Miovic & Block, 2007; Smith-Warner et al., 1998).

Because of the potential for problematic medication use behaviors in patients, prescribers must know how to apply the principles and practices of addiction medicine to the care of all individuals being treated with controlled substances, regardless of whether the patient has cancer. Simply put, having a cancer diagnosis or being a survivor does not protect a patient from the risk of addiction. Although clinicians must be careful not to be overly suspi-
cious of patients, they cannot assume that patients are immune from aberrant behaviors. Indeed, addiction is a risk factor for cancer (e.g., nicotine, alcohol), and patients with cancer and addictive behaviors experience pain that requires treatment.

DIFFERENTIATION OF CANCER SURVIVORS FROM OTHER PAIN POPULATIONS

Although few differences separate cancer survivors with pain from other chronic pain populations, specific issues exist. The main demographic difference between patients with cancer and patients without cancer is age. In general, patients with cancer tend to be older and thus are likely to be beyond the window of risk for addiction by the time they are diagnosed, as approximately 90% of addictions manifest by age 35 (Grant & Dawson, 1997; Hingson, Heeren, & Winter, 2006; Volkow, 2005; Volkow & Li, 2005). Because the median age at onset for all cancers is 65, most patients with cancer are unlikely to exhibit addictive tendencies when exposed to opioids if they have never had difficulties before. Conversely, younger patients with cancer who are exposed to opioids may have some risk of expressing potential addiction tendencies (Compton & Volkow, 2006; Webster & Webster, 2005), especially given the stress of a cancer diagnosis. Thus, age should possibly be considered as a mediating factor from both perspectives.

Although age should be a consideration, no cookie-cutter approach exists to examining risk in any patient with pain, let alone the somewhat unique category of the cancer survivor with pain. Although demographics should be examined, specific risk factors, such as age at first use, might be more indicative of problems with substances such as tobacco as opposed to opioids (Benowitz, 1996; Blum et al., 2000; Breslau, Johnson, Hiripi, & Kessler, 2001; Giovino, Henningfield, Tomar, Escobedo, & Slade, 1995).

An understanding of the rates of occurrence for various addictions is important to keep in mind. Opioid addiction affects approximately 3% of people in the United States, and nicotine addiction in adults varies from 21% to 33% (Fleming, Balousek, Klessig, Mundt, & Brown, 2007; Substance Abuse and Mental Health Services Administration, 2005). When exploring whether a patient with cancer may be at risk for opioid abuse, comparisons to other addictive behaviors may or may not be predictive. Smokers with a family history of smoking are more likely to start and continue smoking and exhibit difficulty with quitting; this pattern is not necessarily seen with opioid use (Buka, Shenassa, & Niaura, 2003; Carmelli, Swan, Robinette, & Fabsitz, 1992; Lessov et al., 2004; Sabol et al., 1999; Wright, Weinman, & Marteau, 2003). Thus, not all addictions manifest in the same way or due to the same reasons; clearly, the genetic and other risk factors underpinning addiction to these two drugs are vastly different, as are the drugs’ likeability profiles.
CHAPTER 18. ASSESSING RISK FOR POTENTIAL SUBSTANCE ABUSE

OPIOID USE IN SURVIVORS WITH OR WITHOUT HISTORIES OF ABUSE AND ADDICTION

Giving opioid analgesics to patients while they are in active treatment, assuming no prior history of substance abuse, is rarely associated with significant abuse or addiction (American Society of Clinical Oncology, 1992; Zech, Grond, Lynch, Hertel, & Lehmann, 1995). One would likely assume that no significant change would occur as the patient becomes a long-term survivor with chronic pain concerns. However, fears of addiction continue to be the focus of the media, public, and inexperienced clinicians whenever opioids are discussed. Conversely, specialists in cancer pain and palliative care widely believe that the major problem related to addiction is not the phenomenon itself but rather the persistent undertreatment of pain driven by inappropriate fear that it will occur. Little support exists for the view that large numbers of individuals with no personal or family history of abuse or addiction and no significant premorbid psychopathology will develop problems when administered opioids appropriately (Meuser et al., 2001; Potter, Hennessy, Borrow, Greenfield, & Weiss, 2004). Furthermore, euphoria, believed to be common during the abuse of opioids, is rare following administration of an opioid for pain. It is much more common to see dysphoria as a side effect, perhaps in part because of the distress of the pain itself.

If no history of substance abuse is present, survivors are likely to represent minimal risk should they have a chronic pain concern and have already been exposed to opioid therapy while in active cancer treatment. Of concern are those patients with a known history of abuse or addiction. Unfortunately, little information is available about the risk of abuse or addiction during or after the therapeutic administration of opioids to patients with a current or remote history of abuse or addiction. Anecdotal reports suggest that successful opioid therapy in patients with cancer pain or chronic nonmalignant pain is possible even if the history of abuse or addiction is remote (Dunbar & Katz, 1996). In a similar disease state, patients with AIDS-related pain have been successfully treated with morphine whether or not they were substance users or nonusers. The major group difference was that substance users required considerably more morphine to reach stable pain control (Kaplan, Slywka, Slagle, & Ries, 2000). These data are reassuring but do not obviate the need for caution. A good risk management program should be put into place but should not be used as a means to deny treatment to survivors with chronic pain. Rather, it should be used to stratify the amount of risk and specialty care that might ultimately be needed.

WHAT IS ADDICTION?

Before discussion of risk management guidance with regard to prescribing opioid medications to cancer survivors with pain, it is necessary to define
the types of problems that can be seen when pain management efforts go awry. Defining abuse and addiction in medically ill populations can be highly problematic because many of the terms were originally developed to assess addicted populations without medical illness. As an example, many patients with pain will be prescribed opioids for legitimate medical purposes and will subsequently experience the pharmacologic phenomena of tolerance and physical dependence after long-term use (Kirsh, Whitcomb, Donaghy, & Passik, 2002). Addiction is a chronic disorder characterized by “the compulsive use of a substance resulting in physical, psychological, or social harm to the user and continued use despite that harm” (Rinaldi, Steindler, Wilford, & Goodwin, 1988, p. 556). This definition focuses on the quality and consequences of drug-taking, is sufficiently broad to be applied to patients such as cancer survivors who develop addiction while receiving an opioid for a painful medical condition, and avoids the inappropriate inclusion of phenomena related to tolerance and physical dependence. Like other definitions, it emphasizes that addiction is a psychological and behavioral syndrome that is characterized fundamentally by compulsive use, loss of control over that use, development of cravings, and continued use despite harm.

Given that problems will be seen that do not rise to the level and definitional criteria of addiction, what else might explain problematic behaviors? As a first step, it is important to label any problematic behaviors as potentially aberrant drug-related behaviors. Patients who receive opioids for a legitimate medical purpose sometimes engage in a broad range of behaviors that are conventionally perceived by prescribers as worrisome. Pain clinic data suggest that nearly half of opioid-treated patients will manifest at least two aberrant behaviors in a six-month period (Passik et al., 2005; Webster & Webster, 2005). A large, primary care–based study of patients on chronic opioid therapy suggested that a patient with a self-reported history of two aberrant behaviors has an 85% likelihood of meeting DSM-IV criteria for substance use disorder (Fleming et al., 2007). In some cases, the behaviors are sufficiently extreme (i.e., changing the route of administration of a medication from oral to IV) to immediately suggest the diagnosis of an addiction disorder. In other cases, aberrant behaviors might reflect an attempt to chemically cope by using medications to deal with stress (Kirsh, Jass, Bennett, Hagen, & Passik, 2007).

Alternatively, the concept of pseudoaddiction may need to be considered as a possible explanation for aberrant behaviors (Weissman & Haddox, 1989). Pseudoaddiction refers to the escalation of dosages in response to insufficient analgesia but with a resolution of the problematic behavior once adequate pain relief is achieved. It may be a possible consideration when a patient reports unremitting symptoms, has frequent requests for higher doses of medication, or engages in sporadic unilateral dose escalation. While this may initially be perceived as addiction, it is possible that such behaviors are indicative of desperation resulting from unrelieved pain and will cease once the patient experiences relief. Although potentially stretching the original definition, issues
such as unilateral dose escalation or even the use of marijuana and alcohol in the face of untreated pain or concurrent anxiety or mood disturbance have been described as evidence of pseudoaddiction (Forbes, 2006).

**Risk Stratification**

As stated earlier, no “one-size-fits-all” approach exists to stratifying risk in cancer survivors with chronic pain concerns when opioid medications are being considered. Fortunately, interest has been growing in the development of tools that can be useful for screening patients to determine their relative risk for having or developing problems with prescription drug abuse or misuse. Passik, Kirsh, and Casper (2008) recently described and reviewed 25 of the most researched tools. Of these, the Screener and Opioid Assessment for Patients With Pain and the Opioid Risk Tool have shown to be both popular and to yield useful information for prescribers (Butler, Budman, Fernandez, & Jamison, 2004; Webster & Webster, 2005). The choice of what risk tool to select is related to the type of prescriber practice, available time, volume of patients, and comfort level with accepting greater type I or type II errors, as all of the available instruments have limitations.

Once an initial risk screening is performed, the clinician needs to determine whether the patient is relatively uncomplicated or if consultation with specialists is needed to manage what might be a high-risk patient. Following the initial evaluation, ongoing assessment and follow-up efforts remain an important part of prescribing opioids. One potential framework for ongoing assessment involves interviewing around four main domains: analgesia, activities of daily living, adverse side effects, and potentially aberrant drug-related behaviors (Passik & Weinreb, 2000). These “four A’s” have been tested and reduced to a one-page, dual-sided chart note called the Pain Assessment and Documentation Tool (Passik et al., 2004, 2005).

**Management of the Dual Diseases of Addiction and Chronic Pain**

Inadequate assessment and risk stratification efforts can lead to potential undertreatment, compromise the effectiveness of therapy when implemented, and prevent an appropriate response when problematic drug-related behaviors occur (Joint Commission, 1999; Katz, 2002; Max, Payne, & Edwards, 1999). A failure to perceive and address problematic behaviors, in turn, can have both regulatory and medical-legal consequences for the clinician.

As a first step in creating a working relationship with a cancer survivor experiencing chronic pain, the clinician should consider using a written agreement for opioid therapy. Written agreements are helpful tools in structuring treatment and should clearly state the roles of the prescriber, roles for any other healthcare professionals involved in the care of the patient, and the rules and expectations for the patient. The patient’s behaviors should be used as the basis for the level of restrictions, and graded agreements that clearly
state the consequences of aberrant drug use should be enforced (Fishman & Kreis, 2002; Passik & Portenoy, 1998).

An important step in managing a patient with suspected aberrant behaviors is to ask for the patient’s self-report about the worrisome behaviors. Given that this will have limitations, it is at times advisable to obtain outside corroboration of the self-report. This can take many forms, including having a spouse give feedback to the prescriber on the patient’s behavior outside of the office (with the patient’s consent), the use of urine toxicology screening, or patch and pill counts. In a study by Katz and Fanciullo (2002), approximately one of every five patients without obvious behavioral manifestations of noncompliance was found to have a problematic urine toxicology screen, showing either the presence of illicit drugs or a nonprescribed controlled substance, or the absence of a drug that had been prescribed and should have been detectable in the urine.

Similarly, pill counts and patch counts (e.g., fentanyl transdermal system) can be another way of monitoring the patient’s medication supply so that one can be reassured that drugs are not being overused or diverted. For patients who live at a distance from the prescriber, a local pharmacy might be approached about helping to perform pill counts without causing the patient to travel a great distance. Patients can be asked to secure the use of their fentanyl patches by affixing used patches to colored paper and bringing them to the clinic so that the prescriber can account for the used and intact patches.

When a problem is encountered, a prescriber must consider how to handle what may be a disease of addiction on top of a chronic pain complaint. It is clear that something must be done at this point to treat both issues, as neither will get better in isolation. Within the context of outpatient management, a clinician may choose to refer patients to a 12-step program. This referral must stipulate that documented attendance is a condition for ongoing drug therapy (Passik, Portenoy, & Ricketts, 1998). Twelve-step programs pose a risk, however, because the liberal use of opioids may not be supported and the side effects misunderstood despite a genuine pain concern and the patient’s history of cancer.

On a final note, prescribers must avoid problems that can arise as a result of poor documentation. For instance, a review of more than 500 randomly selected visits at an outpatient oncology practice found quantitative assessment of pain scores to be virtually absent (less than 1%) and qualitative assessment to be far from universal (60% of cases) (Rhodes, Koshy, Waterfield, Wu, & Grossman, 2001). Similarly, a chart review of 300 patients with chronic pain showed that 61% had no documentation of a treatment plan (Clark, 2002). Finally, a review of the medical records of patients who underwent urine toxicology screens in a cancer center found that documentation was infrequent: a reason was listed for the test only 62% of the time, and 89% of the charts did not include the results of the test (Passik, Schreiber, Kirsh, & Portenoy, 2000). The old axiom of “if it wasn’t written, it didn’t happen” is an important lesson to remember.
SUMMARY

The face of cancer and cancer treatment is changing, with survivorship becoming more common. However, many times, the disease process or treatments used to cure the disease can create lasting problems, including saddling patients with chronic pain issues. In treating this growing population of survivors who have pain, healthcare providers also must be vigilant with regard to potential addiction, abuse, and misuse issues. They must remember that prescribers cannot prevent the occurrence of all aberrant drug-related behavior, and virtually any drug that acts on the central nervous system can be abused, including nonopioid drugs. The effective management of patients with pain who engage in aberrant drug-related behavior must involve a comprehensive approach that recognizes the biologic, chemical, social, and psychiatric aspects of substance abuse while providing practical means to manage risk, treat pain effectively, and ensure patient safety.

The authors would like to acknowledge Amy Lowery, PhD, for her contributions to this chapter.

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INTRODUCTION

Patients with cancer often face fears of death or disability and may be prone to isolation and hopelessness. Not surprisingly, many patients show signs of psychological distress or acute stress reactions at some point during their treatment (Iconomou, Mega, Koutras, Iconomou, & Kalofonos, 2004; Massie, Gagnon, & Holland, 1994; Stanton, 2006). The clinical literature has focused largely on the diagnosis and treatment phases of care; comparatively less is known about the psychological adaptation of cancer survivors after completion of therapy. It is generally believed that most survivors adapt positively after cancer, have a positive psychological outcome, and over time successfully resolve many psychological challenges (Hoffman, McCarthy, Recklitis, & Ng, 2009; Kornblith, 1998; Stanton, 2006).

Although most long-term survivors do not experience significant psychological distress, a sizable minority do (Hoffman et al., 2009; Stanton, 2006). The focus of this chapter is on understanding the long-term risk of depression and suicide that cancer survivors may face after completion of their treatment, and how nurses and other providers can recognize these issues and provide necessary assessment and referral for their patients. With more than 12 million cancer survivors in the United States (National Cancer Institute, 2008), any brief discussion of their psychosocial health must generalize across a wide variety of survivor experiences, including treatment for dozens of different cancers with hundreds of different treatments. As a result, practitioners will need to adapt the information presented here to their particular survivor populations. An understanding of the prevalence of and risk factors for depression and suicide in long-term cancer survivors, along with screening, assessment, and referral, will enable early intervention and appropriate management.
PREVALENCE AND RISK OF DEPRESSION IN LONG-TERM CANCER SURVIVORS

Several factors complicate the characterization of depression in a medical population. The word depression is used to describe (a) normal transient variations in mood, (b) more lasting and potentially pathologic mood states, and (c) a psychiatric disorder characterized by mood disturbance and associated symptoms. Depending on which meaning is intended, it will be defined differently, and the prevalence of “depression” will vary considerably. Symptoms of depression overlap with symptoms of medical conditions and medication side effects, making it difficult to differentiate between depression and these factors. In addition, symptoms of depression are common in the general population, so signs of depression in a medically involved group may reflect only the background level of depression expected in the general population. Understanding these limitations is important in both the assessment of individual survivors as well as the consideration of the research on depression after completion of cancer therapy.

Several population-based studies comparing long-term survivors to controls or normative reference groups on self-report symptom checklist measures have suggested an increased risk for depression in long-term cancer survivors, but the findings have not been consistent. Studies of colorectal cancer survivors, for example, have reported higher levels of depressive symptoms, but studies of breast and testicular cancer survivors have not (Arndt, Merx, Stegmaier, Ziegler, & Brenner, 2004; Dahl et al., 2005; Ganz, Rowland, Meyerowitz, & Desmond, 1998; Ramsey, Berry, Moinpour, Giedzinska, & Andersen, 2002). Several studies examining psychological distress in large cohorts of long-term survivors across cancers have reported that survivors are at higher risk than the general population. Some of these studies used psychological rating scales that emphasized depression but included other symptoms, making it difficult to determine whether the findings are attributable to depression (Baker, Haffer, & Denniston, 2003; Hoffman et al., 2009). Two studies that did use depression-specific ratings across cancer groups also reported significantly elevated rates of depressive symptoms, even in survivors four to eight years after diagnosis (Costanzo, Ryff, & Singer, 2009; Polsky et al., 2005).

Very few studies have examined whether cancer survivors are at increased risk for the psychiatric diagnosis of major depressive disorder (MDD), a major mental illness that negatively affects mental and physical function. MDD is characterized by having at least two weeks of depressed mood or loss of interest and at least five of the following seven symptoms: sleep disturbance; low energy; difficulty concentrating; poor appetite; feelings of guilt, hopelessness, or helplessness; psychomotor retardation or agitation; and thoughts of death (American Psychiatric Association, 1994). These symptoms also must cause impairment in functioning. To determine whether depressive symptoms meet the criteria for MDD, a structured diagnostic interview must be used. Using data from a large epidemiologic study that included diagnostic interviews, one
study reported no difference in the rates of MDD between cancer survivors and controls (Pirl, Greer, Temel, Yeap, & Gilman, 2009). Taken together, these studies indicate that long-term cancer survivors are at increased risk for depressive symptoms but not necessarily a diagnosis of MDD. Furthermore, the risk for depressive symptoms is not likely to be elevated in all survivor groups and may depend on cancer diagnoses and other factors.

Risk factors for depression (see Figure 19-1) vary across individuals and types of cancers but can be used to identify the survivors who are most at risk

<table>
<thead>
<tr>
<th>Figure 19-1. Risk Factors for Depression and Suicidal Ideation After Cancer*</th>
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<tbody>
<tr>
<td><strong>Risk Factors for Depression</strong></td>
</tr>
<tr>
<td>• Personal factors</td>
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<tr>
<td>– Female gender</td>
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<tr>
<td>– History of mental illness or substance abuse</td>
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<tr>
<td>– Economic hardship</td>
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<tr>
<td>– Lack of social support</td>
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<tr>
<td>– Life stressors (e.g., divorce, homeless, unemployed)</td>
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<tr>
<td>• Disease factors</td>
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<tr>
<td>– Residual disease, recurrence, relapse</td>
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<tr>
<td>– Poor prognosis</td>
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<td>– Prolonged or intense treatment (e.g., bone marrow transplant)</td>
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<td>– Problems adjusting or adhering to treatment</td>
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<tr>
<td>• Physical factors</td>
</tr>
<tr>
<td>– Poor health status</td>
</tr>
<tr>
<td>– Physical disfigurement</td>
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<tr>
<td>– Chronic medical conditions</td>
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<tr>
<td>– Chronic pain</td>
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<tr>
<td>– Functional limitations (e.g., ambulation, communication)</td>
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<tr>
<td>– Difficulty in self-care (e.g., dressing, eating, bathing)</td>
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<tr>
<td><strong>Additional Risk Factors for Suicidal Symptoms</strong></td>
</tr>
<tr>
<td>• Personal factors</td>
</tr>
<tr>
<td>– Gender (males at higher risk for completion; females at higher risk for attempts)</td>
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<tr>
<td>– Unmarried status</td>
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<tr>
<td>– Personal or family history of suicidal behaviors</td>
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<tr>
<td>– Hopelessness</td>
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<tr>
<td>– Impulsivity</td>
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<tr>
<td>– Access to firearms or other lethal means, including medications</td>
</tr>
<tr>
<td>• Disease factors</td>
</tr>
<tr>
<td>– Disease sites: lung, head and neck, central nervous system, pancreatic, gastrointestinal cancers</td>
</tr>
<tr>
<td>• Physical factors</td>
</tr>
<tr>
<td>– All physical factors for depression, as above</td>
</tr>
</tbody>
</table>

*Because depression contributes to risk of suicidal symptoms, all of the depression risk factors should be considered potential risk factors for suicide.

Note. Based on information from Hoffman et al., 2009; Massie et al., 1994; Pirl, 2004; Schneider & Shenassa, 2008; Trask & Pearman, 2007.
Demographic risk factors include female gender, younger age, and lower socioeconomic status. Preexisting psychiatric conditions, as well as problems with social or occupational functioning, suggest increased vulnerability. Similarly, extreme emotional reactions occurring during treatment should be considered risk factors for ongoing distress. Aspects of the cancer diagnosis and its treatment also may be associated with future emotional distress. Specifically, poor prognosis, cancer relapse, treatments of long duration and high intensity, and treatments resulting in pain, disfigurement, or loss of mobility all may increase the likelihood of later emotional distress. Lack of resources, such as low income or lack of adequate housing, transportation, or social support, also may be associated with poor outcomes, including depression after cancer. Health and functional status after treatment is very important in understanding the likelihood for subsequent problems in psychological adjustment. Survivors with disabilities, chronic conditions (e.g., heart disease, diabetes, chronic obstructive pulmonary disease), especially those with multiple chronic conditions, or chronic pain may be particularly vulnerable.

**SUICIDE AND SUICIDE IDEATION IN LONG-TERM CANCER SURVIVORS**

Cancer registry studies have consistently reported that rates of completed suicide are elevated in people with a history of cancer. Scandinavian registry studies have reported suicide rates to be 1.4–2.9 times higher than in non-cancer controls depending on gender and country of study (Björkenstam, Edberg, Ayoubi, & Rosén, 2005; Hem, Loge, Haldorsen, & Ekeberg, 2004; Yousaf, Christensen, Engholm, & Storm, 2005). Similarly, a recent U.S. registry study (Misono, Weiss, Fann, Redman, & Yueh, 2008) reported that among individuals diagnosed with cancer, 31.4 suicides occur for every 100,000 person-years of follow-up—almost twice the rate of the general population. Registry studies have typically focused on suicides occurring within the first 2–5 years after a cancer diagnosis, but this study, and at least one other, showed that the rates of suicide remain elevated in cancer survivors as long as 8–10 years following diagnosis (Schairer et al., 2006).

Suicidal symptoms can be thought of as a continuum from ideation to intentions, plans, attempts, and completion. Ideation is most prevalent, and only a small proportion of those with ideation go on to attempt or complete suicide (Kessler, Berglund, Borges, Nock, & Wang, 2005). Most studies of suicide after cancer have examined completed suicides (e.g., Hem et al., 2004; Misono et al., 2008), but examination of ideation is warranted because it is an important risk factor for suicide and an indicator of emotional suffering. A recent study of ambulatory patients with cancer found that 8% reported suicidal ideation (Walker et al., 2008), and a study of childhood cancer sur-
vivors found that ideation was more prevalent in survivors than in controls (Recklitis et al., 2010).

In epidemiologic studies of cancer survivors, suicide risk has been found to be higher in males, in those diagnosed at an older age, and in those with certain cancers including lung, brain, esophageal, pancreatic, and gastrointestinal cancers (see Figure 19-1). Other risk factors include prior suicide attempt, depression, impulsivity, substance abuse, or family history of suicide. Being unmarried or having a recent loss in relationships, work, social, or economic situations also is associated with higher risk. Suicide is strongly associated with depression (Kessler et al., 2005), and the previously discussed risk factors for depression should be considered as potentially increasing the risk of suicide as well. However, it is important to recognize that not all suicidal survivors will have significant depression.

SCREENING AND ASSESSMENT OF LONG-TERM CANCER SURVIVORS

Long-term survivors may be seen infrequently in oncology settings, making it difficult to find time for assessment of emotional concerns. Incorporating routine screening as part of survivor aftercare is the best method to ensure that psychological issues are consistently addressed. The goal of this screening is not to comprehensively evaluate psychological functioning but to identify those survivors who show signs or symptoms warranting further assessment. Cancer survivors often are interested in talking about these issues but wait for providers to “start the conversation” (Detmar, Aaronson, Wever, Muller, & Schornagel, 2000). A simple approach to screening is to include emotional health, economic, social, and functional status items in a nursing assessment or review of systems checklist that survivors complete at their office visit. This self-report assessment adds relatively little burden to providers and survivors, ensures that these topics are addressed, and “primes” survivors and providers to discuss these issues. At a minimum, these items would include 6–10 questions about emotional functioning, including depressed mood, feelings of hopelessness, and suicidality, as well as other symptoms or functional limitations. Although suicidal thoughts are strongly associated with depression, not all survivors with suicidal thoughts will have significant depression, making it important to evaluate these independently. Published symptom checklists of depression can be useful additions, but they may involve additional costs or expertise to score and interpret.

Whatever written assessment is used, reviewing these responses with the survivor is essential. By way of introduction, a provider may simply ask, “When you completed the questions about mood and emotional functioning, did any of the questions seem to apply to you?” The provider can then quickly scan the responses to the items and inquire about any that were endorsed. Assuming that no significant emotional issues were raised, a final question, such as, “Is
there anything else about how you are feeling emotionally, or getting along at home or at work, that we should talk about?” may help to encourage reticent survivors to bring up any other emotional concerns or to close the topic and provide a segue to the next area for discussion.

ASSESSMENT AND REFERRAL

Depending on the specific survivor population being screened, providers could expect 10%–30% of survivors to indicate some significant symptoms of depression, requiring further assessment or referral to a mental health or medical professional (Trask & Pearman, 2007). In talking with survivors about their symptoms, it is important to acknowledge that everyone experiences normal variations in mood. Assessment should focus on symptoms that are lasting or cause distress or impaired functioning. Cancer treatments may have late effects on hormonal, cardiac, pulmonary, and neurologic functioning, and these effects may be associated with depression (see Figure 19-2). Because some survivors may have persistent fatigue, it is important to try to differentiate this effect from depression. Similarly, many commonly prescribed medications may cause depression, and a careful medication history may reveal possible associations with medications (see Figure 19-2). The majority of survivors reporting depression are likely to have transient symptoms or symptoms with limited impact on functioning. For these survivors, educational and support

<table>
<thead>
<tr>
<th>Figure 19-2. Potential Medical Causes of Depressive Symptoms in Cancer Survivors</th>
</tr>
</thead>
</table>
| **Endocrine**  
  - Hypothyroidism  
  - Low testosterone  
  - Menopausal symptoms | **Neurologic**  
  - Brain tumors  
  - Effects of brain resections  
  - Effects of cranial irradiation |
| **Hematologic**  
  - Anemia  
  - Myelodysplasia | **Pain**  
  - Chronic pain |
| **Medications**  
  - Narcotics  
  - Benzodiazepines  
  - Corticosteroids | **Sleep disorders**  
  - Obstructive sleep apnea |
| **Metabolic abnormalities**  
  - Sodium  
  - Calcium  
  - Vitamin B₁₂  
  - Folate | **Substance abuse**  
  - Alcohol  
  - Cannabis  
  - Cocaine  
  - Crystal methamphetamine  
  - Narcotics |

*Note.* Based on information from Braun et al., 2010; Miller & Massie, 2010.
interventions might be beneficial with referral to primary care for evaluation and monitoring as needed. When survivors present with symptoms that are lasting or associated with significant distress, impairment in function, or somatic symptoms not explained by a medical condition, the clinician should recommend evaluation by a mental health professional.

Suicidal ideation will be less common than depression but should be carefully evaluated in the 5%–15% of survivors who may report it (Recklitis et al., 2010; Recklitis, Lockwood, Rothwell, & Diller, 2006; Walker et al., 2008). In our experience, passive thoughts of suicide, such as feeling as though “life is not worth living” or “things might be better if I were dead,” are the most common symptoms likely to be reported by survivors. Survivors reporting any suicidal ideation should be referred for a specialized evaluation by a knowledgeable medical or mental health provider. The nature of that referral may depend on their specific suicidal symptoms, as well as their overall medical and emotional health, other risk factors, and the availability of family or other supports. An evaluation including consultation with members of the medical team, the survivors, and their family, if appropriate, can clarify whether the survivors have (a) serious thoughts of hurting or killing themselves, (b) urges to hurt or kill themselves, (c) plans for suicide, (d) access to lethal means (especially handguns), and (e) have made any past suicide attempts. For survivors with none of these five characteristics, who are not characteristically impulsive, and who have active social support involved, a routine referral to a mental health or primary care provider may be appropriate. Steps to increase safety and ensure follow-up for these survivors include identifying sources of support, providing emergency and crisis hotline phone numbers, and scheduling telephone follow-up to be sure the referral appointment was kept. Whenever survivors present with active thoughts or plans for suicide, or passive thoughts in the context of other risk factors (e.g., mental illness, access to lethal means, past attempt), an urgent or emergent mental health assessment should be initiated.

RESOURCES FOR SURVIVORS WITH PSYCHOLOGICAL CONCERNS

Knowledge of mental health and support resources is critical for caring for the psychological needs of survivors. The Institute of Medicine’s (2007) report on the psychosocial needs of patients with cancer includes an extensive list of services and organizations, and providers can supplement this with local listings. Resources that may be most useful for addressing concerns about depression and suicidality are summarized in Appendix J. A mental health referral sheet intended to educate survivors and facilitate referrals is reproduced in Appendix K. Survivors may be initially reluctant to accept some recommendations. It is important to respect patients’ preferences while indicating appropriate concern for their welfare. Reluctant survivors
may agree to revisit the issue in a follow-up appointment or discuss the issue in a subsequent conversation in person or by telephone. Recommendations may need to be made on several occasions or by multiple individuals before survivors are comfortable initiating it.

SUMMARY

The majority of long-term survivors successfully overcome the physical and emotional challenges of cancer and are not burdened by ongoing psychological distress. Survivors are, however, at elevated risk for depressive and suicidal symptoms, and a significant minority are affected by them. To provide appropriate clinical care that is tailored for an individual survivor’s needs, clinicians must appreciate the risk factors for these symptoms, as well as the best methods for identifying affected survivors and referring them to education, support, or mental health treatment appropriate to their needs.

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REFERENCES


INTRODUCTION

As patients began to live longer following cancer treatment, a recognized need emerged for greater research on the quality-of-life, psychological, and emotional issues of cancer survivors. The cancer survivorship movement developed in the 1980s with the formation of the National Coalition for Cancer Survivorship (Leigh, 2004, 2007). The movement began following a meeting of physicians, nurses, social workers, patients, and family members who gathered together in 1986 in Albuquerque, New Mexico, to discuss their concerns about cancer survival. One concern discussed was the gap between the understanding of the cancer experience as health professionals and what it felt like to actually be the patient. There was an urgency to express concern about the lack of information on the late effects of treatment, problems with employment and insurance, and the need to find a perspective on one’s cancer experience. Participants complained that they did not feel understood as “whole” people. They were coping with mood changes, rethinking meaning in life, and adjusting to changes in their families (Fobair, 2007). They wanted to talk about recovery not just from a physical and emotional perspective, but from a spiritual perspective as well.

SPIRITUALITY AS A SOURCE OF COMFORT

Spirituality is now recognized as an important consideration in compassionate healthcare delivery (King & Koenig, 2009). The experience of suffering during and after cancer without finding understanding or meaning can be emotionally painful (Frankl, 1984; Puchalski, 2001). Cancer survivors often rely on their spiritual beliefs as a way of finding meaning during their
illness experience and survivorship (Vachon, 2008). Spirituality addresses the common human need for certainty in a time of crisis (Schulz et al., 2008).

This chapter will discuss spirituality as a resource for cancer survivors, provide an explanation for the impulse to spirituality, and describe spirituality as an asset to health in the biopsychosocial model of survivorship. Reflections from my personal experience following breast cancer are shared to illustrate my process of working through and resolving the uncertainties of life following treatment.

**SPIRITUALITY AS A RESOURCE IN CANCER SURVIVORSHIP**

Cancer survivors often are stunned to see that their perspectives in life have been altered following diagnosis and treatment. They are challenged within themselves to cope with treatment, to redefine meaning in life, and to find hope and a sense of well-being. In one’s personal quest for understanding answers to the ultimate questions about life, meaning, and relationships, spirituality represents a process of personal growth, a belief in a higher power, and a sense of connectedness to the divine (King & Koenig, 2009). Spirituality can give one an improved sense of well-being, hope, peace, empowerment, or motivation for reconciling relationships (George, Larson, Koenig, & McCullough, 2000). Spirituality results in feelings of joy, forgiveness of oneself and others, acceptance of hardship and mortality, and the ability to transcend beyond the limitations of existence (Tanyi, 2002). As an evolutionary process that drives us forward toward wholeness, spirituality expands our consciousness. All activity, then, whether physical, emotional, or intuitional, that leads us toward greater goodness and wholeness is spiritual (Keys, 1970).

**HOW DO WE EXPLAIN THE IMPULSE TO SPIRITUALITY?**

Death is a powerful motivator. Man senses his finiteness and looks for another root of his being (King & Koenig, 2009). Alper (2001) and Hamer (2004) suggested that a biologic impulse to spirituality may exist in our human makeup. One’s psychological state of mind is highly correlated with one’s spiritual well-being (Kaczorowski, 1989; McCoubrie & Davies, 2006). The spiritual experience lies within us; it is a subjective experience (e.g., “I am part or particle of God” [Emerson, 1836, p. 2]). In 1965, British theologian Harry Williams wrote, “Perhaps the ‘spirit’ is . . . me, at the profoundest level of my being, the level at which I can no longer distinguish between what is myself and what is greater than me . . . where God and me mingle indistinguishably” (King & Koenig, 2009, p. 116).

Cancer survivors reappraise the meaning of life and their feelings of hope and well-being in order to find an anchor of control. Ferrell, Smith, Juarez,
and Melancon (2007) analyzed 21,806 letters, cards, and e-mails received from survivors of ovarian cancer from 1994 to 2000 using a quality-of-life ovarian cancer instrument. They found that survivors relied heavily upon spirituality as a coping mechanism as well as a method of deriving meaning from the cancer experience. Studies with cancer survivors have noted that higher scores of spirituality are correlated with better mental health, less depression, and increased vitality and personal growth. Yanez et al. (2009) conducted a study with 418 patients with breast cancer and asked them to rate components of spiritual well-being. Higher scores of baseline meaning/peace were found with a decline in depressive symptoms and an increase in vitality at 12 months. In a study by Cordova, Cunningham, Carlson, and Andrykowski (2001), breast cancer survivors (n = 70) exhibited a pattern of greater post-traumatic growth in relating to others, appreciation of life, and spiritual change when compared with 70 healthy women without cancer. The breast cancer survivors’ personal growth was associated with perceived life threat, prior talking about breast cancer, income, and time since diagnosis. The groups did not differ in depression or well-being. Levine and Targ (2002) noted in a randomized study of women recently diagnosed with early or metastatic breast cancer (n = 191) that spirituality and spiritual well-being were correlated with functional well-being (the ability to get things done) and several active coping styles.

Recent research has explored the role of spirituality on perceived overall quality of life. Krupski et al. (2006) examined spiritual influences and quality of life among 222 men with prostate cancer and reported that men who rated spirituality as “low” were associated with significantly worse physical and mental health, sexual function, and more urinary bother. Zavala, Maliski, Kwan, Fink, and Litwin (2009) found that greater spirituality was associated with better quality of life and psychosocial function among men with advanced prostate cancer (n = 86) and that the patients with the highest spirituality scores were African American and Latino, as well as those with less than a high-school education. In a randomized study of patients with breast cancer with metastatic disease (n = 112), Sephton, Koopman, Schaal, Thoresen, and Spiegel (2001) reported that spiritual expression was associated with having a more effective immune system. Patients with higher scores on the “importance of spiritual expression” exhibited a greater number of white blood cells and total lymphocyte count with greater helper and cytotoxic T-cell counts.

In a study examining the psychological outcomes in long-term survivors of childhood leukemia, Hodgkin disease, and non-Hodgkin lymphoma, Zebrack et al. (2002) found that young adult cancer survivors (15–39 years old) had a particularly challenging task in coming to terms with treatment and cancer survivorship issues. The study participants (n = 5,736) were significantly more likely than sibling controls (n = 2,565) to report symptoms of depression and somatic distress. Odo and Potter (2009, p. 24) reported that young cancer survivors described themselves as feeling like “rubber bands,” being stretched taut through treatment, sometimes “snapping” from the emotional impact of the cancer experience when treatment ended. To help them cope with
SPIRITUALITY AND THE BIOPSYCHOSOCIAL MODEL OF CANCER CARE

Spirituality is embedded in the patient’s psychological and social world. In 1977, psychiatrist George Engel challenged the biomedical model of patient care, suggesting the need to add the concept of health in a patient’s diagnosis along with illness, and to take into account the social networks of the individual that helped sustain and maximize health and well-being (in Lindau, Laumann, Levinson, & Waite, 2003). Engel might be pleased to discover how current research demonstrates that self-expression, creative arts, and meditation are associated with improved spirituality and health (Arias, Steinberg, Banga, & Trestman, 2006; Stanton et al., 2002). Group support, meditation, yoga practices, art therapy, and journal writing have been found to be helpful in lowering patient distress and in creating environments where cancer survivors discover meaning and hope, develop spiritually, and improve quality of life. Group support has been reported to be helpful for cancer survivors in decreasing traumatic stress (Classen et al., 2001). Levine, Eckhardt, and Targ (2005) demonstrated the efficacy of group support with post-traumatic stress disorder. Group support was also shown to be helpful in improving the five domains of quality of life (i.e., cognitive, physical, emotional, spiritual, and social functioning) (Rummans et al., 2006), improving symptoms of distress, such as anxiety and depression (Devine & Westlake, 1995), and enhancing immune system function (Andersen et al., 2004).

Yoga, meditation, and imagery have been shown to be beneficial to cancer survivors in helping to improve mood and emotional well-being, increase coping skills, and reduce the symptomatology associated with anxiety disorders (Cameron, Booth, Schlatter, Ziginskas, & Harman, 2007; Danhauer et al., 2009). Cameron and colleagues (2007) found that patients with breast cancer (n = 154) who used meditation techniques reported greater use of relaxation techniques, perceived control, emotional well-being, and coping efficacy, as well as greater decreases in cancer worry and anxiety.

In a randomized study that compared a 12-week standard group therapy with a 12-week complementary/alternative medicine (CAM) group, Targ and Levine (2002) reported improved quality of life and decreased depression and anxiety among participants in the CAM group. While the CAM group exhibited patient improvements in measuring spiritual integration, the standard group demonstrated decreases in confusion and helplessness/hopelessness (Targ & Levine, 2002) and a reduction in overall post-traumatic stress (Levine & Targ, 2002).
Art therapy and journal writing have been found to be helpful modalities for cancer survivors. In a randomized study of breast cancer survivors (n = 39) that was designed to study the efficacy of creative-arts therapies in enhancing emotional expression, spirituality, and psychological well-being, Puig, Lee, Goodwin, and Sherrard (2006) reported that the intervention group noted improvements in psychological well-being and spirituality. Stanton and colleagues (2002) conducted a randomized trial with breast cancer survivors to study the effect of written emotional expression and benefit-finding. Using four sessions of writing for expressive disclosure or benefit-finding, the participants produced fewer physical symptom reports and reduced their needs for medical appointments for cancer-related morbidities at the three-month follow-up.

CONSIDERATIONS FOR ADDRESSING SPIRITUAL ISSUES WITH PATIENTS

Nurses, along with chaplains, physicians, and social workers, have identified themselves as responsible for addressing spiritual distress (Kristeller, Zumbrun, & Schilling, 1999). Nurses have frequent contact (e.g., daily or weekly) with patients in hospitals or clinics with opportunities to talk about issues and feelings. Despite these opportunities, many physicians, nurses, and other healthcare professionals describe a reluctance or difficulty in being able to comfortably talk with patients about their spiritual beliefs (Ferrell, 2007; Puchalski, 2001).

In a study conducted by Kristeller, Rhodes, Cripe, and Sheets (2005), four oncologist-hematologists offered patients with cancer (n = 118) a five to seven minute discussion of spiritual matters. The patients were alternately assigned to receive the discussion intervention or usual care during an office visit. When they evaluated the acceptability and satisfaction with spiritual or religious concerns, the authors noted that at three weeks, the intervention group had greater reductions in depressive symptoms, improvement in quality of life, and an improved sense of interpersonal caring from their physician as compared to the control patients. The four physicians found that they were comfortable with the inquiry 85% of the time; 76% of the patients felt the inquiry was “somewhat” to “very” useful (Kristeller et al., 2005). In summary, the patients were less depressed, and the physicians found it more comfortable to talk about spiritual issues than they had imagined.

PERSONALIZED CANCER CARE

How do we offer spiritual discussions in personalized cancer care? Who do we talk with? What do we say? Surveys suggest that health professionals underestimate the degree to which patients want to talk about spiritual
matters (Astrow, Wexler, Texeira, He, & Sulmasy, 2007; Kristeller et al., 1999) despite the fact that talking with health professionals about spiritual coping is highly desired by patients (Balboni et al., 2007). Patients most desirous about discussing their spiritual beliefs were those with advanced disease, and patients from Latino, African American, and other ethnic groups (Levine, Yoo, Aviv, Ewing, & Au, 2007; Zavala et al., 2009).

What do we say? Listening for cues during patient interactions and responding with a question can be the way to start. Kristeller and colleagues (2005) and Ferrell (2007) suggested broaching spiritual concerns with patients by posing questions such as
- “Do you have spiritual beliefs that help you cope?”
- “Are you part of a spiritual or religious community?”
- “Is there some way you are able to find a sense of meaning or peace in all of this?”
- “Would you like to talk more about this?”
- “Do you have someone to talk with?”
- “Perhaps we can arrange for you to talk to someone.”
- “There is a support group I can suggest.”

**FINAL REFLECTIONS: MY SPIRITUAL JOURNEY THROUGH CANCER**

I was a 53-year-old social worker working in a cancer hospital when I looked in the mirror one morning and noticed that the skin on my upper left chest was puckering. “That’s a sign of cancer,” I thought, with a sense of panic. For the next few weeks, my life felt out of control. I was in shock. It felt like a thick plastic hood had fallen over my head, separating me from others. I felt strangely demoralized and guilty that I had caused my cancer. Initially, I felt moments of panic, but when I found myself slipping into feelings of helplessness, I had an epiphany: “Only small children are helpless.” I could problem-solve; I could make a plan. I faced the idea that the malignancy could be fatal. “If the disease is so virulent that it spreads in spite of treatment, I will face death. But, until then, I will use everything I have inside of me to survive.” I realized that I would not be able to run away—I would have to hold firm and work with my doctors.

When surgery was followed by chemotherapy, I found my hardest problem was coping with emotions. Feelings of grief, fear, anger, shame, and disappointment plagued me. I felt defensive, numb, confused. I caught myself blaming, catastrophizing or minimizing problems, or worse, falling into all-or-nothing thinking. Once I realized that I was not really helpless and that I had choices, I began to work on underlying problems and regained my sense of inner control. My perspective in life changed. I was mortal. I reappraised my situation. “My life is in transition; I will have to re-imagine a future.” I asked myself, “What can I rely on now?” The answer came back, “You’re alive, you have
a job, a good family, and while you don’t feel well because of chemotherapy, you can still function four to six hours a day.”

How did spirituality contribute to my survivorship? During treatment, I began to rethink the purpose and meaning of my life. I realized, with a fresh perspective, how helping other patients with cancer was meaningful work. There was nothing I would rather do. I found hope in persisting to work on quality-of-life research and in writing journal articles reporting accomplishments. I felt certain that after getting through the treatment, my life would improve. I became actively involved with the National Coalition for Cancer Survivorship and felt a shared sense of purpose and hope that this organization would make a difference. My personal well-being improved as I gave myself time to look after myself.

I worked on facing negative feelings and in finding active solutions to the daily problems in life. I became more sensitive to the pain of others. I found the benefit of being a patient, someone who “has been there,” to be an asset in working with other patients with cancer.

Other things considered spiritual helped me, too: gratitude for my physicians, forgiveness of myself and others, and figuring out what I could do to feel better. I began by soothing myself with reassuring messages such as “you are going to be okay,” or “this will turn out all right.” I paid attention to setting limits on my schedule and planned in advance for difficult interpersonal situations. With the help of a psychologist and support from a community church, forgiveness became a bigger part of my life. I discovered that I could create a more interesting future. My focus changed to living in the moment. In time, I found the humor in my situation, and went out to “smell the roses.”

It has been said that forgiveness means letting go of the past (Jampolsky, 1999); forgiveness is a key to action and freedom (Arendt & Baehr, 2000); and forgiveness is the final form of love (Niebuhr, 1932). Now, in thinking about the future, should I have trouble accepting change or forgiving others, I know that God will forgive me. Because as Heinrich Heine said, “That’s his job” (BrainyMedia.com, n.d.).

**SUMMARY**

Facing the possibility of death prompts many survivors to seek a spiritual connection. Spirituality serves as an important resource and source of comfort for cancer survivors. As patients locate their positive emotions (e.g., love, compassion, gratitude) and their perspective shifts toward personal growth, their spirituality helps them find meaning in the experience of cancer. Spirituality is an important element in the biopsychosocial model of cancer care and one that patients desire to have recognized as important to their overall well-being.

Modalities such as group therapy, yoga, meditation, imagery, art, and journal writing can be helpful in facilitating and supporting the spiritual insights
and growth of cancer survivors. As healthcare professionals, we can support survivors on their journey through cancer by talking about spirituality and affirming its vital role in the lives of our patients.

REFERENCES


CHAPTER 20. SPIRITUALITY AND CANCER SURVIVORSHIP


Transitioning to End of Life

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INTRODUCTION

In an ideal society, death would be considered a natural part of life and the transition to the end of life would be a normal adult task. This task is supported by Erikson (1968), who identified the final stage of adult psychosocial development as a conflict between integrity and despair. Integrity is defined as a state of accomplishment; despair is defined as a fear of death and regret about lost opportunities. Confronting one’s own mortality is essential to resolve this developmental task of integrity; however, this is not a task that most adults focus on until forced to by life experience.

Cancer is a disease that incurs thoughts of death at the time of diagnosis. Multiple losses, grief experiences, and the impending fear of recurrence occur during the cancer trajectory. Healthcare professionals should encourage conversations about mortality and the healthy contemplation of death, rather than avoid them. This approach is consistent with the model of palliative care by the World Health Organization (2002), which defines palliative care as beginning at diagnosis and increasing in importance as one’s cancer progresses (Finlay & Casarett, 2009).

The process of finding meaning in life begins at diagnosis. Concerns about life and death often follow a diagnosis of cancer. The goals of care may change as the focus of care shifts from curative to palliative and end-of-life care. Quality of life and psychosocial well-being become primary goals. Chan, Ho, and Chan (2007) stated that when an individual is in a situation beyond normal understanding, the search for new meaning or a revision of an old belief begins. For patients with cancer, this search includes an understanding of the possibility of death, the reason they developed cancer, and why they are suffering (Chan et al., 2007). Healthy individuals do not confront these issues, as they believe life to be fair and controlled. For patients with cancer, the concerns about life and death often lead to existential challenges of their view of the
world, themselves, and the future in their search for meaning (Lorenz et al., 2004; Moadel et al., 1999). Spiritual and existential issues involving the cancer survivor’s faith, perceived relationship with God, and the possibility and meaning of death are psychosocial areas of need (President’s Cancer Panel, 2004).

Mahon and Casperson (1997) found that the meaning of recurrence was heavily affected by concerns about death. Frankl (1959/1992) stated that suffering was a path to meaning and a reason for finding meaning; the meaning of life may change based on one’s experiences but never ceases to exist. Cancer survivors tend to alter their belief that life is controllable and often see life as more random. In a study comparing breast cancer survivors and age-matched healthy women, having a sense of purpose and meaning correlated with a higher quality of life (Tomich & Helgeson, 2002).

A diagnosis of cancer can affect one’s feeling of security and invulnerability. The ability to find meaning in the diagnosis of cancer and the transition to the end of life leads to increased quality of life. Ferrell, Smith, Juarez, and Melancon (2003) documented that ovarian cancer survivors viewed spirituality as an important aspect of finding meaning in the illness experience. Breitbart (2002) observed in patients with advanced cancer that finding meaning in the experience helped to decrease the incidence of hopelessness and depression. Hope is an integral aspect of the meaning of life and a dignified death (Benzein, Norberg, & Saveman, 2001).

END-OF-LIFE DISCUSSION

Appropriate end-of-life care helps the dying person adapt to the process of dying and find meaning and quality of life even with decline in physical and functional capabilities (Griffin, Koch, Nelson, & Cooley, 2007). A prospective, longitudinal study by Wright and colleagues (2008) observed that end-of-life discussions led to increased quality of life, decreased aggressive medical care, and earlier referral to hospice. The authors observed no evidence of harm related to end-of-life discussions (Wright et al., 2008). Discussions at the end of life allow individuals to set goals and clarify their expectations.

Therapeutic Presence, Empathetic Communication, and Therapeutic Use of Self

The end-of-life/palliative phase of care offers the professional the opportunity to have meaningful discussions regarding important care, which is often shared among various disciplines in a transdisciplinary modality from inpatient to outpatient settings. Consistency of communication, from all disciplines, when talking to the patient and family is vital. Lack of consistency in what is communicated leads to confusion for the patient and family and often causes unnecessary distress and anxiety.
Interventions for psychosocial well-being include the use of presence, therapeutic use of self, spiritual care, enhancement of coping, and communication. Moadel and colleagues (1999) confirmed that patients want assistance to overcome fears, find hope, talk about peace of mind, and find meaning in life and spiritual resources with a person to talk to about the meaning of life and death. Seow and colleagues (2009) defined communication as primarily verbal interactions between the care team and the patient and family including conversations about prognosis, the patient’s goals of care, concerns about fears, and understanding of meaning. The importance of communication crosses all areas of psychosocial care. In a randomized control study, a facilitated verbal intervention that discussed forgiveness, life review, heritage, and meaning was helpful in preparation for the end of life (Steinhauser et al., 2008).

The psychosocial interventions of eliciting concerns, active listening, empathy, pacing of information, cognitive restructuring techniques, clarifying meaning, grief facilitation, facilitating hope, giving unconditional positive regard, and being nonjudgmental are all helpful and necessary interventions for end-of-life/palliative care. Lorenz et al. (2004) noted that both research and expert opinion focused on the importance of empathetic communication. Finlay and Casarett (2009) reinforced that providing quality end-of-life care requires open discussion of patient goals and honest, well-paced prognostic information.

Therapeutic use of self is a useful and necessary technique for quality end-of-life/palliative care. Therapeutic use of self requires healthcare professionals to use who they are to promote healing and self-actualization in the patient. To do this successfully, the healthcare professional must be self-aware.

**Stages of Grief**

The classic work *On Death and Dying* by Elizabeth Kübler-Ross (1969) elucidated the stages of the grief cycle: denial, anger, bargaining, depression, and acceptance. Initially Kübler-Ross suggested that the work of the healthcare provider was to move patients through these stages in a linear manner. In later writings, she acknowledged that individuals actually move back and forth along a continuum of feelings before finally reaching acceptance. When facilitating the grief process, it is important to remember that each person’s grief is individual. People will experience their own unique journey through this process.

An understanding of each stage of the cycle is useful to the practitioner because it gives one a start in assessment and understanding of what the grieving person needs. The stage of denial (e.g., “no, not me”) is a conscious or unconscious refusal to accept facts, information, or reality related to a specific situation (Kübler-Ross, 1969). It is a frequently used defense mechanism. The use of denial helps individuals to absorb information or the experience at an acceptable rate for them. The only time the use of this mechanism be-
comes problematic is when the individual is using denial exclusive to all the other defense mechanisms. The stage of anger (e.g., “why me?”) can be focused against oneself or others. The healthcare professional who happens to be in the room at the time is often the target of anger. Family members also may be the target of anger because they may be the people the individual can count on for unconditional love. Knowing this may occur helps the caregiver to remain detached and nonjudgmental when experiencing the anger of someone who is very upset. This knowledge can also be useful to the family members when the anger is directed at them.

Bargaining (e.g., “I promise I’ll be a better person”) is an attempt to negotiate with whatever god or higher power the person believes in. The stage of depression (e.g., “I don’t care anymore”) usually occurs when bargaining is no longer effective. Some refer to this as preparatory grieving (Kübler-Ross, 1969). Depression brings with it sadness, often regrets, perhaps fear, and uncertainty. This type of depressed mood is very different from clinical depression and usually does not require medication. Rather, the practitioner might offer grief facilitation and hope instillation (Bulechek, Butcher, & Dochterman, 2008). Acceptance (e.g., “yes, me!”) can happen with the individual long before it occurs for their family members. Yet, this is not always the case. Sometimes, the family is further along in the grief process than the individual is.

Each family member grieves at his or her own pace. Rarely will an entire family be in the same phase of the grief process. One of the challenges of working with a family and the dying patient is effectively attending to these family members in the various stages of grief. Educating patients and family members about the grief process is an excellent intervention and part of grief facilitation. This heightened awareness of the needs of suffering family members is an important aspect of psychosocial care for families whose loved ones are receiving treatment in palliative and end-of-life care. According to Grassi (2007), a growing body of evidence supports the need for screening for dysfunctional anticipatory grief patterns to prevent complications during bereavement for family members. Screening and measurement tools for dysfunctional or complicated grief, such as the Inventory of Complicated Grief, are available. The National Cancer Institute also has explanations of this phenomenon for both patients and healthcare providers (see Grief, Bereavement, and Coping With Loss [PDQ®] at www.cancer.gov/cancertopics/pdq/supportivecare). More effective support and treatment for grieving family members can be tailored to their needs if there is adequate preparation for the end-of-life stages.

**Hope at the End of Life**

Fanslow-Brunjes (2008) expanded the five stages of grief to include hope, stating, “Hope is such an integral part of our lives that, like breath, we could not live without it” (p. 16). She recognized that dying people have three basic needs: (1) to know they will not be abandoned, (2) to have the opportunity to
express themselves, and (3) to maintain hope. The “Hope System” describes the changing nature of hope from diagnosis through death. Hope is defined as an inner dynamic life force that helps each dying patient live his life until the moment of death (Fanslow-Brunjes, 2008). Assessing the patient’s level of hope should begin at admission and be a priority of care.

Patients and their families experience hope in four stages: hope for cure, hope for treatment, hope for prolongation of life, and hope for a peaceful death. As with the stages of grief, this process is not linear. When the healthcare provider assesses the patient and the family, the focus should be on their concerns. When the patient and family are engaged in the different stages, it often is difficult for them to be supportive of each other. If the patient is hoping for a cure, assess awareness of prognosis. Denial may support hope and should not be “fixed” by the practitioner. There is a great power in hope. Discussing hope with a patient is a way in which healthcare providers can be fully present and meet the patient and family where they are in that moment (Fanslow-Brunjes, 2008). When in doubt as to what to say to a person who is dying, ask, “What are you hoping for today?” and “How may I help you?”

ADVANCE CARE PLANNING

Advance care planning is a critical component in the transition to end-of-life/palliative care. Patients have a right to make decisions about their treatment and how much or how little they want done as long as they have the mental capacity to do so. However, most people die while under the care of health professionals, and up to 50% cannot make their own decisions when near death, according to data from the National Cancer Institute (2000). Advance directives, including living wills, durable powers of attorney for health care, and healthcare proxies, are legal documents that allow people to convey instructions ahead of time and specify what actions should be taken regarding their health care in the event that they are no longer able to make decisions. Advance directives also provide a mechanism for patients to discuss and communicate their wishes to family and friends in addition to healthcare providers. This decision-making process can serve to empower patients and families by decreasing feelings of loss of control and minimizing confusion at the end of the patient’s life.

Advance care planning is a process that should begin as early as possible in the continuum of care, preferably at the time of diagnosis, to ensure that the patient has the capacity to make such decisions. It is important to acknowledge that decisions regarding treatment and end-of-life care may change over time. Advance care planning should be considered a process. Some patients may want to try all available treatments as their illness progresses, whereas others may decide to stop aggressive treatment and choose comfort care. Ethically, advance care planning is based on respect of patients’ values and their right to self-determination, including the right to die and the right to a death with
dignity (“Advance Directives,” n.d.). The advance care planning process creates an environment of shared decision making among the patient, their significant others, and healthcare professionals. It allows for choices to extend life, as well as those that provide comfort and prepare for death. Although this decision-making process is sometimes difficult for patients and their families, it ensures that patients can face their end of life with the same values by which they have lived (National Cancer Institute, 2000). Types of advance directives that may come into play during transition to the end of life include the durable power of attorney for health care, a living will, and do-not-resuscitate orders.

HOSPICE

Hospice is both a philosophy and type of end-of-life care. The goal of hospice is to provide comfort, dignity, and support as it is defined by the patient or the patient’s legal spokesperson and the patient’s family (Kutner, 2010). Hospice focuses on measures that enhance the quality of life rather than extend life (Christakis & Iwashyna, 2003). This type of end-of-life care is sought when a patient has a prognosis of six months or less as certified by two physicians, usually the patient’s primary physician and the hospice medical director. The patient or patient advocate wishes to forgo treatments, tests, and medications aimed at extending life. Hospice patients occasionally do receive medications and treatments that are traditionally viewed as life-prolonging, such as antibiotics, artificial nutrition and hydration, and radiation therapy; however, these may be provided if it is determined that the measure improves the individual’s comfort or quality of life.

Hospice care is offered in a number of different settings. The most common is within the home. When care is provided in the home, the patient’s family and support network provide the day-to-day care. Members of the interdisciplinary hospice team visit regularly to assess the comfort and well-being of the patient and family and to provide support, education, and assistance. As needs arise, nurses contact the patient’s physician regarding changes in the patient’s condition or adjustments needed in medications for symptom management. Hospice care is also provided in extended-care facilities, where patients may be admitted for long-term care or for brief respite periods that allow caregivers much-needed breaks from daily care responsibilities.

Hospice, a multidisciplinary approach to end-of-life care, seeks to provide a level of physical, emotional, mental, and spiritual comfort that supports a peaceful death. This is invaluable not only for the patient but for the family as well. In support of closure, most hospices provide bereavement services to family members for a year after death, supporting them through what can be very painful holidays and anniversaries. Skilled counselors seek to help people transform their grief and loss to a sense of hope and renewed life.
CASE STUDY

K.J. was 22 when she was diagnosed with cancer. She was enrolled in an accelerated program to become an advanced practice nurse. She had noticed pain and a lump in her left leg for several weeks, but as a busy student, she had been ignoring her symptoms. During an advanced physical assessment class, she talked about her symptoms, and her nursing professor advised her to see her physician immediately. After multiple tests and a biopsy, she was diagnosed with stage III, poorly differentiated sarcoma. With the encouragement of her family, K.J. immediately began treatment, which involved surgery and chemotherapy. Despite these aggressive interventions, she was told that there was not a “good” treatment for her type of sarcoma and that the typical life expectancy was usually three to four years.

Having focused on getting through the treatment, K.J. was now confronted with how to live her life. She began to question the meaning of her life and decisions for her future. She wondered if she should continue with her goal to become a nurse considering the financial burden involved. She thought about her desire to get married and have a family, and wondered whether any man would commit given her uncertain future.

K.J. sought guidance from a psychiatric nursing instructor and an oncology and mental health clinical nurse specialist. Their discussions focused on what was important to her and how she wanted to live her life despite the threat of a shortened life span. She decided to continue with school because becoming a nurse was very important to her and she enjoyed the experience of education. She chose not to shut herself off from relationships and was always open about her illness with new friends and boyfriends.

Despite participation in clinical trials with experimental interventions, K.J.’s disease progressed. Overcoming these challenges, she graduated as an advanced practice nurse. She wanted to seek employment but anticipated that the side effects from her disease and treatment would prevent her from maintaining a full-time schedule. Although she questioned whether anyone would hire her, she was able to secure part-time employment as a clinical nursing instructor, which she enjoyed and valued. She met a young man, and their relationship developed into one of mutual love, trust, and respect. Her disease continued to progress, and she continued to question the meaning of these life experiences. She asked herself if she had the right to put this young man through the grief that was to come, and if marriage was fair to him.

Nevertheless, K.J. married the love of her life. Shortly after the honeymoon, she began to experience increased symptoms related to her disease, which forced her to quit her job. A friend and fellow nurse began to talk to her about hospice care. K.J.’s initial response was, “That would be giving up, wouldn’t it?” They continued to talk about various aspects of hope and the benefits of hospice. After much thought, she began hospice care. She had a period of improved symptom control, which allowed her more quality time with her loved ones. She died about four months later.
SUMMARY

This chapter explored the cancer survivor’s search for meaning of life at the transition to the end of life. The stages of grief and hope provide a framework to understand the process and give direction for healthcare provider interventions. Empathetic communication and therapeutic presence are key interventions in helping the patient and family move through this process. Advance directives and hospice empower patients and family toward a more peaceful transition to the end of life.

REFERENCES


SECTION IV

Practical Issues for Survivors

The completion of cancer treatment is not a finite event after which a patient bids farewell to the treatment team. Instead, it is a transition point when a person goes from being a patient—marked with a flurry of medical appointments and treatment decisions—to a post-treatment survivor who will need lifelong follow-up care to monitor side effects and risk of recurrence. Although every person’s cancer profile is unique, post-treatment survivors share a common set of practical concerns that should be addressed—but often are not—in the follow-up care they receive. During treatment, patients are often so focused on the acute medical issues related to their diagnosis and treatment that the full emotional impact of being diagnosed with cancer is not apparent until treatment is completed. Few, if any, patients completely return to their “pre-cancer” life. In fact, many post-treatment survivors report feeling lost and uncertain about how to best move forward.

Post-treatment survivors want to know what they need to do to stay healthy, and yet may need guidance in learning adaptive behaviors that foster a healthy lifestyle. In addition, survivors may express numerous concerns that have not been addressed by their healthcare team, such as the fear of recurrence or a second primary, including the possibility of a second cancer arising from the treatment itself. Issues related to health insurance may arise with concerns about sufficient coverage for specialized needs or availability of insurance if the person is no longer working. Other challenges and concerns include the financial issues related to personal and family support, unexpected out-of-pocket health expenses, and workforce issues, including when and how to divulge their cancer experience to their employers, coworkers, or prospective employers. Cancer survivors also must deal with the adjustment factors surrounding the life-altering
effects of cancer and subsequent changes to their lives, including the impact on their families and loved ones.

In the same manner that patients with cancer learn new terminology and identify resources to navigate through their cancer diagnosis and treatment, post-treatment survivors likewise must gather information that empowers them to deal with issues related to survivorship. This process can be initially facilitated with a cancer survivorship care plan that includes a written treatment summary, follow-up recommendations to manage long-term side effects, and a personalized plan of care that maximizes healthy outcomes. A quality cancer survivorship care plan should expand beyond the immediate medical, emotional, and social needs of survivors. The plan should also allow screening for issues that may affect the cancer survivor’s ability to access and optimize follow-up medical care. The goal of cancer survivorship care planning is to enable survivors to achieve the best quality of life possible after a cancer diagnosis.

Ideally, survivors should possess a basic understanding of their immediate and long-term medical issues, be able to identify resources that are available for emotional support, and access local and national organizations that can provide assistance with issues related to insurance, finances, and employment, as well as other survivorship issues that may arise.

Cancer survivors must become their own advocates, as today’s fast-paced medical environment is often not conducive to detailed discussions with the oncology healthcare team. At the very least, the oncology healthcare team should ensure that each patient is provided with a list of resources to begin the survivorship journey. Multiple organizations are dedicated and available to provide support and resources for survivors although little coordination or collaboration exists among these organizations. A recent innovative model of collaboration is the Cancer Financial Assistance Coalition (www.cancerfac.org). Twelve of the main organizations that provide financial assistance for cancer treatment joined forces to help patients experience better health and well-being by reducing financial challenges. This coalition was facilitated through communication and collaboration among member organizations, education of patients and providers about existing resources, and links to organizations that disseminate information. The Cancer Financial Assistance Coalition is a combined effort to advocate on behalf of patients with cancer who continue to bear financial burdens associated with the costs of cancer treatment and care.

Cancer survivors face a broad range of challenges and practical issues, including access to information and resources and the capability to act on their own behalf as they continue their survivorship journey. The economic burden associated with cancer potentially affects survivors in regard to family relationships, employment, insurability, and long-term social and economic health. Improved leveraging of existing resources is necessary to help the increasing number of cancer survivors. This book is a tremendous step forward and offers opportunities to creatively work
together toward a common goal: to improve the quality of life for cancer survivors.

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CHAPTER 22

Personalizing Information to Meet Survivors’ Needs

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INTRODUCTION

The quest for cancer-related information begins long before one receives a formal diagnosis and can last a lifetime. The information received and the manner in which it is conveyed can set the stage for a survivor’s ability to understand, internalize, and seek out information in the future. Survivors’ ability to discuss information needs with providers can affect their compliance with and personal investment in post-treatment follow-up care. Gaining access to adequate information can improve their ability to cope and make healthcare decisions.

Traditional cancer information sources are somewhat generic and typically have not been personalized to address an individual survivor’s concerns as they arise and change over time (Rutten, Arora, Bakos, Aziz, & Rowland, 2005). Ideally, information should be tailored with regard to one’s type of cancer, stage of life, and specific issues of concern (e.g., emotional, financial). Improving the fit between survivors’ information needs and the support they receive has the potential to significantly improve their physical, psychosocial, and economic outcomes (Epstein & Street, 2007).

Given the importance of support through appropriate cancer-related information, this chapter discusses the current state of information sharing, including common sources for information, common information needs, and ways of personalizing or tailoring information needs. The chapter then explores opportunities for personalizing cancer-related information and identifies strategies for improving the information-sharing process.

COMMON SOURCES FOR INFORMATION

Survivors increasingly have numerous cancer-related information sources at their fingertips. Despite the availability of information electronically, through
healthcare providers (e.g., physicians, oncology nurses), and in printed educational materials, family and friends appear to be the most frequently used sources for acquiring general medical information (Ankem, 2006). Survivors report gathering information about general diagnosis, prognosis, and medical treatments from educational materials such as pamphlets and books (Davison et al., 2002). Although often underutilized, allied health providers (e.g., social workers, psychologists) and support groups are reportedly the most helpful sources for obtaining information about supportive and complementary services (Mills & Davidson, 2002).

The Internet is another major source for information support. Conservative estimates yield that approximately 40% of individuals with cancer are using the Internet to search for general and cancer-specific information, to share information, and to gain social support (Eysenbach, 2003). Variability in research methodology has made it difficult to approximate the number of patients using the Internet solely for obtaining information on cancer (Eysenbach, 2003).

COMMON INFORMATION NEEDS

Since the first study of cancer survivors’ information needs was published in 1980 (Cassileth, Zupkis, Sutton-Smith, & March), researchers have consistently found that survivors desire information in the following areas (Beckjord et al., 2008; Hawkins et al., 2008):

- Cancer etiology, treatment, and potential adverse effects
- Lifestyle and preventive health
- Psychosocial impact
- Financial concerns related to job stability and insurance coverage.

While cancer survivors will request information spanning any or all of these areas, their specific information needs often vary based on their illness characteristics and stage of cancer (Rutten et al., 2005).

Cancer Etiology, Prognosis, and Treatment

People newly diagnosed with cancer most frequently request information on the etiology of cancer, the prognosis, the recommended treatment, and treatment side effects (Cox, Jenkins, Catt, Langridge, & Fallowfield, 2006). Confronted with the new diagnosis, people often grapple with understanding the etiology and meaning of it. They also may seek information on the environmental, nutritional, and other contributors of their cancer. In addition, individuals want to know their prognosis and likelihood of cure based on their stage of disease and the types of treatments that are available (Davison et al., 2002).

Collaborative treatment decision making between patients and physicians depends on a patient’s clear understanding about treatment, including effi-
cacy, and anticipated adverse and late effects. If people diagnosed with cancer cannot access or understand specific information relevant to their individual treatment plan, they may be ill-equipped to make informed decisions or advocate for their needs. Although information needs related to prognosis, treatment, and side effects are high among those who are between diagnosis and treatment, these needs may continue well beyond the completion of treatment for many (Epstein & Street, 2007). As survivors complete treatment and have less contact with medical providers, they may continue to seek information on their chances for cure, risks of recurrence, and late effects of treatments previously received.

Preventive Health Information Needs

As mortality rates improve for some cancers, survivors’ concerns about improving long-term health and reducing the risk of recurrent disease often emerge (Wold, Byers, Crane, & Ahnen, 2005). Weight management, nutrition, exercise, smoking cessation, and other health behaviors often become important topics of interest (Wold et al., 2005). Although offering information on health behaviors has been shown to effectively increase health behavior, studies have found that survivors often lack understanding in these areas (Wold et al., 2005). For example, obesity has repeatedly been linked to the risk of recurrence in breast and other forms of cancer, yet research has shown that survivors often lack understanding about the effects of diet on weight gain and subsequent cancer risk. Survivors who requested and received information about the risks of obesity and the preventive effects of exercise were found to significantly increase their weekly engagement in physical activity (Jones, Courneya, Fairey, & Mackey, 2004). Information needs have also been documented with regard to smoking (Wold et al., 2005). Offering information on these topics can be helpful soon after and farther from diagnosis as survivors seek to improve their long-term health and well-being (Epstein & Street, 2007).

Psychosocial Impact

Although clinicians provide information about the clinical characteristics of cancer and preventive health, they do not always readily discuss information about the psychological impact of cancer. Survivors have frequently reported the following to be areas of informational need: managing psychosocial concerns (e.g., isolation, anxiety), coping with the stress placed on family and friends, and finding adequate social and psychological support (Hawkins et al., 2008; Moadel, Morgan, & Dutcher, 2007). Providing patients with both medical and psychological information has been shown to decrease overall stress and anxiety and increase coping abilities (Epstein & Street, 2007). Additionally, survivors in several studies have reported needing information about ways of sharing diagnostic and treatment information with others, as
well as limiting the burden they feel they are placing on family and friends (Kennedy & Lloyd-Williams, 2009).

In contrast to the stress and other negative psychosocial effects of cancer, studies focusing on psychological resilience have shown that cancer survivors also report experiencing positive emotional and behavioral outcomes after being diagnosed with cancer. Reported positive outcomes include improvements in quality of life, social relationships, spirituality, and life appreciation (Aspinwall, 2005). Information about building on resiliency factors at various stages of cancer has been shown to improve psychological functioning in survivors (Baum, 2000).

Financial Concerns

Upon diagnosis, people with cancer often are inundated with information about the best treatment interventions; however, information about the economic burden of paying for costly procedures, hospitalizations, and medications is not always forthcoming. Both insured and uninsured patients have reported information needs with regard to cost reimbursement for rendered cancer-related services, paying for services not covered by insurance, sustaining employment during treatment, and financing transportation during treatment (Hawkins et al., 2008). Although such needs are not always viewed as urgent, they can have multifaceted implications in the lives of survivors. Addressing economic concerns proactively should be paired with patients’ referrals to available resources early and often.

EXAMINING WAYS OF PERSONALIZING INFORMATION NEEDS

Providing and accessing reliable and effective information in an individualized, time-sensitive manner may seem like an uphill battle for both patients and providers. Providers face many challenges in clinical practice that make it difficult to provide adequate diagnostic, treatment, and post-treatment information to patients (Wilson & Childs, 2002). For patients, making sure to ask the “right” questions, record or remember the answers, and decipher unfamiliar medical jargon while coping with the emotional and physical complexities of their illness can be equally difficult (Epstein & Street, 2007). Information support will be most effective in addressing patient needs to the extent that it takes a more personalized and patient-centered approach.

Demographic and Socioeconomic Factors

The types of information that cancer survivors prefer to receive vary based on demographic characteristics. For instance, research has revealed that younger adult survivors desire more information about sexuality, physical fit-
ness and appearance, nutrition, insurance, psychosocial factors (e.g., self-care, socialization), and specific treatment-related information than older adult survivors (Bilodeau & Degner, 1996; Davison et al., 2002; Degner & Sloan, 1992; Jenkins, Fallowfield, & Saul, 2001; Zebrack, 2009).

Gender also affects information seeking. Large-scale studies have found that female survivors request more information about psychosocial needs, whereas male survivors seek more information related to treatment, sexual functioning, and fertility (Moadel et al., 2007). Differences in information needs based on education level and literacy also may exist. Studies have indicated that prostate cancer survivors with lower levels of education requested more information on self-care (Davison et al., 2002). Breast cancer survivors with higher levels of education have been found to request more information about hereditary risks (Bilodeau & Degner, 1996). Survivors with low health literacy may struggle to receive and understand written and oral cancer information and may have trouble accessing cancer information (Davis, Williams, Marin, Parker, & Glass, 2002).

Social factors that have significant implications for information seeking include family structure, marital status, and employment status. Survivors with children commonly request information about age-appropriate ways of sharing illness information and gaining social support for themselves and their affected family members and friends (Kennedy & Lloyd-Williams, 2009). Survivors who are divorced, separated, widowed, or single have been documented as being more passive in their information-seeking styles than survivors who are married (Eheman et al., 2009). Likewise, unemployed and retired survivors have been found to request significantly less cancer-related information than their employed counterparts (Mayer et al., 2007). Acknowledging that some survivors might exhibit more passive styles of information seeking, providers may consider being more assertive in helping individuals to access information.

Exploration of ethnic and racial differences in information needs is a topic that emerged from research on racial and health disparities. Racial differences in cancer-related information needs have been studied primarily in African American, Asian, Caucasian, and Hispanic survivors. As compared to Caucasian survivors, African American and Hispanic survivors needed more information about diagnosis, mainstream and alternative treatments, side effects, genomics, quality-of-life outcomes, psychosocial support and treatment, financial and transportation assistance, and spirituality (Moadel et al., 2007).

Hispanic survivors desired more information about side effects, interpersonal and emotional functioning, and insurance and fertility issues; Asian survivors desired more information about health promotion; and African American survivors desired more information on side effects and insurance (Beckjord et al., 2008). Diverse sample studies of survivors who were two to five years post-treatment found that individuals who identified themselves as African American, Asian, or Hispanic were more likely to report unmet information needs compared to their Caucasian counterparts (Beckjord et al., 2008).
Diagnostic and Treatment Factors

It is important for providers to consider how a patient’s prognosis, type and stage of cancer, and other comorbidities might affect the quantity, timing, and content of information needs. Many studies have reported that most patients want to know as much information as possible about their diagnosis and treatment options, especially surrounding the time of initial diagnosis (Ankem, 2006; Degner & Sloan, 1992). In contrast, patients with more critical prognoses have been shown to want less detailed assessments of life expectancy and prefer that physicians ask which types of information they wish to receive before disclosure occurs (Cox et al., 2006; Hagerty et al., 2004). Although most research has not found significant differences in information needs based on the type of treatment received, some studies have reported that radically or vigorously treated survivors requested more detailed information about their illness and the treatments received (Ankem, 2006). A survivor’s type of cancer can have significant implications for the type of information needed. For example, patients with breast, prostate, gynecologic, and testicular cancers have requested more information about sexual functioning, fertility, and psychological concerns compared to patients with other forms of cancer (Galloway et al., 1997; Thewes, Butow, Girgis, & Pendlebury, 2004).

Psychological Factors in Personalizing Information

A survivor’s level of emotional and neuropsychological functioning is an important consideration within efforts to personalize information. Survivors who experience emotional and neurocognitive concerns have reported benefiting from information about individual and group psychotherapeutic services, neuropsychological testing, self-care and management of emotional distress, and ways of helping their family members and friends cope (Epstein & Street, 2007). Survivors have reported positive psychological functioning and coping abilities when their information needs were met by providers early and throughout the duration of their medical care (Baum, 2000). When addressing information needs, providers should be aware that a survivor’s negative or positive psychological response may be moderated by personality characteristics, coping abilities, and decision-making styles (Epstein & Street, 2007).

SUMMARY

Effective information sharing is paramount because of the large numbers of patients reporting unmet information needs and difficulties accessing, comprehending, and retaining cancer-related information (Epstein & Street, 2007). The uniqueness of an individual’s diagnosis, treatment, and psychosocial and personal background creates a filter through which all information must pass to address individual concerns. Not surprisingly, this filter sometimes renders
generic information insufficient to address an individual’s concerns. As a result, increasing access to personalized information is an emerging goal in cancer care and survivorship (Epstein & Street, 2007).

Clinical providers of cancer treatment are uniquely positioned to improve current information dissemination practices given that survivors trust and utilize information from clinicians more than any other source (Hesse et al., 2005). Unfortunately, the current medical model of service delivery limits the amount of time oncology nurses and physicians have to adequately address patient concerns and engage in information sharing during visits (Wilson & Childs, 2002). Additionally, not all oncology nurses and physicians have the knowledge base or interest in sharing information on the wide variety of topics of concern to patients (e.g., alternative treatments, psychosocial support) (Epstein & Street, 2007). Allied health professionals, such as social workers and psychologists, are well positioned to offer their expertise and to provide helpful information; however, access to care is another barrier that prevents adequate information dissemination to survivors (Epstein & Street, 2007). With physicians and nurses being the number-one source of trusted information about cancer, survivors with limited access to medical care are at a disadvantage.

Providers and survivors have begun to advocate for individualized care planning and a patient-centered medical home model of care, which espouses an ongoing relationship with a personal physician; integrated, multidisciplinary, and culturally sensitive care; and enhanced access to care via extended hours and open appointment scheduling (American Academy of Family Physicians, 2008). The implementation of medical home models has been associated with better access to quality care, fewer racial and ethnic disparities, and increased information dissemination (Beal, Doty, Hernandez, Shea, & Davis, 2007).

One promising method of assessing the individual needs of survivors is to use existing standardized measures of evaluation (Epstein & Street, 2007). Several highly effective evaluation tools are available to examine general information needs and specific areas of concern frequently reported by survivors, including psychological functioning, neuropsychological functioning, socioeconomic concerns, and quality of life (see Table 22-1) (Epstein & Street, 2007). In order to expand the utility of these measures, developers will need to adapt existing measures for use with underserved, minority, low-literacy, multilingual, and specific cancer diagnosis populations (Moadel et al., 2007).

Delineating personalized information needs and increasing the fit between a survivor’s needs and the support received remain ongoing goals for clinical practice and research. Clinicians may realize these goals through fully assessing the needs of cancer survivors, effective care planning, efficacious information dissemination, and increased utilization of evaluation measures. Helping people with cancer to find answers to their information needs can have significant implications for patient involvement and decision making, behavioral change, and psychosocial well-being. Taking steps to increase information access, quality, and personalization can assist individuals in managing their illness and making informed choices about their health care, which ideally can enhance their outcomes.
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<tr>
<th>Assessment Measure</th>
<th>Practical Use</th>
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<tr>
<td><strong>General Information Needs</strong></td>
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<tr>
<td>• Information Styles Questionnaire (Cassileth et al., 1980)</td>
<td>Assesses attitudes of patients with cancer about information and participation in decision making</td>
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<td>– 12-item self-administered questionnaire</td>
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<td>• Toronto Information Needs Questionnaire—Breast Cancer (Galloway et al., 1997)</td>
<td>Assesses areas of information need for adult patients diagnosed with breast cancer</td>
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<td>– 51-item self-administered questionnaire</td>
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<td><strong>Psychological/Neuropsychological Functioning</strong></td>
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<td>• Behavior Assessment System for Children (Reynolds et al., 2008)</td>
<td>Assesses emotional and behavioral functioning in children, adolescents, and young adults</td>
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<td>– 100–160-item self-report, teacher-report, or parent-report measure</td>
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<td>• NEPSY, a developmental neuropsychological assessment (Korkman et al., 1998)</td>
<td>Assesses attention/executive function, language, memory, sensorimotor, and visuospatial skills in children 3–12 years old</td>
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<td>– Administered only by neuropsychologists/psychologists and trained professionals</td>
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<tr>
<td>• State-Trait Anxiety Inventory (Spielberger et al., 1970)</td>
<td>Assesses anxiety in adults</td>
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<td>– 40-item self-administered questionnaire</td>
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<tr>
<td>• Wechsler Adult Intelligence Scale (Wechsler, 1981)</td>
<td>Assesses cognitive functioning in adults</td>
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<tr>
<td>• Wechsler Memory Scale (Wechsler, 1987)</td>
<td>Assesses memory and attention in adults</td>
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<td><strong>Socioeconomic Concerns and Quality of Life</strong></td>
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<td>– 30-item self-administered questionnaire</td>
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<tr>
<td>• Pediatric Quality of Life Scale (Varni et al., 2001)</td>
<td>Assesses functioning (e.g., physical, emotional, social, cognitive, communication, worry, family, daily activities, psychosocial) in children with varying forms of medical illness</td>
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<td>– 36-item self-administered questionnaire</td>
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REFERENCES


INTRODUCTION

In 2007, approximately 11.7 million individuals in the United States were alive with a history of cancer (Altekruse et al., 2010), with an additional 1.4 million cancers estimated to be diagnosed the same year (American Cancer Society, 2007). The number of new patients with cancer is expected to increase over time because of population changes in the United States (Mariotto, Yabroff, Shao, Feuer, & Brown, 2011). Survival following diagnosis and treatment for many cancers has also improved. As a result of these trends, a larger prevalence of cancer survivorship is expected in the future. Based on increased prevalence alone, the economic burden of cancer is expected to increase (Mariotto et al., 2011). Other trends, including increasing costs and, in particular, expensive new chemotherapy drugs, make measuring and projecting the economic burden of cancer an important issue for policy makers as well as for cancer survivors and their families.

This chapter will describe the components of the economic burden of cancer and provide recent estimates of burden in the United States. It will then discuss the role and challenges of economic evaluation in the growing field of personalized medicine. Finally, it will identify areas where future research efforts will enhance the quality of information regarding the burden of cancer and may ultimately improve the cancer survivorship experience.

COMPONENTS OF THE ECONOMIC BURDEN OF CANCER

Cancer and its treatment result in the loss of economic resources and opportunities for patients, families, employers, and society as a whole. These
losses include financial loss, morbidity, reduced quality of life (QOL), and premature death. When estimating the economic burden of disease, the monetary valuation of resources used to treat disease and the loss of opportunities due to disease is measured as cost. Cost domains typically include direct costs, such as the use of resources for medical care; indirect costs, such as the loss of resources and opportunities; and psychosocial costs, such as pain and suffering.

**Direct Costs of Cancer**

Direct medical costs of cancer are based on services that patients receive, such as hospitalizations, physician visits, chemotherapy/immunotherapy, and radiation therapy. Costs associated with these services typically are measured by insurance payments and patient out-of-pocket co-payments and deductibles. In 2006, the direct medical costs of cancer care for all cancer survivors were estimated to be approximately $104.1 billion in the United States alone (National Cancer Institute, 2007). The most costly cancer sites in 2006 were breast ($13.9 billion), colorectal ($12.1 billion), lung ($10.3 billion), and prostate ($9.7 billion) cancers, reflecting underlying disease prevalence, stage distribution at diagnosis, patterns of care, and survival (National Cancer Institute, 2007).

In addition to measuring the direct medical costs for cancer survivors in a specific year, costs are also measured longitudinally, starting from diagnosis or the initiation of treatment. Across the trajectory of care, costs are highest in the initial period following diagnosis, and among those who die from their disease, at the end of life (Riley, Potosky, Lubitz, & Kessler, 1995; Yabroff et al., 2008). Costs are lowest between the initial and end-of-life periods, referred to as the continuing phase, following a “u”-shaped curve. Importantly, direct medical costs are generally higher for cancer survivors than for similar individuals without cancer in all phases of care (Riley et al., 1995; Yabroff et al., 2008).

Patient and socioeconomic factors are associated with direct medical costs. Among older adult Medicare beneficiaries, costs associated with cancer care generally are higher for patients diagnosed with advanced cancer compared to those with localized disease in the initial, continuing, and last year of life phases of care (Yabroff et al., 2008). Because individuals of lower socioeconomic status tend to have lower rates of screening and less access to care, they are more likely to be diagnosed with advanced rather than localized disease (Halpern et al., 2008), which may lead to an increased economic burden for this group. Nonmedical direct costs of cancer include transportation to care, housekeeping services, and other household accommodations resulting from disease and its treatment. These costs are measured less frequently because, in part, these data are not routinely collected.

**Indirect Costs**

Indirect costs of cancer include time spent seeking medical care for patients and caregivers, time lost from work or other usual activities, and lost produc-
ivity due to premature death (mortality costs). In the few studies that have measured both mortality costs and direct costs of medical care, mortality cost estimates generally were at least the equivalent of the direct costs of medical care (Max et al., 2002, 2003). Because these lost opportunities are not typically reflected in monetary transactions, a critical component of studies of indirect costs is the method for valuing lost time.

The two main approaches for valuing time are the human capital approach and the willingness-to-pay (WTP) approach (Russell, 2009). In the human capital approach, gender- and age-specific average earnings are combined with expected productivity trends and lost productivity or years of life lost due to premature death to estimate unrealized earnings. This approach explicitly values the time of individuals with greater earnings as greater than the time of individuals with less earnings. WTP approaches, in contrast, incorporate both lost productivity and the intrinsic value of life by estimating the amount an average individual would be willing to pay for an additional year of life. Because cancer incidence and mortality rates are highest in older adults, a population less likely to be in the workforce than their younger counterparts, comparison of these two approaches is particularly relevant.

Patient and caregiver time data are not routinely collected, and as a result, few studies have estimated these costs. Time spent traveling to and from care, waiting for appointments, and receiving care represents time not spent pursuing usual activities, including work and leisure. Both patient and caregiver time are recommended for inclusion in cost-effectiveness analyses (Gold, Siegel, Russell, & Weinstein, 1996), yet these data are rarely considered, potentially resulting in a bias toward underestimating the costs of interventions that place a higher burden on patients with cancer and informal caregivers (Russell, 2009).

These time costs can be substantial. In 11 of the most common cancer sites, patient time costs in older adults during the first year following diagnosis were estimated to be approximately $2.3 billion (Yabroff, Davis, et al., 2007). Other studies have suggested that caregiver time costs may be of a similar magnitude (Hayman et al., 2001; Yabroff & Kim, 2009). These studies used patient or caregiver surveys or modeled approaches for patient time that combine healthcare service (e.g., hospitalizations) frequencies with estimates of time for specific services.

**Psychosocial Costs**

A diagnosis of cancer may lead to a decrease in overall QOL for both cancer survivors and their families. These costs typically are referred to as psychosocial costs and can be substantial. Similar to indirect costs, psychosocial costs are not reflected in monetary transactions. These costs frequently are measured by eliciting patients’ preferences for their health state or “utility” using validated survey instruments, such as the EuroQol or the Health Utilities Index, or other utility elicitation techniques (Torrance, 1987). The resulting summary measure, typically anchored by the values of 1 (perfect health) and
0 (death), incorporates multiple domains of health-related QOL and can be compared across health states. Psychosocial costs can be conceptualized as a QOL outcome and then used in cost-effectiveness or cost-utility analyses to “quality-adjust” the results.

Cancer survivors’ QOL may change following diagnosis and treatment. A number of studies have examined changes in QOL over the first few years following diagnosis (Ganz et al., 2002; Ramsey, Berry, Moinpour, Giedzinska, & Andersen, 2002). However, less research has examined QOL among long-term cancer survivors. In the recent study by Ramsey and colleagues (2002), multiple health-related QOL indicators were examined within a sample of patients with colon cancer at different points in time after diagnosis. In general, the measures of health-related QOL and utility for these patients did not substantially vary by years since diagnosis or stage of disease although symptoms present earlier in treatment tended to persist. Other studies have found that cancer survivors report poorer outcomes than similar individuals without cancer, even many years following diagnosis (Yabroff, McNeel, et al., 2007). The development of tools to better capture changes in QOL among cancer survivors is a growing area of research interest.

Family caregivers share the emotional and psychological impacts of cancer. Over the past decade, shorter hospital stays and higher cancer survival rates have led to an increased burden among caregivers. This burden is often separated into three distinct stages (Northouse, 1989): (a) the acute phase, where the patient and caregiver come to terms with the diagnosis, (b) the chronic phase, where the patient completes primary treatment and the caregiver takes on additional responsibilities, and (c) the adjustment phase with survivorship or bereavement. Few prospective studies have examined the psychosocial, occupational, and economic impact of caregiving longitudinally, but in general, caregivers’ depression and perceived burden are correlated with the cancer survivors’ functional status. Caregivers of cancer survivors with declining functional status report increasing depression and perceived burden over time (Grunfeld et al., 2004).

**Economic Perspectives in Personalized Medicine**

The topic of personalized medicine has received increased attention as healthcare costs in the United States continue to rise. The premise behind personalized medicine is that information from patients’ genetic profiles can be used to tailor their medical care, which in turn can improve patient outcomes and decrease unnecessary healthcare-related costs to healthcare payers, patients, and society. The economic perspective is particularly relevant because many of the new targeted therapies are considerably more expensive than traditional treatments (Schrag, 2004).

One of the first personalized medicine breakthroughs occurred in breast cancer with the discovery of the role of estrogen receptor (ER) status in treatment response. An early cost-effectiveness modeling study of adjuvant
treatment among premenopausal patients with ER+ and ER– early-stage breast cancer reported the cost-effectiveness of different treatment strategies (Smith & Hillner, 1993). Chemotherapy was found to provide clinical benefit for all groups of women at a modest cost. Tamoxifen alone added benefit, but only in women with ER+ cancers. Combined therapy was effective for all women, but cost-effective only in women with ER+ cancers. More recently, concerns about the late effects and toxicity associated with chemotherapy have led to efforts to predict the risk of breast cancer recurrence using gene expression profiling techniques and to evaluate these tools (Eng-Wong & Zujewski, 2008). Additional research to determine the cost-effectiveness of this approach will be important.

In evaluating targeted therapies for colorectal cancer, researchers found that patients with colorectal cancer carrying KRAS mutations do not respond to treatment with the biologic drugs cetuximab or panitumumab (Morton & Hammond, 2009). Limiting the use of these expensive drugs to patients without KRAS mutations increases the likelihood of response to therapy and may save money for both healthcare payers and patients. To quantify the economic impact of restricting cetuximab to patients with colorectal cancer with tumors with wild-type KRAS, Mittmann et al. (2009) measured the healthcare costs and utility values from clinical trial participants. They estimated the incremental cost-effectiveness ratio (ICER), a measure assessing the increased cost required by an intervention to obtain one additional year of life, and incremental cost per quality-adjusted life year (QALY) associated with cetuximab treatment. When restricted to patients with tumors with wild-type KRAS, the ICER for cetuximab treatment was $120,061 per life year gained and $186,761 per QALY, significantly less than when the entire population is treated. Although the ICER is more favorable in the population with wild-type KRAS, the ICER is still in excess of commonly accepted cost-effectiveness thresholds (Grosse, Teutsch, & Haddix, 2007). Furthermore, the costs of the KRAS mutation tests were not included in these analyses but are an important consideration for policy making and implementation.

Two challenges in conducting economic evaluations of targeted therapies using a personalized medicine approach are that (a) the collection of genetic data is not standardized, and (b) many of the most frequently used data sources for economic evaluations fail to capture this information. Administrative claims record information on the types of laboratory examinations performed, but the results of these tests are unknown. Even medical record abstraction may have missing data on genetic testing results, as laboratory values may not be recorded back to the medical record. One potential solution to this issue is the standardization of health information through electronic health records.

Beyond the research challenges associated with the economic evaluation of personalized medicine approaches, a number of barriers to wide acceptance and dissemination of this knowledge in clinical practice also exist. Established methodologies to assess the effectiveness of particular biomarkers are lacking (Ginsburg & Willard, 2009), and clinical trial designs for examining biomark-
ers in treatment are not yet standardized (Freidlin, McShane, & Korn, 2010). Providers are uncertain about the application of personalized medicine in their daily clinical practice. Healthcare payers are under increased pressure to cover additional genetic tests, but are concerned about how these additional costs will affect future spending on their covered populations, particularly because membership turnover is high. The economic impacts of targeted therapies and genetic testing to guide treatment decisions will likely play an important role in the adoption of personalized medicine for cancer care in the United States.

FUTURE DIRECTIONS

The economic burden of cancer is substantial at the individual patient, family, and national levels. Greater understanding of the roles of insurance and unemployment on the burden of cancer, standardization and measurement of cancer costs, improved assessment of the costs and cost-effectiveness of personalized medicine, and the use of simulation modeling to assess economic burden may enhance the quality of the cancer survivorship experience.

Health Insurance, Employment, and the Financial Burden of Cancer

Because health insurance is predominantly employment based in the working-age population of the United States, its relationship with cancer outcomes is complex, as cancer survivors who are unable to work may also lose their insurance coverage. If they do not qualify for Medicaid, cancer survivors may not be able to purchase insurance independently, as it may be prohibitively expensive or their policy may have a preexisting condition exclusion for cancer care. High patient cost-sharing (i.e., deductibles, co-payments, and co-insurance), limits on annual and lifetime benefits, and waiting periods for public programs contribute to the financial burden for patients with cancer (Schwartz, Martin, & Finan, 2009). Even with health insurance, some patients may delay treatment or not seek care because of cost and concerns about medical debt. Furthermore, medical care expenses are reported to be the underlying reason for many bankruptcies, with cancer as a leading cause (Himmelstein, Thorne, Warren, & Woolhandler, 2009). Evaluation of recent healthcare reform in the United States will be important for understanding the relationship between socioeconomic status, health insurance, and cancer outcomes in the future.

Standardized Measurement and Reporting of Cancer Costs

A critical step in the process of effective policy making is the synthesis of high-quality research studies. Therefore, standardization of measurements and reporting of inputs and assumptions for studies is necessary. However, a
recent review of studies on the burden of cancer reported substantial variation with regard to study settings, services included, measurement of costs, and study methods (Yabroff, Warren, & Brown, 2007). Furthermore, in burden studies, documentation and reporting of patient characteristics that influence outcomes and costs (e.g., stage at diagnosis) and analytic methods are lacking. Although the quality of cost-effectiveness studies of cancer treatment has improved over time, many studies still do not report all critical modeling assumptions (Greenberg, Earle, Fang, Eldar-Lissai, & Neumann, 2010). Looking ahead, greater adherence to published standards for conducting cost-effectiveness analyses will be important (Gold et al., 1996). Future standardization efforts for both burden and cost-effectiveness studies will improve quality and enable international comparisons.

**Cost-Effectiveness of Personalized Medicine Strategies**

Recent discoveries in genetics have provided cancer researchers with new tools that may help to advance the field of personalized medicine. One area of increased attention is the tailoring of expensive cancer treatments based on individual genetic markers. As a result, a number of studies (Garrison et al., 2007; Mittmann et al., 2009) have focused on the cost-effectiveness of adjuvant treatments across different genetic subpopulations. Yet, advances in the field have largely outpaced the standardization of data collection and analytic methods. In addition, ethical and privacy issues must be carefully considered when deciding how to use individuals’ genetic information for healthcare coverage decisions. The rise and adoption of electronic health records may aid in the standardization of genetic data collection and address issues of privacy. Guidelines for the conduct of cost-effectiveness analyses using genetic data should be developed so that comparisons and synthesis of information across studies and settings will be possible.

**Projections and Simulations of the Impact of Cancer Control Interventions**

Population-based simulation modeling efforts, such as the Cancer Intervention and Surveillance Modeling Network, can incorporate trends in population characteristics, cancer risk factors, prevention and screening, treatment, and competing mortality to estimate and project cancer incidence, mortality, and costs of care (National Cancer Institute, n.d.). For example, projections of the cost of colorectal cancer care in the United States between 2010 and 2020 are expected to increase by 23% from $14.1 billion to $17.3 billion based on population trends alone (Mariotto et al., 2010). When current trends of decreasing colorectal cancer incidence, improving survival, and increasing costs of care are considered, projected costs are estimated to increase even more, by 49% to $21 billion in 2020. These projections may be particularly
useful for policy makers in anticipating the future burden of cancer care in the United States.

SUMMARY

The economic burden of cancer is substantial for survivors and their families, as well as for employers, insurers, and the nation as a whole. Ongoing efforts to improve data resources for estimating cancer costs, standardizing methods and reporting, and developing simulation modeling scenarios should enhance the quality of information related to the economic burden of cancer and, ultimately, improve the QOL for cancer survivors and their families.

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CHAPTER 24

Employment and Cancer Survivorship

Cathy J. Bradley, PhD

INTRODUCTION

The number of working-age individuals diagnosed with and treated for cancer will increase as more sensitive screening tests lead to earlier detection, and treatments hold potential for higher rates of cure. It is estimated that approximately half of the 12 million American cancer survivors are of working age (Stricker & Jacobs, 2008). Patients’ motivations to remain working include career aspirations, health insurance continuity, wages, and distraction from health concerns. Work also provides patients with a sense of normalcy and can help them maintain positive self-esteem (Main, Nowels, Cavender, Etschmainer, & Steiner, 2005). Continuing to work is also associated with a good quality of life during treatment (Lehto, Ojanen, & Kellokumpu-Lehtinen, 2005).

In at least one study of survivors, the importance of work emerged as the greatest issue of focus following concerns about health and family (Amir, Neary, & Luker, 2008). Yet, surprisingly little information on managing work-related issues is available for patients newly diagnosed with cancer, the health professionals who treat them, and the employers who employ them. This chapter describes key work-related considerations for cancer survivors, including employment during treatment, long-term employment, cancer- and treatment-related disability, and health insurance.

BALANCE OF WORK AND TREATMENT

If a patient decides to continue working, concerns regarding how to balance work with treatment demands and the extent to which treatment will limit job performance are paramount. In spite of these concerns, three out of five survivors who were employed prior to diagnosis manage to work during treatment.
(Short, Vasey, & Tunceli, 2005). However, absenteeism among patients who remain employed during treatment can add up to several months or more (Bradley, Neumark, Bednarek, & Schenk, 2005; Bradley, Oberst, & Schenk, 2006). Many patients may plan to continue working throughout treatment only to feel the need to cut back after the side effects of treatment emerge (Main et al., 2005). A study of patients with cancer who were undergoing radiation found that of those patients who planned to continue working without making changes in work status, about one-half eventually reduced their work hours or changed their work duties, and an additional 20% of patients stopped working altogether for the duration of treatment (Poirier, 2007). Most patients with breast cancer (85%) miss at least four weeks of work, with an average of about six months off from work (Drolet et al., 2005; Lauzier et al., 2008). Patients may change positions (especially those whose jobs require physical activity), stop working temporarily, go on disability, or make multiple decisions regarding changes in work, particularly when beginning and finishing treatment.

The literature suggests that treatment-induced symptoms are primarily to blame for absenteeism from work. For example, patients who experience fatigue are two and a half times more likely to take a long leave of absence from work than those with less-debilitating fatigue (Spelten et al., 2003). Pain is another challenging symptom and affects approximately 40% of patients with cancer (Fortner et al., 2003). About one-fourth of patients experience abrupt flares of pain that “break through” the relief provided by medication (Fortner et al., 2003). Those experiencing pain are much more likely to take time off of work than those without pain (Main et al., 2005).

Employed patients with uncontrolled chemotherapy-induced nausea and vomiting (CINV) missed three to six days of work per month and were more likely to take a leave of absence than patients with controlled CINV (Shih, Xu, & Elting, 2007). In addition, patients with cancer may experience difficulty with concentration that interferes with work ability (Bradley, Neumark, Luo, & Schenk, 2007; Feuerstein, Hansen, Calvio, Johnson, & Ronquillo, 2007; Kennedy, Haslam, Munir, & Pryce, 2007; Spelten, Sprangers, & Verbeek, 2002), as well as other work-related cognitive difficulties such as memory loss (Feuerstein et al., 2007). Mood-related factors, such as anxiety and depression, are relatively common among patients with cancer and are associated with difficulty at work and the likelihood of temporarily or permanently being absent from work (Feuerstein et al., 2007; Main et al., 2005; Spelten et al., 2002). Improved management of treatment-induced side effects through medical intervention and careful self-monitoring may improve patients’ return to work.

**DISCLOSURE OF CANCER DIAGNOSIS AND SYMPTOMS**

Disclosing a cancer diagnosis and its symptoms to employers and coworkers can be stressful. Patients may not know how to communicate their needs and may be reluctant to appear vulnerable (Main et al., 2005). For example,
patients experiencing fatigue or concentration difficulties may feel less able to complete their work successfully and may fear that others view their work as inadequate (Main et al., 2005). This is especially true for patients whose jobs entail manual labor or other physically demanding work. These individuals often need to change or cut back on their duties or find a job that is less physically demanding (Bradley et al., 2007; Spelten et al., 2002). Being able to discuss treatment demands and needs for accommodation with employers can positively affect patients’ ability to remain employed. When employers make accommodations for workers with a temporary disability, the time that employees spend away from work is significantly reduced (Bouknight, Bradley, & Luo, 2006; Franche et al., 2005).

**FAMILY AND MEDICAL LEAVE ACT**

One of the most daunting issues facing newly diagnosed patients with cancer is whether to try to work during treatment. Some patients have the option of taking an extended leave of absence during treatment and other patients have the option of taking sick days as needed, whereas others are forced to take uncompensated time away from work and have few options for balancing the demands of treatment and work. The Family and Medical Leave Act (FMLA) gives employees the right to take time off due to their own illness or if they are caring for an ill dependent, without the threat of losing their job (U.S. Department of Labor, Wage and Hour Division, n.d.). This law provides for 12 weeks of unpaid leave per year for serious illness, which is defined as one that incapacitates the patient for more than three consecutive days, requires a doctor’s or other healthcare professional’s care, or requires a regimen of continuous treatment. Cancer is a condition generally considered serious enough for the FMLA to apply to patients and the family members caring for them.

The 12-week leave under the FMLA does not have to be taken all at once but can be taken in blocks of time. For example, those taking several hours of leave per day over a period of weeks for treatments receive the same protection as those taking 12 consecutive weeks. During this time, the employer is required to continue providing health benefits. An important limitation of the FMLA is that it only applies to employers with 50 or more employees.

**LONG-TERM EMPLOYMENT**

Although the majority of patients take varying amounts of time off from work during active treatment, many employed patients feel the need to return to work once treatment ends. Financial pressures from the extra costs required for treatment, lost wages during treatment, and the need to return to normalcy prompts many patients to return to work. Across several cancer sites, Taskila and Lindbohm (2007) reported that 41%–84% of patients return to work.
following treatment. Most patients resume working full-time. Employed long-
term cancer survivors tend to retire at approximately the same age as other
workers although some evidence suggests survivors feel pressured to retire at
an earlier age than their peers (Bednarek & Bradley, 2005).

Patients with cancer now face a more supportive and welcoming work en-
vironment than they did several decades ago. The implementation of fed-
eral laws, specifically the Americans with Disabilities Act of 1990 (U.S. Depart-
ment of Labor, Office of Federal Contract Compliance Programs, n.d.), the
Rehabilitation Act (U.S. Department of Health and Human Services, 1973),
the FMLA, and the Employee Retirement Income Security Act of 1974 (U.S.
Department of Labor, n.d.), have helped protect individuals with cancer and
other disabilities from discrimination, as well as provide medical leave, pro-
tect benefits, and provide flexible work schedules for patients needing time
to attend appointments (Hoffman, 2005).

CANCER-RELATED DISABILITY

Although many survivors return to work after treatment, a substantial pro-
portion of these patients report disability that interferes with their ability to
work in the same capacity or at the level as they did prior to their diagnosis.
A cancer diagnosis and treatment often means surgery, chemotherapy, and/or
radiation therapy. Some procedures require reconstructive surgery, which
increases the time needed to recover and return to normal functioning. Che-
motherapy can have serious short- and long-term consequences, and some
regimens require a year or more to complete (Boykoff, Moieni, & Subrama-
nian, 2009). Approximately one-fifth of survivors report physical and psychol-
ogical symptoms that interfere with work one to five years following diagno-
sis (Short et al., 2005).

In a study of breast cancer survivors five years after their diagnosis, 41%
required special accommodations to perform their jobs. These women were
nearly three times more likely to be impaired relative to their peers without
cancer (Chirikos, Russell-Jacobs, & Jacobsen, 2002). Approximately one-third
of female cancer survivors and 27% of male survivors reported limitations in
their ability to work (Short, Vasey, & Belue, 2008). Two years following diag-
nosis, 57% of employed survivors reduced weekly hours worked by more than
four hours, and 56% changed their occupational role. One year following di-
agnosis, both breast and prostate cancer survivors reported difficulty perform-
ing tasks requiring physical effort, heavy lifting, and stooping. Patients with
breast cancer frequently reported difficulties performing tasks requiring con-
centration, analysis, learning new tasks, and keeping up with the pace set by
others (Bradley et al., 2007). Unfortunately, vocational rehabilitation servic-
es, workplace supports, career counseling, and job placement assistance are
not part of rehabilitation programs for people with disabilities related to can-
cer and its treatment (Henderson, 1997; Main et al., 2005).
SOCIAL RESOURCES AT WORK

Many survivors find their coworkers to be a great source of support and the work itself to be a distraction from the day-to-day worries from cancer (Hakanen & Lindbohm, 2008). An encouraging work environment may have a positive influence on the extent to which survivors report treatment-induced impairments. Survivors with a strong commitment to work or a good work environment reported fewer obstacles than survivors without a supportive work environment (Taskila & Lindbohm, 2007). Social support from an immediate supervisor and coworkers also is associated with willingness to work and ongoing commitment to work (Hakanen & Lindbohm, 2008).

Employers need support and resources to help them facilitate employment and job retention of individuals diagnosed with cancer (Amir et al., 2008). In many cases, employers are unsure of how to help cancer survivors and of the laws that protect cancer survivors. One cannot assume that employers or employees are aware of or adhere to federal regulations such as the Americans with Disabilities Act.

HEALTH INSURANCE

Employers are the primary source of health insurance for workers younger than age 65. Cancer survivors may feel pressure to work to maintain the family’s financial situation or access to health insurance if the family is reliant on these factors (Bradley et al., 2007; Main et al., 2005). Insurance-related factors that can affect cancer survivors include waiting periods, preexisting conditions, incomparable coverage, and higher premiums. Employers, particularly smaller ones, may not find individuals (or their family members) with such medical risks desirable because the employer’s risk rating and premiums will dramatically increase. The risk of losing insurance coverage is greatest for workers with less experience and limited skills. In addition, some survivors have reported that they are more likely to be rejected for health insurance than their cancer-free counterparts. Cancer survivors with employment-provided health insurance and benefits are more likely to remain employed in their jobs (Tunceli, Short, Moran, & Tunceli, 2009). Although these survivors have health insurance coverage, they may be constrained from making career choices that include job changes.

SUMMARY

Many cancer survivors will face challenges when they either negotiate time away from work during treatment or return to work following treatment. As of this writing, the evidence suggests that few healthcare providers offer advice about managing work concerns. Therefore, survivors need to be proac-
tive in initiating conversations with their physicians and discuss occupational concerns before initiating treatment. Likewise, survivors need to have conversations with their employers regarding benefits (e.g., health insurance, leave, disability, accommodations) so that they can make informed decisions. Survivors need to seek help for rehabilitation and know their legal rights in the workplace. In time, the healthcare system may encompass work-related concerns in the information and assistance it provides to patients with cancer, but at this time, the burden is largely on survivors. The key concerns discussed in this chapter are summarized in Table 24-1. Critical employment-related information needs are listed in Figure 24-1.

Much work remains to be done to fully understand and minimize the work-related impact of cancer and its treatment. Areas for future investigation include proactive discussions between patients and healthcare providers about potential adverse consequences and rehabilitation needs, and discussions with employers regarding accommodation needs during and following treatment. Another investigative area is the discovery of specific barriers to work that are associated with particular combinations of cancer sites, cancer treatment types, and occupational categories (e.g., physical or labor-intensive jobs, high-stress jobs, jobs requiring long periods of concentration).

<table>
<thead>
<tr>
<th>Challenges</th>
<th>What Can Help</th>
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| Treatment-induced symptoms                 | • Proactive symptom management  
• Informing healthcare providers of work demands and selecting treatments that can minimize impact  
• Workplace accommodations  
• Planning realistic time away from work |
| Scheduling time away from work             | • Informing healthcare providers of work schedule  
• Family and Medical Leave Act; leave benefits  
• Informing employers of needs |
| Long-term disability                       | • Vocational or occupational rehabilitation  
• Job changes |
| Physically intensive work                  | • Work accommodations  
• Changing jobs or job tasks |
| Absence of health insurance; concerns about losing health insurance | • Investigating the possibility of switching to spouse’s health insurance policy  
• Investigating alternatives to private health insurance |
| Balancing work, treatment, and uncertainty about future functioning | • Trying to remain employed until treatment is complete and assessing work limitations and financial needs following treatment  
• Avoiding acting hastily |
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**Figure 24-1. Critical Employment-Related Information Needs**

Advise patients to consider the following areas for information.

**Health Insurance**

Obtain information about the extent of coverage, out-of-pocket costs including co-pays, spending limits, options to switch to spouse’s policy, cost of extending health insurance should the survivor leave work (i.e., cost of Consolidated Omnibus Budget Reconciliation Act [COBRA] and time limit on COBRA), and the possibility of obtaining public health insurance.

**Leave**

Consider the range of leave possibilities, including sick and vacation leave. Some leave is paid, while other leave, such as that taken under the Family and Medical Leave Act, is not paid. Get advice about short-term and long-term disability benefits and required documentation. Start completing the paperwork early if long-term disability is a possibility.

**Retirement Benefits**

Fully understand eligibility requirements, including length of service. Determine whether health insurance benefits are available to retirees and the limitations and cost of health insurance during retirement. Estimate expected pension amount.

**Accommodations**

Determine what accommodations are needed and allowed under the Americans with Disabilities Act.

**Vocational Rehabilitation**

Ask healthcare providers about ways to increase function and minimize symptoms during and following treatments.


SECTION V

Maximizing Health Outcomes for the Cancer Survivor

While survivorship should be celebrated, it is also clear from the previous sections in this book that cancer has a significant impact on survivors. Many have postulated that the cancer experience can be a “teachable moment” where survivors may be more interested in health promotion (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005). However, a number of studies have not supported this hypothesis (Bellizzi, Rowland, Jeffery, & McNeel, 2005; Coups & Ostroff, 2005; Mayer et al., 2007).

I sometimes wonder whether it is more our wish as health professionals to make this a teachable moment than a desire of survivors. We do know that cancer survivors are at greater risk for developing recurrences, second malignancies, and other diseases, such as cardiovascular disease, diabetes, and osteoporosis, as well as other late and long-term effects of the disease and treatment (Institute of Medicine, 2006; Jemal et al., 2004). Hewitt, Rowland, and Yancik (2003) reported that cancer survivors have almost a twofold likelihood of having at least one functional limitation. When the survivor has another comorbid condition, the odds of having a functional impairment increase significantly. Some of the factors contributing to these morbidities are modifiable while others are not. So, now what?

This section will address how to maximize health outcomes for survivors to minimize the impact of the cancer and its treatment. We are learning more about the importance of tobacco cessation, increasing physical activity, and obtaining or maintaining a healthy weight in ameliorating some of these problems. However, knowing this and being able to alter behaviors are quite different. For example, since the 1960s and the first surgeon gener-
al’s report, we have known that smoking and tobacco use have negative consequences, yet about 20% of the adult population continue to use tobacco (Centers for Disease Control and Prevention [CDC], 2009). An overall decrease in smoking has occurred as a result of a coordinated effort within the United States that included smoking bans, controlling advertising, tax increases to make smoking less affordable, and the development of evidence-based smoking cessation programs and medications. It has taken 50 years of these systemic efforts to see a societal decrease from more than 40% in the 1960s to 20.6% in 2008 (CDC, 2009). Will it take that long to see changes in levels of inactivity and obesity in our society? Hopefully not. We can apply the many lessons learned with smoking to these other two contributors to morbidity and mortality.

Another development in maximizing health outcomes for survivors is in the area of personal growth after the cancer experience; some refer to this as post-traumatic growth or benefit-finding. While no one would voluntarily undergo cancer and its related treatment to experience growth, many survivors discover a silver lining to the experience. Receiving a cancer diagnosis may cause one to ask, “Am I living the life I want to be leading?” More programs than ever are available to help the cancer survivor address these existential questions. Over the past 20 years, tremendous growth in and acceptance of integrative therapies have occurred. Long gone are the days when we could ignore the impact that the cancer experience has on the whole person. Many survivors may experience physical sequelae from their disease and treatment but find their lives enriched psychologically, spiritually, and socially. In turn, that helps maximize some of the health outcomes of survivors.

We need to open our gaze when seeing the cancer survivor to encompass the full continuum from prevention through survivorship and end-of-life care. We need to remember that at any one time we are seeing people as a snapshot, but they are really living in a longer video. Let us not forget what else is occurring and who else participates in that video. This section will address issues in delivering survivorship care including when and how many of the health promotion interventions can be implemented. We have come a long way in delivering cancer care, but we have further to go.

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REFERENCES


INTRODUCTION

The etiology of cancer is multifactorial, with genetic, environmental, and lifestyle factors interacting to produce a malignancy. Risk for cancer recurrence is largely affected by the type of cancer, the stage and grade of the cancer at diagnosis, and the treatment received (American Cancer Society, 2010b). Nonmodifiable factors, such as genetics and aging, and modifiable behaviors, such as physical activity, diet, weight, alcohol, and tobacco use, can potentially affect cancer recurrence and the development of second primary cancers. Although many cancers cannot be prevented, cancer survivors can be empowered to reduce their risk of a cancer recurrence or a second primary cancer by avoiding known risk factors that can be controlled and by making healthy lifestyle choices.

NONMODIFIABLE RISK FACTORS

Cancer Treatment as a Risk for Second Primary Cancers

Systemic and local cancer treatments can substantially reduce the risk of locoregional and distant cancer recurrence in appropriately selected tumors and patients. However, these therapies can increase the risk of developing second primary cancers. Although this is of concern, the benefits of cancer therapies in reducing recurrence and death from the first cancer are large as compared to the risk of developing a second cancer. The most common treatment-related second cancers and their associated risk factors include angiosarcoma (radiation), myeloid leukemias (chemotherapy, particularly topoisomerase II inhibitors, anthracyclines, and platinum agents), and
uterine carcinoma (tamoxifen) (Bernstein et al., 1999; Kirova et al., 2007; Smith, 2003; Travis et al., 1999, 2002). Modifications of treatment regimens continue to be studied to reduce the risk of second cancers while retaining the maximum effect of the selected agents in eradicating the primary cancer (Bernstein et al., 1999; Kirova et al., 2007; Smith, 2003; Travis et al., 1999, 2002).

**Family History and Genetic Susceptibility to Cancer**

Approximately 5% of all cancers have a strong hereditary component, in that an inherited genetic alteration, or mutation, confers a very high risk of developing one or more specific types of cancer (American Cancer Society, 2010a). Even in individuals with inherited syndromes, the development of cancer still depends on acquiring additional mutations that are related to the cancer, host, and environmental factors. Although high-penetrance mutations associated with cancer susceptibility, such as \( \text{BRCA1} \), \( \text{BRCA2} \), \( \text{MSH2} \), and \( \text{APC} \), are implicated in this minority of cancer diagnoses, emerging data suggest that additional inherited cancer susceptibility can arise from a number of intermediate- or low-risk DNA variants, each of which, in isolation, confers a limited increase in risk (Robson, Storm, Weitzel, Wollins, & Offit, 2010; Tuma, 2009).

Approximately 5%–10% of breast and ovarian cancers are caused by an inherited mutation of either the \( \text{BRCA1} \) or \( \text{BRCA2} \) gene, which are associated with early-onset breast and ovarian cancers and increased risk of second primaries of the breast, ovaries, and other sites (Loman, Johannsson, Kristoffersson, Olsson, & Borg, 2001). Familial adenomatous polyposis and hereditary nonpolyposis colorectal cancer (HNPCC) are genetic syndromes that confer a high risk for developing colorectal cancer at an early age and in multiple sites within the colon and rectum. Its estimated prevalence among patients with colorectal cancer is approximately 5%–10% (Lynch & Lynch, 2000). Endometrial cancer is the second most common cancer found in HNPCC carriers; its risk has been estimated at 30%–40% by age 70 (Vasen et al., 1994).

Several other types of cancers have been found to cluster in families, including non-Hodgkin lymphoma, testicular cancer, lung cancer, and prostate cancer, although specific genetic mutations are either yet to be identified or testing is not available outside of research settings (Dong, Lönnstedt, & Hemminki, 2001). Hereditary cancer syndromes should be suspected when several generations of a family are diagnosed with certain cancers at a young age or when several individuals in a family develop multiple primary cancers. Criteria to identify families who may benefit from a referral to genetic counseling are outlined in Figure 25-1. Genetic testing for inherited cancer predisposition has become an accepted part of oncologic care and is well established as part of the care of individuals who may be at hereditary risk for cancer (Lindor, McMaster, Lindor, & Greene, 2008).
Aging

The risk of being diagnosed with cancer increases with age. About 78% of all cancers diagnosed in the United States are in people 55 years old and older (American Cancer Society, 2010a). The mechanisms that may explain this trend are duration of carcinogenic exposure and somatic aging, primarily caused by the accumulation of harmful substances in the extracellular matrix, and chronic inflammation. Age at initial cancer diagnosis is strongly associated with the risk of developing a second cancer. People diagnosed with cancer who are younger than 17 years of age have a substantially increased risk of developing second cancers (Fraumeni, Curtis, Edwards, & Tucker, 2006). In part, the risk of developing second cancers is based on remaining decades of life in which to develop cancers, similar to the general population.

MODIFIABLE RISK FACTORS

Evidence suggests that one-third of the cancer deaths that occur annually in the United States may be attributed to diet, weight, and physical activity habits; another third are related to exposure to tobacco products (American Cancer Society, 2010a). The World Health Organization (WHO) estimates that 35% of the cancers diagnosed annually worldwide are attributable to nine potentially modifiable risk factors (see Figure 25-2) (Danaei, Vander Hoorn, Lopez, Murray, & Ezzati, 2005). Smoking, alcohol use, and diet are the leading risk factors for death from cancer in low- and middle-income countries. In high-income countries, smoking, alcohol use, overweight, and obesity are the most

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**Figure 25-1. Features of Hereditary Cancer**

<table>
<thead>
<tr>
<th>In the Individual Patient</th>
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<tbody>
<tr>
<td>- Multiple primary cancers in the same organ</td>
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<tr>
<td>- Multiple primary cancers in different organs</td>
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<td>- Bilateral primary cancers in paired organs</td>
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<tr>
<td>- Younger-than-usual age at cancer diagnosis</td>
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<tr>
<td>- Cancers with rare histology</td>
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<td>- Cancers occurring in the sex not usually affected (e.g., breast cancer in men)</td>
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<tr>
<th>In the Family</th>
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<tr>
<td>- Multiple relatives with cancer of the same site or a related cancer</td>
</tr>
<tr>
<td>- Multiple relatives with cancer at younger-than-usual ages</td>
</tr>
<tr>
<td>- Multiple generations of a family with cancers of the same site or related sites</td>
</tr>
<tr>
<td>- Two or more first-degree relatives with tumor types belonging to a known familial cancer syndrome</td>
</tr>
<tr>
<td>- Multiple cases of a rare type of cancer</td>
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<tr>
<td>- More than one childhood cancer in siblings</td>
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*Note. Based on information from Lindor et al., 2006.*
significant risk factors (Danaei et al., 2005). Lifestyle factors affect numerous physiologic systems that can alter the cancer development process at many points (Pierce, 2009). In cancer survivors, lifestyle modifications can decrease the rates of second primary cancers. Emerging data suggest that modifications in lifestyle and diet after a diagnosis of cancer may decrease recurrence or improve survival (Chlebowski et al., 2006; Meyerhardt et al., 2006).

**Physical Activity**

Physical activity has demonstrated a decrease in the incidence of breast, colon, endometrial, and prostate cancers (Friedenreich & Cust, 2008; Giovannucci, Liu, Leitzmann, Stampfer, & Willett, 2005; Monninkhof et al., 2007). A recent review of 62 studies reported that physical activity was associated with a 25%–30% decrease in the risk of breast cancer, with 83% of the positive studies reporting a dose response (Friedenreich & Cust, 2008; Monninkhof et al., 2007).

Numerous observational studies have examined the relationship between physical activity and colon cancer risk. The majority of studies indicated that physically active people have a reduced risk of colon cancer development (Giovannucci et al., 2005). A meta-analysis of 19 cohort studies demonstrated a 22% reduction in the risk of colon cancer in active males and a 29% reduction in active females in the risk of colon cancer (Samad, Taylor, Marshall, & Chapman, 2005).

Recent data suggest that physical activity may reduce cancer recurrence and mortality among patients treated for early-stage breast, colon, and prostate cancers (Giovannucci et al., 2005; Meyerhardt et al., 2006). The evidence for an association between physical activity and breast cancer survival has been examined in several observational studies that reported decreased total mortality among physically active women with breast cancer and, in some studies, decreased mortality (Holmes, Chen, Feskanich, Kroenke, & Colditz, 2005; Irwin et al., 2008; Sternfeld et al., 2009). The estrogen and insulin

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**Figure 25-2. Modifiable Risk Factors That Could Reduce Cancer Incidence**

- Tobacco use
- Overweight or obesity
- Low fruit and vegetable intake
- Physical inactivity
- Alcohol use
- Sexually transmitted human papillomavirus infection
- Urban air pollution
- Indoor smoke from household use of solid fuels
- Exposure to ultraviolet light

*Note.* Based on information from Danaei et al., 2005.
pathways are two potential mechanisms by which physical activity may affect breast cancer survival (Irwin et al., 2008; Sternfeld et al., 2009). The Health, Eating, Activity, and Lifestyle Study reported a 45% decreased risk of death for women who increased their physical activity after diagnosis (Irwin et al., 2008; Sternfeld et al., 2009). Prospective observational studies of exercise in patients with colon cancer following diagnosis have shown reduced deaths and recurrences with higher levels of physical activity (Meyerhardt et al., 2006).

**Diet**

WHO (2010) estimates that dietary factors account for approximately 30% of all cancers in industrialized countries. Numerous dietary epidemiologic observations and animal studies consistently suggest possible protection against various cancers, but in general, these findings have not yet been validated in randomized trials. The World Cancer Research Fund and the American Institute for Cancer Research (2007) published a comprehensive assessment of the overall evidence of diet in relation to cancer prevention. With respect to dietary factors that may protect against cancer, the greatest consistency was observed for fruits and non-starchy vegetables. These foods were associated with decreased risk for cancers of the mouth, esophagus, and stomach. Fruits also were associated with a decreased risk of lung cancer (World Cancer Research Fund & American Institute for Cancer Research, 2007).

Increased fat and red meat intake have been implicated as risk factors for several types of cancers. Colon cancer rates are high in populations with high total fat intakes and are lower in those consuming less fat (Rose, Boyar, & Wynder, 1986). Dietary fiber, vegetables, and fruit have also been evaluated with respect to cancer risk. Ingestion of fiber may modify carcinogenesis, particularly in the large bowel, by a number of potential mechanisms (Steinmetz & Potter, 1991). A meta-analysis of 13 case-control studies from nine countries concluded that intake of fiber-rich foods was associated with a reduced incidence of cancers of the colon and rectum (Howe et al., 1992).

While a healthy diet has many benefits, the data are mixed on whether diet alone can prevent cancer recurrence. The Women’s Healthy Eating and Living Study evaluated the effectiveness of increased vegetables, fruits, and fiber and decreased total fat to reduce breast cancer events and deaths in patients with early-stage breast cancer (Pierce et al., 2007). The intervention group achieved and maintained a statistically significant increased consumption of vegetables, fruits, and fiber and decreased total fat; however, adoption of this diet did not reduce breast cancer recurrence or mortality (Pierce et al., 2007). The findings conflict with results from the prospective, randomized Women’s Intervention Nutrition Study, which demonstrated that a low-fat diet decreased breast cancer recurrence by 24% at five years in postmenopausal women with early-stage breast cancer (Blackburn & Wang, 2007; Chlebowski et al., 2006).
Vitamin and mineral supplements have been advocated for cancer prevention, including beta-carotene, vitamins C, E, and A, selenium, and calcium. These supplements have antioxidant properties, which theoretically protect cells from free-radical damage and possibly slow or prevent the development of cancer. To date, vitamin and dietary supplements have not statistically demonstrated the prevention of cancer (World Cancer Research Fund & American Institute for Cancer Research, 2007).

**Weight**

Obesity and weight are increasingly recognized as important cancer risk factors. Obesity and increased body mass index (BMI) are convincingly linked to postmenopausal breast cancer and cancers of the esophagus, pancreas, colorectum, endometrium, and kidney (World Cancer Research Fund & American Institute for Cancer Research, 2007). In the United States, obesity contributes to an estimated 14%–20% of all cancer-related mortality (Calle, Rodriguez, Walker-Thurmond, & Thun, 2003). The current increase in the prevalence of obesity poses a severe challenge to cancer prevention efforts. A recent report from the Nurses’ Health Study suggests that weight gain, specifically after menopause, increases the risk of breast cancer, and importantly, that weight loss after menopause reduces breast cancer risk (Eliassen, Colditz, Rosner, Willett, & Hankinson, 2006). Obesity has also been associated with a significant increase in the risk of colorectal cancer (Terry, Miller, & Rohan, 2002); elevated BMI and obesity have been associated with increased risk of endometrial cancer (Bergström, Pisani, Tenet, Wolk, & Adami, 2001).

The link between obesity and cancer recurrence or a second primary is less well understood. Retrospective analyses of several trials of adjuvant chemotherapy have suggested that substantial weight gain after a diagnosis of breast cancer is an adverse prognostic factor with respect to recurrence and survival (Camoriano et al., 1990). Another study demonstrated that obese women had a 50% increased risk for a second, contralateral breast cancer (Li, Daling, Porter, Tang, & Malone, 2009). A study of adiposity and weight change in relation to prostate cancer incidence and mortality found that while BMI was not correlated with prostate cancer incidence, higher BMI and adult weight gain increased morbidity from prostate cancer (Wright et al., 2007).

**Alcohol**

Excessive alcohol increases the risk of developing cancers of the breast, oral cavity and pharynx, larynx, esophagus, colorectum, and liver (World Cancer Research Fund & American Institute for Cancer Research, 2007). The relative risk increases with the amount of alcohol consumed. For some cancers, the risks associated with concomitant excessive alcohol consumption and tobacco
use are much higher than for either exposure alone. Alcohol consumption combined with tobacco use accounts for approximately 75%–85% of cancers of the oral cavity, pharynx, larynx, and esophagus (Schottenfeld, 1999).

**Tobacco**

Tobacco use is strongly linked to an increased risk for numerous cancers (U.S. Department of Health and Human Services, 2004). Cigarette smoking contributes to cancers of the lung, oral cavity and pharynx, larynx, esophagus, bladder, kidney, pancreas, stomach, uterine cervix, and colorectum, and acute myeloid leukemia (U.S. Department of Health and Human Services, 2004). The relative attributable risk for morbidity from smoking is greater than 90% for lung cancer, 85% for cancers of the head and neck, and 60%–70% for other smoking-related cancers (Shopland, 1995). Oral cavity cancers have been linked to both smoking and smokeless tobacco use. Patients with primary cancers of sites related to tobacco use have an increased risk of developing subsequent cancers at tobacco-related sites. The risks of subsequent cancers of the lung and oral cavity are especially high among lung cancer survivors who continue to smoke cigarettes. Substantial evidence has shown that continued smoking may reduce the effectiveness of treatment, worsen the side effects of treatment, and increase the likelihood of a second primary cancer (Browman et al., 2002).

**SUMMARY**

Cancer survivors represent a heterogeneous population with varying degrees of risk for recurrence and development of second cancers. A variety of nonmodifiable and modifiable factors contribute to the risk of cancer recurrence and second cancers, including genetic predisposition, advancing age, physical activity, diet, weight, alcohol consumption, and tobacco use. Lifestyle modifications can have a positive impact on quality of life and potentially reduce the risks for cancer recurrence or the development of second cancers. The oncology and primary care healthcare teams must work together with cancer survivors to monitor nonmodifiable risks and improve modifiable behaviors. Cancer survivors should be counseled to modify those lifestyle habits that may positively affect their survival.

**REFERENCES**


INTRODUCTION

Convincing evidence is emerging that diet, exercise, and weight management can significantly influence the risk of first cancers and recurrence of cancer (Jones & Demark-Wahnefried, 2006). Health promotion efforts that address a healthy diet, regular exercise, maintenance of a healthy weight, and reduction in stress are important lifestyle approaches for cancer survivorship (Flynn & Reinert, 2010; Holmes, Chen, Feskanich, Kroenke, & Colditz, 2005; Jones & Demark-Wahnefried, 2006; Smith et al., 2009).

Excess weight and obesity have been implicated in increasing cancer recurrence rates and in the development of second tumors (Calle, Rodriguez, Walker-Thurmond, & Thun, 2003; Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005). A body of evidence has identified the link between stress and immune function (Judd & Sternberg, 2009; Sternberg, 2001), and other studies have identified potential mechanisms of action and tumor biology as they relate to stress (Antoni et al., 2006). Health promotion efforts focused on healthy diet and adequate physical activity have been associated with lower levels of fatigue, increased social support, better physical functioning, and improved health-related quality of life (Alfano et al., 2009; Demark-Wahnefried et al., 2005; Jones & Demark-Wahnefried, 2006; McNeely et al., 2006).

A healthy diet, physical activity, healthy body weight, and stress management compose the requisite domains for a model of integrative health and ideally
should be considered as interrelated and interdependent goals for optimal health. This chapter will focus primarily on nutrition and chemoprevention as specific domains within a broader model of integrative health promotion and will include an application of the model in practice, the LIVESTRONG™ Week at Canyon Ranch.

CANCER PREVENTION AND SURVIVORSHIP

On July 23, 2008, four former U.S. surgeons general stood with two non-profit organizations, the Lance Armstrong Foundation and the Canyon Ranch Institute, as well as numerous other government, private, and nonprofit collaborators, to issue the National Call to Action on Cancer Prevention and Survivorship, or the NCTA (Cabe & Springer, 2008). The collaborators of this initiative joined forces because of the human and economic burden of cancer. As a public health crisis, cancer exacts a toll on the U.S. economy in excess of $305 billion a year (Economist Intelligence Unit, 2009). More than 1.4 million Americans will be diagnosed with cancer each year, and at least half of those new cases can be prevented or detected earlier, when they are most treatable.

Using expertise and access to the best available science, innovations, and best practices in disease prevention and health promotion, the former U.S. surgeons general Richard H. Carmona, David Satcher, Joycelyn Elders, and Antonia Novello collaborated with experts in the cancer prevention and survivorship community to develop the NCTA. The NCTA document has since served as a roadmap for all Americans, including cancer survivors, healthcare professionals, policy makers, employers, educators, insurers, and scientists, to identify the best strategies for cancer prevention and survivorship. Table 26-1 outlines the four primary goals and subsequent strategies for action in the NCTA. This groundbreaking report emphasized empowering survivors to understand and adopt healthy lifestyles to prevent cancer and cancer recurrence. Their recommendations specifically addressed strategies for (a) nutrition for cancer prevention and survivorship, (b) appropriate health education that meets cultural and literacy competencies for consumers to understand healthy eating choices, and (c) improved access to and affordability of healthy food choices (Cabe & Springer, 2008).

The Role of Nutrition in Optimal Health

In the landmark report by Doll and Peto (1981), the authors estimated that 35% of cancers can be attributed to diet and nutrition. More recent studies have indicated that obesity or being overweight contributes to an increased risk of cancer and significantly increase the risk for cancer recurrence (Calle et al., 2003). Increased consumption of refined carbohydrates, such as fast foods and processed foods, contributes to the obesity epidemic and suggests that modern ways of processing grains have dramatically lowered the nutritional quality of
<table>
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<th>Goal</th>
<th>Strategies for Action</th>
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| **Empower healthy lifestyles to prevent cancer.**                    | • Provide resources to support innovative public and private partnerships in all settings to develop, implement, and evaluate community-based public health campaigns and media outreach to promote tobacco prevention and cessation, healthy eating, and physical activity.  
• Ensure that health benefit programs include coverage for evidence-based tobacco prevention and cessation services, nutrition counseling, and physical activity promotion.  
• Improve access to and affordability of evidence-based tobacco prevention and cessation programs, healthy foods and beverages, and safe areas for physical activity.  
• Enact and enforce policies to ensure that healthy food choices are provided in all settings and that physical activity options are available in all settings. |
| **Apply what we know about cancer screening and early detection to all people.** | • Improve health literacy about cancer screening and early detection by providing culturally competent information, health messages, and screening services.  
• Ensure that all people receive all recommended cancer screenings.  
• Ensure that cancer survivors are provided screening guidelines and are screened for recurrence of the primary cancer and development of new cancers.  
• Focus research strategies on advancing existing screening and early detection technologies to improve sensitivity and availability and to reduce costs. |
| **Ensure that all people can navigate through the healthcare system.**| • Develop and evaluate innovative, culturally competent patient navigation tools and programs that address barriers for cancer survivors, caregivers, families, friends, and people at high risk for cancer.                                                                                                                                                                                                                     |
| **Provide survivorship care plans and systems of support for all cancer survivors.** | • Ensure that cancer survivors are given a treatment summary that includes all care received, important disease characteristics, and a survivorship care plan focused on patient-centered, evidence-based standards of follow-up care.  
• Engage cancer survivors and caregivers as active participants in their survivorship care plans.  
• Ensure that survivors and their caregivers, families, and friends are empowered to access available resources.  
• Educate healthcare professionals and cancer survivors about the long-term care needs of cancer survivors, including pain management and palliative care, and the value of survivorship care plans.  
• Establish policies to balance appropriate regulatory barriers related to palliative care with the needs of cancer survivors and caregivers to ensure pain management. |

*Note.* Based on information from Cabe & Springer, 2008.
these otherwise healthy foods (Hu, 2010). Some studies have indicated that a “Western dietary pattern,” characterized by regular consumption of processed foods, increased intake of refined flours and sugars, and low consumption of fruits, vegetables, and fiber, may be associated with higher risk of recurrence and mortality among patients with colon cancer (Meyerhardt et al., 2007).

A plant-based diet is emphasized for cancer survivors including foods such as whole grains, vegetables, fruits, nuts, beans, and seeds. Highly processed foods such as soft drinks, candies, syrups, and presweetened cereals, as well as processed and red meats, especially those that are cooked at high temperatures or charred, are not favored for cancer survivors (Kushi et al., 2006).

The relationship between dietary fat and cancer continues to be a controversial topic. However, evidence is accumulating that the quality of dietary fat may be more important than the quantity of dietary fat. For example, good quality dietary fat includes sources of omega-3 fatty acids found in salmon, sardines, mackerel, herring, walnuts, and flax seeds. Other healthy sources of dietary fat include monounsaturated oils found in extra virgin olive oil and in a variety of nuts and seeds. However, store-bought, processed foods are abundant in fats such as partially hydrogenated vegetable oils (including partially hydrogenated soybean oil), which have been associated with elevated concentrations of inflammatory biomarkers (i.e., C-reactive protein) and inflammatory cytokines (i.e., interleukin-6 and tumor necrosis factor-alpha) (Esmailzadeh & Azadbakht, 2008; Teng, Voon, Cheng, & Nesaretnam, 2010). Numerous studies have illuminated the relationship between inflammation and cancer, noting that the origin of cancer is often inflammatory in nature (Balkwill & Mantovani, 2001; Coussens & Werb, 2002). In contrast, epidemiologic studies have consistently indicated that a plant-based diet abundant in fruits, vegetables, and whole grains is most effective for cancer prevention (Liu, 2004; Willett, 2000).

**Nutrition and Chemoprevention for Cancer Survivorship**

Nutrition is one of the cornerstones of cancer survivorship and continues to play an important role in the prevention of primary cancer recurrence and second cancers. Although a plant-based, unprocessed whole-foods diet is the optimal dietary pattern for cancer prevention and survivorship (American Cancer Society, 2010; American Institute for Cancer Research, 2010; Kushi et al., 2006), few survivors consume adequate amounts of many of these recommended foods (Demark-Wahnefried et al., 2005).

Cancer chemoprevention is a term that was coined in the late 1970s by Michael Sporn (Mehta, Murillo, Naithani, & Peng, 2010; Sporn, Dunlop, Newton, & Smith, 1976) and is a key concept for prevention of cancer recurrence and primary prevention of second tumors. Chem refers to natural or synthetic chemical agents in foods or pharmaceutical products. When combined with prevention, the term chemoprevention refers to measures that seek to prevent, inhibit, or reverse carcinogenesis by identifying and intervening with synthetic or naturally occur-
ring entities found in the diet or environment (Theisen, 2001). Tamoxifen is an example of a synthetic/pharmaceutical chemopreventive agent. However, naturally occurring, plant-based chemopreventive agents are ubiquitous in nature and abundant in the human diet. For example, certain foodstuffs such as berries, tomatoes, broccoli, cabbage, citrus fruits, soy, and olives are just some of the chemopreventive agents found in nature that supply the body with bioactive compounds that can prevent, inhibit, or reverse the cancer process. These foods contain bioactive compounds known as *phytochemicals* (*phyto* is derived from the Greek word meaning “plant”). Phytochemicals are defined as “bioactive non-nutritive compounds in fruits, vegetables, grains, and other plant foods that have been linked to reducing chronic diseases” (Liu, 2004, p. 3479S). A product of secondary metabolism in plants, phytochemicals are used to defend plants against predators and microbial infection, and provide color and flavor to the plant (Stoner, Wang, & Casto, 2008).

More than 5,000 phytochemicals have been identified. Two of the most studied classes of phytochemicals include the phenolics and carotenoids (Liu, 2004). A number of bioactive compounds such as lycopene, sulforaphane, monoterpenes, epigallocatechin gallate, and indoles are included within these two categories and are highly concentrated in a number of different “chemopreventive” foodstuffs, including green and black tea, dark chocolate, spices, and fresh herbs. Each of these compounds provides a physiologic function in the human body. For example, cruciferous vegetables are a rich source of isothiocyanates, bioactive compounds known to interfere with the metabolism of nitrosamines. Cruciferous vegetables include broccoli, brussels sprouts, cauliflower, and cabbage.

In addition to their physiologic function, phytochemicals also provide the colorful pigments seen in a variety of fruits, vegetables, and whole grains. Because each pigment produces a specific response in the body, it is important to counsel cancer survivors to eat a “rainbow” of colors found in deep, rich-colored fruits and vegetables. It is the synergy among an array of phytochemicals that produces the chemopreventive effect (Liu, 2004; Mehta et al., 2010) and further emphasizes the importance of recommending a wide variety of foods instead of isolated compounds, nutrients, or single food items that can lead to toxicities at intakes or doses. Berries provide an abundance of nutritive and non-nutritive compounds that can affect tumor initiation and progression (Stoner, 2009). Black raspberries in particular are excellent sources of vitamins A, C, and E, magnesium, zinc, calcium, and fiber. They also contain high concentrations of ellagic acid and anthocyanins. Working together, each of these compounds has a specific role in the cancer process and can affect all stages of the carcinogenesis process, from initiation to promotion to progression (Mehta et al., 2010). Studies indicate that black raspberries modulate a number of biomarkers through various mechanisms of action, including protection against oxidative DNA damage by the scavenging of reactive oxygen species, enhancement of DNA repair, modulation of signaling pathways involved with cellular proliferation, apoptosis, inflammation,
angiogenesis, and cell cycle arrest (Mehta et al., 2010; Stoner et al., 2008). Although specific recommendations for berry consumption do not currently exist, recommending 1–2 servings out of the 5–10 recommended servings of fruits and vegetables per day is a modest recommendation for cancer survivors.

**Dietary Supplements**

A whole-foods approach is favored over supplement use when possible. A systematic literature review conducted by the World Cancer Research Fund and American Institute for Cancer Research (2007) analyzed 39 randomized controlled clinical trials that investigated dietary supplement use and concluded that micronutrient supplement use (e.g., vitamin C, vitamin B₆, vitamin E, selenium) is not beneficial for cancer survivors. Of warning, high-dose supplements and other isolated plant-based chemicals (beta-carotene, isoflavones) can be harmful, if not toxic, at high levels (American Institute for Cancer Research, 2010). Renewed interest exists in the awareness and importance of whole foods rather than purified compounds (Mehta et al., 2010). Even if it were feasible to identify and measure all of these compounds in a particular food, the information would be difficult to use because antioxidant compounds work in combination, and the synergistic effects are hard to predict. This further emphasizes the benefits of eating whole foods and their essential role in health promotion and disease prevention.

**A Person-Centered Approach to Nutrition and Health Promotion**

A multidisciplinary approach to health promotion for survivors, the Integrative Health Promotion Model, was developed by the author and Michael J. Miller, MD, of The Ohio State University Medical Center (see Figure 26-1) and represents a multimodal and person-centered approach to cancer survivorship. Through an integrative approach to care, the multidisciplinary healthcare team works together to treat and care for the whole patient. The intersection and interface among physical, mental, spiritual, and emotional health is visually presented in Figure 26-1. The overlap of these four domains creates the optimal approach to survivorship care planning and ongoing care of cancer survivors. This approach considers all of the factors that can potentially influence the risk of cancer recurrence or second tumors and the essential components in the treatment and care of patients.

Although the discussion of this chapter has focused specifically on nutrition and chemoprevention, it is important to remember that health promotion for cancer survivors is dependent on looking at the whole person. One of the basic tenets of integrative health relies on understanding that the relationship between healthcare professionals and patients is a major contributor to health outcomes (Maizes, Rakel, & Niemiec, 2009). By creating a synergy among health disciplines, the Integrative Health Promotion Model supports and empowers cancer survivors in making healthy lifestyle choices.
As depicted in Figure 26-1, alongside the four key domains of optimal health are nutrition, physical activity, healthy weight, and stress reduction. This model emphasizes the need to create synergy among the health messages provided by nurses; physicians; registered dietitians; exercise specialists; counselors; behavioral, occupational, and rehabilitation therapists; and other health professionals. Through the collaborative communication and reinforcement of health messages, the goal is to create an ideal scenario to prevent cancer recurrence and second tumors. The model further emphasizes the important role that healthcare professionals play in cancer survivors’ outcomes: helping them to manage the complex balance that exists among all aspects of their physical, mental, emotional, and spiritual health.

**CASE STUDY**

An example of the application of the Integrative Health Promotion Model in practice is the Canyon Ranch Institute (CRI) LIVESTRONG Week, a collaborative effort between CRI and the Lance Armstrong Foundation. The week consisted of a fellowship program that provided an educational and experiential program for cancer survivors and their friends and families.
to learn about and experience an integrative approach to optimizing their health for cancer prevention and survivorship. Activities included hands-on cooking classes, guided physical activity sessions, and relaxation techniques for stress management. Linda, a breast cancer survivor who was one of the CRI LIVESTRONG fellows, described her experience as transformative:

The LIVESTRONG Week at Canyon Ranch helped me in a variety of ways to make positive lifestyle changes. The integrative approach addressed many ways to care for oneself, and hopefully, prevent a recurrence. I had an opportunity to meet with experts in various fields including nutrition, exercise, meditation, and yoga. The nutritional changes I have integrated into my daily schedule include eating more fruits and vegetables, especially berries, taking fish oil and calcium citrate with vitamin D daily, limiting alcohol consumption, and eating primarily olive oil and avocados for fat intake. Exercise was an area that I really struggled with. I learned to find exercise activities that I enjoy and could integrate easily into my schedule. I also learned that even relatively small amounts of exercise make a big difference. In the past, I had felt that I wasn’t doing enough so I just gave it up. It was very much an all-or-nothing approach that clearly did not work for me. I now enjoy regular walks, neuromuscular integrative action dance, yoga, and lifting free weights. I was reintroduced to meditation and have incorporated various forms of meditation into my schedule along with journal writing. I have found that meditation, journal writing, and prayer have made a big difference in managing stress and anxiety in my life. I feel grateful to have had the opportunity to learn more about integrative approaches to cancer prevention and recurrence and make them a part of my life.

In addition to the guided activity sessions, each CRI LIVESTRONG fellow received a one-on-one consultation with a multidisciplinary team of healthcare professionals including a physician, nurse, nutritionist, exercise physiologist, and behavioral therapist. It was through this integrative approach to care that the participants experienced a “whole-person” approach to care and integrative health. As outlined in the Integrative Health Promotion Model, the physical, mental, spiritual, and emotional domains of health were addressed through one-on-one and group sessions focused on the interplay among healthy nutrition, regular physical activity, effective stress management, and positive behavior change.

**SUMMARY**

As the five-year survival rates of cancer continue to climb, health promotion efforts play an increasingly important role in survivorship and quality of life. Although cancer survivors are motivated to make positive changes in diet
and exercise after their cancer diagnosis (Alfano et al., 2009), a number of psychosocial factors and physical conditions may create barriers to making these changes (Jones & Demark-Wahnefried, 2006). Cancer survivors require assistance in addressing these barriers in order to take responsibility for their care. According to the World Cancer Research Fund and American Institute for Cancer Research (2007) report, “the best way to improve quality of life and increase the chances of prolonged life and recovery from cancer is when cancer survivors take responsibility for themselves, supported by associates, friends, and family, while always also consulting their professional advisors and making the best use of available medical care systems and qualified social support” (p. 342).

Adopting an integrative health approach to cancer survivorship provides a multidisciplinary approach to caring for the whole person throughout survivorship. It also opens the door to successful survivorship care planning. Through this patient-centered approach to reducing risk of recurrence and second tumors, the healthcare team aims to reinforce their encouragement of cancer survivors to adopt healthy lifestyle changes in the areas of nutrition, physical activity, weight management, and stress reduction.

The author would like to acknowledge Michael J. Miller, MD, professor of surgery, chair, Department of Plastic Surgery, The Ohio State University Medical Center, for his contribution in the development of the Integrative Health Promotion Model.

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CHAPTER 27

Motivation for Lifestyle Changes After Cancer

Bernardine M. Pinto, PhD, and Joseph T. Ciccolo, PhD

INTRODUCTION

With the increasing longevity and number of cancer survivors, there is a need to understand and manage their increased risk for other chronic conditions, such as cardiovascular diseases, diabetes, osteoporosis, and cancer recurrence. Modifying risk behaviors such as smoking, unhealthy diets, and sedentary lifestyles among survivors is gaining attention (Pinto, Eakin, & Maruyama, 2000). This chapter will focus on how cancer survivors have been motivated to make health behavior changes in intervention trials that explicitly identified and described the underlying theory or theories (see Figure 27-1) aimed at enhancing motivation for reducing risk behaviors. Participants in these studies were adults of either sex, diagnosed with any type or stage of cancer, in current treatment or finished with treatment. For modifying sedentary behavior, rehabilitation or physical therapies were excluded, as were relaxation exercises such as yoga or Tai Chi. For dietary change, studies that offered only dietary supplements were excluded.

Figure 27-1. Theories of Behavior Change Used to Promote Exercise, Diet Change, or Smoking Cessation After a Cancer Diagnosis

- Cognitive-behavioral theory
- Theory of planned behavior
- Transtheoretical model of health behavior change
- Social cognitive theory
- Motivational interviewing

*Note. Based on information from Ajzen, 1991; Bandura, 1986; Beck, 1993; Miller & Rollnick, 2002; Prochaska & DiClemente, 1983.*
EXERCISE ADOPTION

Several theories of behavior change are used to promote exercise and physical activity after a cancer diagnosis. Cognitive-behavioral therapy (CBT) is a collaborative approach between the practitioner and the patient in which the focus is on modifying cognitions, assumptions, beliefs, and behaviors to improve emotional well-being and functioning (Beck, 1993). CBT techniques include education, goal setting, self-monitoring, analysis of behavioral antecedents, building coping skills, and social skills training, and all generally involve practice outside of the therapy setting.

Several randomized controlled trials have used CBT techniques to improve the quality of life and physical functioning and increase exercise participation in survivors of prostate, breast, and other cancers. Some of these studies demonstrated increases in exercise (Culos-Reed et al., 2009; Daley et al., 2007) and fitness (Rogers et al., 2009). However, one study that examined the additional benefit of adding CBT to group exercise did not find additional benefits in fitness and exercise at postintervention or at follow-ups (May et al., 2008).

The theory of planned behavior (TPB) is another approach that has been examined in cross-sectional studies among various cancer populations, which posits that behavior is directly predicted by intention, which in turn is directly predicted by attitude, subjective norm, and perceived control (Ajzen, 1991). Hence, individuals will intend, and be motivated, to perform a behavior when they view it favorably, believe that important others think they should perform it, and believe that the behavior is under their control and can be carried out.

TPB has been applied in a few intervention studies (Jones, Courneya, Fairey, & Mackey, 2004; Vallance, Courneya, Plotnikoff, Yasui, & Mackey, 2007). In a randomized controlled trial among breast cancer survivors, breast cancer–specific exercise print materials on promoting changes in belief and implementing intentions to become physically active were found to significantly increase exercise at 12 weeks (approximately 40–60 minutes/week) (Vallance et al., 2007).

The transtheoretical model (TTM) of health behavior change (Prochaska & DiClemente, 1983) has also been used to promote exercise adoption among cancer survivors. TTM postulates that individuals move through a series of six stages of motivational readiness while making a behavior change (i.e., precontemplation, contemplation, preparation, action, maintenance, and termination). While progressing through these stages, the individual engages in 10 different cognitive and behavioral processes of change (e.g., self-reevaluation, contingency management) that are important in the adoption and maintenance of a new behavior. Other constructs used in interventions along with stages of motivational readiness include decisional balance (e.g., considering the pros and cons of initiating the behavior) and self-efficacy.

Constructs from the TTM were used in several trials targeting sedentary behavior among patients treated for breast cancer (Basen-Engquist et al., 2006; Mutrie et al., 2007; Pinto, Frierson, Rabin, Trunzo, & Marcus, 2005) and prostate cancer (Taylor et al., 2006). At least two of these trials were effective
in increasing exercise in the intervention group (Mutrie et al., 2007; Pinto et al., 2005). TTM variables have also been used with TPB to promote self-efficacy for exercise and overcome barriers to exercise as seen in a six-month home-based intervention (IMPACT study) for patients with newly diagnosed breast cancer (Cadmus et al., 2009).

Another theory used to promote exercise among cancer survivors is social cognitive theory (SCT). According to SCT, behavior change is influenced by a number of interacting psychosocial, environmental, and behavioral factors (Bandura, 1986). Interventions based on SCT focus on the importance of individuals’ ability to control their behavior and how changes in the individual or the environment can produce changes in behavior. Success in being able to initiate and maintain the behavior change is determined by an individual’s ability to regulate his or her own behavior through personal strategies (e.g., applying realistic expectations for change, setting goals, monitoring progress toward goals), as well as environmental approaches (e.g., using social support or environmental prompts).

Several interventions have used SCT either alone or with TTM to guide their interventions targeting sedentary behavior among patients treated for breast cancer (Basen-Engquist et al., 2006; Matthews et al., 2007; Pinto et al., 2005), prostate cancer (Taylor et al., 2006), and colorectal cancer (Pinto, Goldstein, & Papandonatos, 2009). SCT-based interventions often focus on the construct of self-efficacy. Self-efficacy can be enhanced by encouraging participants to set realistic, easily attainable goals, particularly at the outset of the intervention (Pinto et al., 2009), choosing specific physical activities as opposed to prescribed exercise (Basen-Engquist et al., 2006), and focusing on participants’ progress and reinforcing successes (Pinto et al., 2009). Efforts to strengthen outcome expectations and techniques such as decisional balance, social modeling, self-regulation strategies, and building social support for exercise are other features of SCT-based interventions (Matthews et al., 2007; Taylor et al., 2006).

More recently, motivational interviewing (MI) (Miller & Rollnick, 2002), an individually administered, client-centered approach to bring about behavior change, has been used to reduce sedentary behavior among cancer survivors. MI seeks to reduce resistance to change by developing a discrepancy between individuals’ current behavior and their values and goals. Four general principles underlie this approach: (a) express empathy, (b) develop discrepancy, (c) roll with resistance, and (d) support self-efficacy. Two studies using this approach among cancer survivors supported the use of MI (Bennett, Lyons, Winters-Stone, Nail, & Scherer, 2007; Pinto et al., 2009).

**DIETARY CHANGE**

Improving dietary intake alone (e.g., increasing fruit and vegetable consumption, increasing fiber intake through food choices) among cancer
survivors has been tested in two large multisite randomized controlled trials: the Women’s Intervention Nutrition Study (WINS) and the Women’s Healthy Eating and Living Study (WHELS). WINS was a multicenter trial investigating the effects of reducing dietary fat intake with adjuvant systemic therapy on cancer recurrence rates in 2,437 postmenopausal women with early-stage, surgically treated breast cancer (Chlebowski et al., 2006). The intervention was based on SCT and included self-monitoring, goal setting, modeling, social support, and relapse prevention. At 60-month follow-up, the intervention group reported significant reductions in dietary fat intake ($p < 0.001$) and mean body weight ($p = 0.005$) compared to the control group. Cancer relapse rates were lower in the intervention group ($p = 0.07$). The primary aim of WHELS was to examine the effects of a high-vegetable, low-fat diet in reducing breast cancer recurrence and mortality among 3,088 pre- and postmenopausal women treated for early-stage breast cancer (Pierce et al., 2007). Participants were randomly assigned to an intensive diet intervention group in which they received telephone counseling based on SCT, decision making, and MI; cooking classes; and newsletters, or to a comparison group in which they received print materials on dietary guidelines. Although the intervention group achieved and maintained significant increases in servings of vegetables, fruit, and fiber intake, and reduction in energy intake from fat, no advantages were seen in terms of reduction of breast cancer events or mortality during the 7.3-year follow-up.

Prior to WINS and WHELS, other researchers have undertaken efforts to promote dietary change among smaller samples of patients with breast cancer. The interventions were based on CBT, social learning and self-control theory (Kristal, Shattuck, Bowen, Sponzo, & Nixon, 1997), and SCT and patient-centered counseling (Hebert et al., 2001). These interventions were effective in reducing fat consumption and achieving weight loss.

**MULTIPLE BEHAVIORS: EXERCISE WITH DIETARY CHANGE**

Dietary change and exercise adoption have been promoted among breast and prostate (Demark-Wahnefried et al., 2006, 2007; Morey et al., 2009) and colorectal cancer survivors (Campbell et al., 2009; Morey et al., 2009). The interventions were based on TTM and SCT using tailored, mailed, print materials (Demark-Wahnefried et al., 2007), and print materials and telephone counseling (Morey et al., 2009). In the most recent work, the RENEW trial (Morey et al., 2009), researchers used SCT in telephone counseling (to overcome barriers, set incremental behavioral goals, monitor progress, and reinforce goal achievement), while TTM was used for the tailored progress reports provided to the intervention group. The intervention group showed significant improvements in self-reported physical functioning, intake of fruits and vegetables, physical activity, and several aspects of quality of life (Morey et al., 2009).
Similarly, TTM, SCT, and principles of MI were the bases of a trial that targeted fruit and vegetable consumption and physical activity in a sample of older adults including colorectal cancer survivors and those without colorectal cancer (Campbell et al., 2009). The researchers examined the effects of tailored print communication and telephone-based MI either alone or in combination over 12 months. The interventions aimed to enhance self-efficacy and motivation. Intervention effects were found in a significant increase in fruit and vegetable intake in the combined intervention group. However, these changes were not reported among the cancer survivors. Finally, none of the interventions increased physical activity participation.

It is important to mention that very few randomized controlled trials have been conducted targeting both dietary behavior and exercise to promote weight loss among overweight or obese survivors (Djuric et al., 2002; Mefferd, Nichols, Pakiz, & Rock, 2007; von Gruenigen et al., 2008). Two of the studies used SCT constructs for the counseling components (Djuric et al., 2002; von Gruenigen et al., 2008), and the third used CBT in the intervention (Mefferd et al., 2007). Results have been promising, with greater weight loss in the intervention groups. However, these studies have been conducted among relatively small samples of overweight or obese breast cancer survivors (Djuric et al., 2002; Mefferd et al., 2007) and endometrial cancer survivors (von Gruenigen et al., 2008). One may expect increasing interest in developing appropriate weight loss interventions, particularly for subgroups of cancer survivors for whom obesity increases the risk of future cancers.

SMOKING CESSATION

Smoking is well known to be associated with numerous cancers. Unfortunately, approximately one-third of smokers who develop cancer continue to smoke after diagnosis (McBride & Ostroff, 2003). Thus far, more smoking cessation studies have been conducted with adult cancer survivors than with adult survivors of childhood cancer. Because adult survivors of childhood cancer are more likely to have severe or life-threatening illnesses (Mulrooney et al., 2008), and 17%–20% of this population smokes cigarettes (Bellizzi, Rowland, Jeffery, & McNeel, 2005; Emmons et al., 2009), smoking cessation is a key issue.

In one of the larger studies focused on smoking behavior among young adult survivors of childhood cancer, 796 participants were randomly assigned to either a self-help or a peer-counseling program that included up to six MI-based telephone calls from a trained childhood cancer survivor, printed tailored and targeted mailed materials, and free nicotine replacement therapy (Emmons et al., 2005). Quit rates were significantly higher in the peer-counseling group compared with the self-help group at 8 months (16.8% versus 8.5%) and 12 months (15% versus 9%). In addition, long-term (24–48-month) quit rates were higher among the peer-counseling versus the self-help participants (Emmons et al., 2009).
Approximately 20 years ago, Gritz (1991) was among the first to characterize the critical need to develop systematic smoking cessation programs for adult patients with cancer, and expressed the importance of integrating such programs into primary care. Unfortunately, recent data indicate a wealth of missed opportunities for clinicians to provide patients with smoking cessation advice (Coups, Dhingra, Heckman, & Manne, 2009). To date, fewer than 10 studies have investigated the use of a smoking cessation intervention for adult cancer survivors, with only a few of these using a theoretical background to guide the research (Griebel, Wewers, & Baker, 1998).

Most recently, Duffy et al. (2006) developed and tested a tailored smoking, alcohol, and depression intervention for patients with head and neck cancer. Participants were randomized to usual care or a nurse-administered intervention consisting of CBT, telephone counseling, and pharmacotherapy. The authors found significant differences between the intervention and usual care groups at six months in self-reported quit data (47% in the intervention versus 31% in usual care). They also noted improvements in depression and alcohol consumption rates although no differences were seen between the groups. The limitation of this study is its use of self-report.

Much needs to be done to further our understanding of how to develop and implement effective smoking cessation programs. As outlined by de Moor, Elder, and Emmons (2008), any future smoking cessation program for cancer survivors should include seven distinct characteristics:
1. Attention to health risk behaviors that may influence smoking status and smoking cessation
2. Intervention content designed around a theoretical framework
3. Intervention content tailored to survivors’ stage of readiness to quit smoking
4. Use of peers to deliver intervention content
5. Regular reinforcement of the importance of smoking cessation
6. Use of a combination of nicotine replacement therapy or other pharmacotherapy and behavioral strategies for smoking cessation
7. High-intensity delivery over multiple sessions.

**SUMMARY**

Motivating patients with cancer to make lifestyle changes has received increasing attention over the past decade. Considerable interest exists in promoting exercise and dietary change among specific subgroups of cancer survivors (more commonly, patients with breast and prostate cancer) and smoking cessation (particularly among those treated for cancers of the respiratory system and head and neck cancers). Many of these studies have shown promising results. However, less has been done to promote healthy behaviors among survivors of other types of cancers. Healthcare providers have not played a major role in the interventions reviewed, and much opportunity ex-
ists for expanding their contributions (e.g., smoking cessation advice) given the frequency and length of medical follow-up after cancer treatment. As the population of cancer survivors continues to grow, and there is a greater understanding of the risks for cancer recurrence and other chronic diseases in this population, one might expect to see further examination and understanding of how to motivate these survivors to optimize their well-being and health.

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CHAPTER 28

Promoting Inner Strength

Gayle Roux, PhD, RN, NP-C, and Catherine Dingley, PhD, RN, FNP

INTRODUCTION

The increase in cancer survival rates challenges healthcare professionals to expand their knowledge base of human responses to chronic, yet potentially fatal, conditions. One means of understanding the experiences of individuals as they live with a chronic condition involves the use of an interpretive framework that can assist healthcare professionals to identify client needs and improve health outcomes. The middle-range theory of inner strength in women (TIS-W) (Dingley, Bush, & Roux, 2001; Dingley, Roux, & Bush, 2000; Roux, Dingley, & Bush, 2002) provides such a framework for understanding the experiences faced by women with a challenging life situation or chronic health condition such as cancer. This chapter will review the current research in the application of the TIS-W in cancer survivorship. Theoretically based assessments and interventions also will be discussed.

A primary goal of the current research in cancer survivorship is to provide cancer survivors with the best chance for a long and healthy life by identifying potential adverse effects and developing effective prevention or intervention strategies (Vaughn & Meadows, 2002). An area of focus for research includes an emphasis on health and optimized quality of life (QOL) during and beyond acute diagnosis and treatment (Dow, 2003), clearly indicating a paradigm shift toward a chronic illness model. The TIS-W suggests that enhanced QOL and self-management are outcomes of inner strength. Results of quantitative testing on the relationships between these concepts are described in this chapter and suggested as a foundation for theoretically based assessments and interventions. Demographic and health status variables related to inner strength in women cancer survivors also are discussed.

Although a diagnosis of a chronic condition such as cancer is distressing on many levels, some women report positive changes in QOL issues after cancer, such as improved personal resources and skills, an enhanced sense of purpose, being different than before, increased spirituality, reevaluation of and closer relationships with family and friends, harmony with nature, and
changes in life priorities (Moch, 1990; Roux, Bush, & Dingley, 2001; Roux & Keyser, 1994). In a commission report sponsored by the Institute of Medicine (2006), the authors described the development of survivorship care plans as a strategy for planning ongoing care for cancer survivors throughout their trajectory, with assessment of psychosocial distress as a specific area of focus. Findings from these and other studies suggest that enhanced adjustment to chronic conditions can influence both physiologic and psychological health parameters throughout the continuum of care and survivorship.

THEORY OF INNER STRENGTH IN WOMEN

Over the past 14 years, the TIS-W has been developed and researched as a gender-sensitive theory in populations of women with chronic health conditions such as breast cancer, heart disease, and multiple sclerosis, and those who have undergone transplantation. Theory generation included the development of the concept of inner strength from literature sources (Dingley et al., 2000; Roux et al., 2002) and the inductive generation of the theory based on five qualitative studies and three quantitative instrument development studies conducted by the author and colleagues. A synopsis of the research illustrates the construction of the TIS-W.

Based on study findings, a definition of inner strength was devised: inner strength is having capacity to build the self through a developmental process that positively moves the individual through challenging life events such as living with cancer or other chronic conditions (Dingley & Roux, 2009; Lewis & Roux, 2009; Roux et al., 2002). As a universal concept, enhancement of inner strength provides a potential benefit to both men and women. However, the authors’ current theory development has focused on the gender-specific needs of women. The theory addresses the human response when confronted with a difficult circumstance and describes a process that is dynamic with fluctuating patterns. The theory provides a basis for the instrument, the Inner Strength Questionnaire (ISQ), which has the potential to be used as a measure to predict relationships and test nursing interventions. The growth and realization of inner strength are theorized to result in positive health outcomes of improved QOL and self-management.

The concepts and corresponding definitions of the theory of inner strength are (a) anguish and searching describes the fear, vulnerability, and search for meaning to process the challenging life event; (b) connectedness describes the nurturing of supportive relationships with self, family, friends, and a spiritual power; (c) engagement describes self-determinism, reframing, and engaging in possibilities; and (d) movement describes the dimension of movement, rest, activity, honest self-appraisal, and balance (see Figure 28-1). Analysis revealed that living a new normal was determined to be a consequence or outcome of inner strength (Dingley et al., 2001; Roux et al., 2002; Roux, Lewis, Younger, & Dingley, 2003). The new normal was expressed...
through stories of new activities, relationships, a new understanding, a sense of purpose, and a renewed faith in God or a “Greater Source of Strength.” One research participant described her new normal: “You’ll never be the same again, inside of you . . . I had to adjust. I did” (Dingley et al., 2001, p. 47). The qualitative findings indicated that living the new normal encompasses a sense of self-determination, mastery, positive self-concept, and a balance with life experiences. The renewal and adjustment as described by the new normal and facilitated by inner strength are theorized to result in the positive health outcomes of improved QOL and self-management.

**Empirical Testing of the Theory of Inner Strength in Women**

The first reference to inner strength as a central concept of research in the nursing literature is found in Rose’s (1990) phenomenologic study of the psychological health of women. Other inquiries revealed inner strength as a coexisting theme or contributing factor to other phenomena, such as spirituality or QOL. However, the phenomenon of inner strength lacked conceptual clarity. The authors’ first study utilizing a phenomenologic approach involving women with breast cancer (Roux et al., 2001) served to provide insight and understanding of women’s strengths that are predicated on their own experiences and perspectives outside of the generally accepted androcentric view. The following study (Dingley et al., 2001), which was focused on women with coronary artery disease, served to generate a draft of the theoretical model of inner strength that was useful for further theory development and refinement.
Three subsequent qualitative studies were conducted to further examine, compare, and contrast the patterns of the reformulated theory; confirm or refute theoretical concepts and relationships; and add a perspective of specific ethnic and cultural relevance. Each study provided a sample focus of women living with various chronic health conditions, for example multiple sclerosis, heart/lung transplantation, as well as a cultural subgroup of older Hispanic women living with chronic illness (Dingley & Roux, 2003; Koob, Roux, & Bush, 2002; Roux, Dingley, Lewis, & Grubbs, 2004). Throughout the process, theoretical interpretation and clinical application of the concepts of inner strength were analyzed. The inductively founded evidence implied a relationship between inner strength and a healthful life and well-being. As the theory refinement process progressed, instrument development and testing commenced to address the possibility of defining quantifiable measurements based on the theory (Lewis & Roux, 2009; Roux et al., 2003; Roux, Lewis, Younger, & Dingley, 2004). The items for the ISQ were initially developed based on the theoretical formulation from the previous studies. The instrument development process further refined understanding of the structure and constructs as it delineated clustered items that were consistent with the theoretically derived factors. The third psychometric testing study sample was composed of 281 women with self-reported chronic health conditions. The four-factor structure was supported with a total of 27 items with loadings of 0.50 or greater. The reliability for the entire instrument (version 4) was 0.91 (Lewis & Roux, 2009). The instrument takes approximately 10–12 minutes to complete and is at the Flesch-Kincaid reading level of fourth grade. The instrument may be useful as a clinical assessment measure that can guide the development of nursing interventions to enhance inner strength in women living with chronic health conditions.

The current state of the science related to the phenomenon of inner strength has progressed to inductively derived theory and instrument development resulting in a reliable measure. Recent theory testing focused on examining the relationship of inner strength to the positive outcomes of QOL and self-management with the goal of determining the associations between these variables (see Figure 28-1). The relationships among the primary variables in the TIS-W (inner strength, QOL, and self-management) were tested in a sample of women with cancer. Inner strength was hypothesized to predict enhanced QOL and self-management. Demographic, clinical, and health characteristics (including depression) were examined for potential confounding effects (Dingley & Roux, 2009). Using a nonexperimental survey design, participants (N = 107) were recruited from two outpatient urban cancer centers. Statistical analyses using multiple regression revealed that the most predictive variables for QOL were depression ($t = -9.5$, $p = 0.000$), inner strength ($t = 8.2$, $p = 0.000$), and time since diagnosis ($t = 3.27$, $p = 0.002$). Because of multicollinearity between depression and inner strength, an analysis was computed without depression. When removing depression, the most predictive variables were inner strength, time since diagnosis, and number of comorbid conditions, explaining 64% of the variance in QOL.
In this model, the ISQ was the most predictive variable, explaining 48% of variance in QOL. Depression and inner strength were the most predictive variables for self-management. The most recent study (Dingley & Roux, 2009) advances previous descriptive work and theory development toward a predictive model and provides evidence for theoretically based interventions derived from the ISQ when the ISQ is used as an assessment tool. Future research should include tailored intervention studies on health behavior changes to enhance inner strength, QOL, self-management, and positive patient outcomes in women surviving cancer. The ISQ instrument and theoretical relationships of the theory can guide further intervention studies to provide a strong foundational understanding.

Implications for Cancer Care

The middle-range TIS-W provides description and insight into human responses to challenging life experiences. The theory can serve as a framework for assessment of client needs and tailored interventions, as well as future research investigations. The theory exemplifies the metaparadigm related to health, person, environment, and nursing. It also supports the view of health as a process and experience, encompassing both disease and non-disease. Chronic illness is conceptualized as a meaningful component of the whole and serves as a facilitator of health and the woman’s “new normal.”

The focus on inner strength during survivorship delineates an element of human experience from a positive, strengths-based perspective. The theory of inner strength provides an alternative perspective on processes and outcomes from the typical focus on negative clinical outcomes. Currently, healthcare and nursing-sensitive outcomes focus on prevention of untoward events or unwanted clinical outcomes, such as complications of treatment. However, further expansion and use of the theory of inner strength may reveal the development of positive clinical outcomes that can be assessed, quantified, and utilized for potential improvement in care and QOL issues. The application of the theory among interdisciplinary oncology care team members supports the premise that women who experience inner strength have enhanced QOL and self-management beyond clinical factors and demographic variables. As such, understanding ways to facilitate inner strength may be valuable for women as they move through the recovery process.

From an interdisciplinary practice perspective, the inner strength theory applied to cancer survivorship reinforces the need to focus on individual client strengths and the relationship to positive outcomes such as QOL. As an example, the interventions suggested in Table 28-1 were developed within the dimensions of the theory. The interventions were based on the descriptions of the concepts for facilitating inner strength using the items from the ISQ for assessment questions. For example, within the Anguish and Searching subscale, interventions initiated by the oncology team could include assessment of clients as they move through the experience of shock and fear to searching and finding acceptance and meaning (see Figure 28-2). Specific questions from the ISQ in the Anguish and Searching subscale could identify the need
to provide opportunities for discussion of the client’s current understanding of illness, fears, and worries about the future. In addition, needs related to client-centered education and possible referrals could be identified.

<table>
<thead>
<tr>
<th>Concepts and Definitions</th>
<th>Item Examples From Inner Strength Questionnaire: Assessment Parameters</th>
<th>Theoretically Based Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Anguish and Searching</strong></td>
<td>There are many times when I am afraid of dying.</td>
<td>Discuss what the client knows about her illness.</td>
</tr>
<tr>
<td>Point of shock and fear to one of accepting</td>
<td>I am scared about the future.</td>
<td>Provide client-centered education. Explore fears and worries regarding the future.</td>
</tr>
<tr>
<td>Establishing meaning</td>
<td>I dwell on my illness.</td>
<td>Discuss potential meanings. Make appropriate ancillary referrals.</td>
</tr>
<tr>
<td><strong>Connectedness</strong></td>
<td>I have at least one person close to me.</td>
<td>Determine the client's possible sources of support.</td>
</tr>
<tr>
<td>Sense of support and nurturance from self, family, friends, and a spiritual power</td>
<td>I feel the presence of God or a Greater Source of Strength.</td>
<td>Assess nurturing support, including social and spiritual support.</td>
</tr>
<tr>
<td>Nurturing of relationships resulting in a deeper connectedness</td>
<td>I have at least one person close to me.</td>
<td>Assist the client to develop insight related to needing and asking for help. Refer for supportive services as needed.</td>
</tr>
<tr>
<td><strong>Movement</strong></td>
<td>I can live with my physical limitations.</td>
<td>Discuss balance of lifestyle.</td>
</tr>
<tr>
<td>Movement, harmonizing, and facilitating desired change</td>
<td>I try to balance work and play.</td>
<td>Daily patterns should include time for both reflection and physical activity.</td>
</tr>
<tr>
<td>Composure of the body achieved through both silent reflection and actualizing the athletic and creative self</td>
<td>I take time for myself.</td>
<td>Encourage activities to promote physical and emotional strength. Set activity goals. Discuss changes in function, and assess fatigue and sleep.</td>
</tr>
</tbody>
</table>

(Continued on next page)
Table 28-1. Theoretically Based Nursing and Oncology Team Interventions (Continued)

<table>
<thead>
<tr>
<th>Concepts and Definitions</th>
<th>Item Examples From Inner Strength Questionnaire: Assessment Parameters</th>
<th>Theoretically Based Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Engagement</td>
<td>I can change my attitude when I need to.</td>
<td>Assist in reframing circumstance and refocusing thoughts and attitude.</td>
</tr>
<tr>
<td></td>
<td>I believe I have inner strength.</td>
<td>Encourage humor when appropriate. Assess for anxiety and depression. Make appropriate referrals. Recommend support groups if client is amenable.</td>
</tr>
</tbody>
</table>

Figure 28-2. Women Survivors of Cancer: Inner Strength Questionnaire

Instructions: Circle one of the choices (5, 4, 3, 2, or 1) that corresponds with strongly agree, agree, slightly agree, disagree, or strongly disagree.

Answer how you feel TODAY about YOUR HEALTH

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Slightly Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I tell myself I can do this.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
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<tr>
<td>2. I can change my attitude when I need to.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
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<tr>
<td>3. I believe I am a strong person.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>4. I am determined to get well.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>5. I believe I have inner strength.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>6. I can decide what to do.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>7. I have at least one person close to me.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

(Continued on next page)
### Figure 28-2. Women Survivors of Cancer: Inner Strength Questionnaire (Continued)

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Slightly Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
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<tbody>
<tr>
<td>8.</td>
<td>5</td>
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<td>9.</td>
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<td>10.</td>
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<td>26.</td>
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<tr>
<td>27.</td>
<td>5</td>
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<td>3</td>
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<td>1</td>
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</table>

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CASE STUDY

Renee, a 27-year-old female, was diagnosed with brain cancer (grades II and III anaplastic astrocytoma of the right temporal lobe) two-and-a-half years ago. Prior to her diagnosis, her family had grown increasingly concerned about her lifestyle and “high-risk” behavior related to alcohol. They had noticed changes in her decision-making abilities and general behavior. However, after Renee was rushed to the emergency room after a witnessed seizure, a brain computed tomography scan confirmed the diagnosis of brain cancer. She was treated surgically and received radiation therapy and several regimens of chemotherapy. She developed complications requiring additional treatment (infection, depression, and hormonal imbalance) and required follow-up magnetic resonance imaging scans and frequent monitoring for seizure activity.

Over the course of her cancer journey, Renee experienced life as a “new normal” emerged and she grew in inner strength. At first she was filled with fear and disbelief, automatically going through the motions from one diagnostic study or treatment to another, almost not allowing herself to feel. Her family attempted to shield her from knowing more about her diagnosis and prognosis, fearful she would be overwhelmed. But she soon began asking relevant questions and searching the Internet for answers. During recovery from a subsequent surgery for infection, she unrealistically pushed herself to engage in exercise activity that was too strenuous and found she was unable to tolerate it. The experience resulted in her staying in bed for several days of rest afterward. As she learned to listen to her body and set realistic goals, she established a balance between rest and activity. She began going to the gym and walking on the treadmill with her partner, making sure not to go alone, and enjoyed sharing this activity with him.

After a period of exploring her spirituality, she returned to the faith of her childhood, reestablished a relationship with her pastor, and attended services with her brother. Although Renee appeared to have a positive attitude and was upbeat whenever around family and friends, her insightful grandmother expressed concern that she have at least one person with whom she could express her feelings honestly and authentically. She was concerned that Renee was carrying the burden of having to be positive and “put on a happy face” for the benefit of those around her. Renee found a trusted counselor and began therapy, which she found helpful in navigating this experience. After a number of challenges with her partner, she ended their three-year relationship and expressed the need to conserve her physical and emotional energies and focus on staying well. The work of maintaining the relationship had become too demanding and draining. Currently, Renee continues in her journey—remaining in counseling, keeping engaged in her spiritual life, balancing exercise with healthy eating, and undergoing treatment with chemotherapy.
SUMMARY

The assessment parameters from the TIS-W and ISQ can be applied to promote inner strength with tailored nursing interventions as illustrated in Table 28-1. One caveat of this exploration relates to the emerging implicit concept of the “good patient” who is “compliant and without complaints.” As healthcare providers and researchers explore potential growth experiences with clients and their families, they must pay particular attention to the potential to develop subliminal underlying assumptions. The theory assumptions are explicit: All humans have the potential and the capacity for building inner strength. The research suggests that inner strength contributes to enhanced QOL and provides a means for assessing the individual’s inner strengths before initiating theoretically based interventions. The theory does not imply that an individual should be subjected to comparison to the “good” or “ideal” patient. Rather, theory application, assessment of strengths, measurement via the ISQ, and implementation of theoretically based interventions are viewed as means for nurses, interdisciplinary clinicians, and researchers to create a positive environment that may facilitate enhanced QOL and self-management.

In summary, findings of the literature and recent studies support the TIS-W, and it contributes valuable clinical implications involving the perception and portrayal of women experiencing cancer. This theory challenges the generally perceived view of women with cancer as being weak, and also challenges the way nurses relate and interact with those in their care. This view of survivorship reinforces the need to focus on individual clients’ strengths and the relationship of survivorship to positive outcomes such as QOL and self-management. Application of the theory and empirically based interventions by nurses and other interdisciplinary oncology team members hold potential to enhance QOL for women living with cancer. Future research implications include further study of the outcomes with men and investigation of outcomes in clients living with cancer across diverse stages of survivorship.

REFERENCES


INTRODUCTION

Cancer survivors are at greater risk for a variety of health problems than those who have not had cancer (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005). Not only are survivors at risk for recurrence, but they also are at heightened risk for the development of second cancers and many other serious diseases and health conditions, including osteoporosis, obesity, diabetes, and cardiovascular disease. Therefore, living a healthy lifestyle is particularly important for cancer survivors and may have important implications for their treatment responses, recovery, recurrence, and subsequent general health.

Survivors’ healthy lifestyles positively correlate to their quality of life. For example, breast cancer survivors who exercise regularly experience higher levels of physical and emotional well-being than those who do not (Courneya, 2003; Pinto & Trunzo, 2005). Furthermore, not only are health behaviors important for survivors’ well-being, but post-cancer changes in healthy behaviors may be even more powerful in improving well-being (Doyle et al., 2006). For example, a study of breast cancer survivors demonstrated that increases in exercise over 13 years related to better physical quality of life (Kendall, Mahue-Giangreco, Carpenter, Ganz, & Bernstein, 2005).

Although the health behaviors of diet and exercise have received the most attention in the context of survivorship, a healthy lifestyle should be considered more broadly and may include minimal alcohol and other drug use,
abstinence from tobacco products, adherence to medical regimens, weight maintenance, adequate sleep, stress management, social engagement, and spiritual sustenance. It is likely that these additional aspects of lifestyle not only directly influence health and well-being but also provide the basis for healthy exercise and dietary habits (Doyle et al., 2006).

INDIVIDUAL DIFFERENCES IN HEALTHY LIFESTYLES AMONG SURVIVORS

Despite their heightened health risks, cancer survivors do not necessarily engage in health behaviors (Park & Gaffey, 2007). Reports of positive changes following cancer have been noted for behaviors such as diet and exercise in breast cancer survivors (Demark-Wahnefried et al., 2005), yet the majority of survivors do not adhere to guidelines for an overall healthy lifestyle. Instead, cancer survivors generally engage in health behaviors at about the same levels as people without cancer. Two analyses of a nationally representative U.S. survey comparing cancer survivors with individuals without cancer noted few differences (Coups & Ostroff, 2005). No differences between cancer survivors and age-matched controls were seen on three dietary behaviors: fruit and vegetable intake, low-fat diet, and high-fiber diet (Coups & Ostroff, 2005). Some survivors were more likely to exercise (Bellizzi, Rowland, Jeffery, & McNeel, 2005), but for those 40–64 years of age, average exercise levels were lower than in the age-matched control group, and nearly three-fourths of cancer survivors did not meet recommendations for physical activity. Furthermore, little variability occurred in the prevalence of behavioral risk factors across cancer types. Overall, health behaviors in survivors were poor, similar to that of the general U.S. population. Clearly, significant improvement in cancer survivors’ health behaviors is needed (Coups & Ostroff, 2005).

INDIVIDUAL DIFFERENCES IN SURVIVORS’ HEALTH BEHAVIORS

Although reports of positive lifestyle change are common among survivors, national data indicate that survivors’ lifestyles are similar to those of their peers who did not have cancer (Coups & Ostroff, 2005). This seeming contradiction is due, in part, to the substantial individual differences that exist among cancer survivors in regard to the patterns and frequency of lifestyle changes. Thus, studies that report average levels of change may actually obscure important individual variations in lifestyles and lifestyle change (Park & Gaffey, 2007).

The biopsychosocial model is useful in conceptualizing individual differences that may exist among survivors because of the biologic, psychological, and social influences on health behaviors (Park & Gaffey, 2007). Per the biopsychosocial perspective, in order to understand and assist a cancer survi-
It is necessary to take into account that person’s unique constellation of biologic, psychological, and social influences on his or her health behaviors. These influences include (a) demographics, (b) aspects of disease, treatment, and general health, (c) pre-cancer health behaviors, (d) information, (e) perceived control, (f) self-efficacy, (g) distress, (h) coping, (i) spirituality, (j) perceived benefits, (k) social support, (l) community factors, and (m) race, ethnicity, and culture.

In regard to demographic influences, gender does not appear to be related to survivors’ lifestyle change (Park & Gaffey, 2007), whereas older age was correlated with less improvement in diet and exercise in some studies (Pinto, Trunzo, Reiss, & Shiu, 2002) but not in others (Harper et al., 2007).

Influences related to aspects of disease, treatment, and general health demonstrated that cancer survivors whose disease was more advanced and those who have undergone more extensive or invasive treatment are more likely to make greater improvements in their diet, exercise, and smoking behavior (Christensen et al., 1999; Gritz, Schacherer, Koehly, Nielsen, & Abemayor, 1999), perhaps because the impact of the disease serves as a motivation to make necessary changes (Park & Gaffey, 2007). However, many survivors experience adverse health conditions and late effects from their cancer treatments, such as pain and fatigue, as well as other comorbidities, rendering it more challenging for them to lead a healthy lifestyle or improve their health behaviors (Earle, 2006).

Pre-cancer health behaviors refer to prediagnostic health behaviors. Cancer survivors who were already leading a healthy lifestyle prior to their diagnosis will have resources available (e.g., experience, skills) that others may need to acquire. Many survivors continue to engage in healthy habits during their treatment, such as maintaining their exercise regimens, while others may lapse during treatment and may or may not resume healthy habits following their treatment (Courneya, 2003).

In order to make healthier choices and implement lifestyle changes, survivors need to have information regarding what those behaviors are. At this point, the extent to which survivors are aware of their heightened risks and the impact that optimal health behaviors may have on these risks have not been clearly established. While copious resources are available through which survivors may acquire this information, such as survivor-oriented Web sites and printed materials (e.g., American Cancer Society, n.d.; Lance Armstrong Foundation, n.d.), many survivors remain uncertain about what kinds of changes they should make (Stolley, Sharp, Wells, Simon, & Schiffer, 2006).

Perceived control refers to the extent to which people believe they can affect outcomes that are relevant to themselves. The extent to which survivors feel they can control their health (e.g., beliefs regarding the causes of their cancer or the effectiveness of health behavior change on reducing risks for subsequent cancer) appears to be associated with actually making health behavior changes. For example, for gynecologic cancer survivors, attributing their cancer to stress and environmental toxins and attributing a potential
recurrence to lack of diet and exercise and stress was linked to more positive dietary changes, whereas attributing cancer to God’s will led to reductions in exercise behaviors (Costanzo, Lutgendorf, Bradley, Rose, & Anderson, 2005). Similarly, Rabin, Pinto, Trunzo, Frierson, and Bucknam (2006) found that breast cancer survivors’ beliefs that specific health behaviors caused their cancer or would prevent recurrence led to an improved diet, increased exercise, and decreased use of alcohol.

Self-efficacy regarding one’s ability to perform health behaviors is strongly related to individuals’ performance of those behaviors (e.g., when a person feels capable of eating a healthy diet, that person is more likely to eat healthfully). Studies of cancer survivors have demonstrated the importance of self-efficacy in making health behavior changes. For example, in a study of newly diagnosed patients with head and neck cancer, perceived efficacy was related to quitting smoking and excessive drinking (Gritz et al., 1999).

Distress related to one’s cancer experience has been found to relate to behavior changes in both more and less healthful directions. Distress, especially fear, may give rise to motivation to change; making adaptive health behavior changes may be a way of coping with and decreasing one’s distress. For example, in a sample of colorectal cancer survivors, worrying, intrusive thoughts, and fear of recurrence were positively related to intentions to change health behaviors and, to a lesser extent, to having actually made positive health behavior changes (Mullens, McCaul, Erickson, & Sandgren, 2004). On the other hand, distress has been shown to lead to a variety of dysfunctional health behaviors (Reardon & Aydin, 1993).

Studies of cancer survivors indicate that, in general, approach-focused coping (e.g., problem solving, reappraisal) is helpful, whereas avoidance coping strategies tend to be related to poorer outcomes (Holland & Holahan, 2003). Only a few studies have examined relations between survivors’ coping responses and their health behavior changes. These studies found that approach-focused coping with the stress of cancer was related to self-reported positive changes in diet and exercise in breast cancer survivors (Reardon & Aydin, 1993) and in younger adult cancer survivors of a variety of cancers (Park, Edmondson, Fenster, & Blank, 2008).

Spirituality is important to many cancer survivors and may serve as a resource in assisting them in making healthy lifestyle changes. In the study of younger adult survivors of various cancers, different aspects of spirituality were differentially related to different health behavior changes. Specifically, religious attendance was unrelated to change, daily spiritual experiences were related to increased adherence, and spiritual struggle was related to less healthy use of alcohol (Park, Edmondson, Hale-Smith, & Blank, 2009).

Perceptions of benefits (e.g., feeling closer to friends and family, appreciating life more, reprioritizing values and goals, being more spiritual) are quite common among cancer survivors (Algoe & Stanton, 2009; Park, 2009) and may lead to positive health behavior changes. For example, in a sample of longer-term female survivors of various cancers, positive life changes (e.g.,
in philosophy, in supporting others, in sexuality) demonstrated moderate positivity to adaptive health behavior changes (Kurtz, Wyatt, & Kurtz, 1995).

The extent to which cancer survivors experience social support, meaning feeling integrated into and supported by their social environment, affects their likelihood of making adaptive health behavior changes. For example, with breast cancer survivors, higher social support in the form of a confidante and being married predicted greater subsequent increases in vigorous exercise (Pinto et al., 2002). Social support from family appears to be particularly helpful (Emery, Yang, Frierson, Peterson, & Suh, 2009).

In addition to individual psychosocial factors, a variety of community factors may influence health behavior change among cancer survivors. In many communities, formal support or exercise groups encourage making healthy lifestyle changes. For example, dragon boat race training has recently received attention and appeared to enhance health-related quality of life in breast cancer survivors (Parry, 2008). Other non-cancer-specific but highly influential community-based factors affecting the ability to make healthy lifestyle changes should also be considered. These include access to exercise facilities and safe areas to walk or run, as well as environments where walking is easily incorporated into one’s daily life, and access to food stores that provide fresh fruits and vegetables (Schneider & Stokols, 2008).

To date, little information is available regarding the extent to which issues such as race, ethnicity, or culture might affect post-cancer lifestyles. In one recent qualitative study, African American breast cancer survivors noted their heightened needs for healthy changes and the increased challenges they faced in making healthy changes (Stolley et al., 2006), including not having someone with whom to exercise, not feeling motivated, and feeling confused about what they were supposed to do. Clearly, issues of race, ethnicity, and culture deserve greater research attention.

A PERSONALIZED APPROACH TO FACILITATE SURVIVORS’ HEALTHY LIFESTYLES

The biopsychosocial model highlights the imperative of personalized care in approaching adaptive health behaviors in cancer survivorship (Greer, 2003). Each survivor possesses a unique constellation of prediagnosis experiences vis-à-vis health behaviors, each has a unique treatment history, and each has a unique set of resources and barriers. The status of each survivor on these many factors necessitates that efforts to optimize healthy lifestyles involve a personalized approach. Importantly, this personalized approach must consider not only the emotional, psychological, intellectual, and spiritual challenges faced by each particular survivor, but the entire constellation of factors and their interrelationships. For example, distress may be related to adaptive or maladaptive health behavior changes. It may be that high distress, in conjunction with high self-efficacy and good information, might actually be related
to making *more* adaptive health changes, but in the context of low self-efficacy or information, it might be related to less (Mullens et al., 2004). Different aspects of health behavior may be differentially affected by different biopsychosocial factors. For example, exercise behaviors might be more adversely affected by the fatigue resulting from treatment, whereas diet might be more influenced by cultural factors or accessibility to healthy foods (Stolley et al., 2006). Thus, a personalized approach is critical in health behavior assessment and intervention.

**NURSES FACILITATING ADAPTIVE CHANGE**

Nurses can facilitate survivors’ changes toward positive health behaviors by providing information as well as guidance regarding specific change strategies based on an assessment of survivors’ needs, resources, and barriers. Survivors are more likely to make health behavior changes that have been recommended by their physician; such effects would likely be true for other healthcare providers (Jones, Courneya, Fairey, & Mackey, 2004). Given the personal relationship that nurses have with their patients throughout treatment, they may be in a particularly potent position for facilitating survivors’ positive changes as they transition into survivorship.

**SUMMARY**

Although much work remains to be done, enough knowledge has been established to provide preliminary guidance for health professionals working with cancer survivors on leading healthy lifestyles (see Figure 29-1). Future work in the area of survivors’ healthy lifestyle changes must be solidly based on an individualized approach that views each survivor holistically, accounting for the complexity of each survivor and targeting the specifics of that person’s health status, desires, needs, and situational context. Future interventions should be developed taking into account these individual differences and targeting various specific points on the survivorship continuum.

<table>
<thead>
<tr>
<th>Figure 29-1. Personalized Strategies for Facilitating Survivors’ Health Behavior Change</th>
</tr>
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<tbody>
<tr>
<td><strong>Assess the survivor’s current health behaviors</strong>: Take stock of the survivor’s current lifestyle. Noting where the person is on the continuum of survivorship, assess his or her current status on a variety of health behaviors as well as his or her history on these behaviors. Note healthy behaviors that have been or are currently practiced, as well as those that require improvement.</td>
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(Continued on next page)
• **Provide information:** Information on health behaviors and health behavior change should be provided with as much tailoring to the specific survivor as possible. Include experts' recommendations for healthful lifestyles in survivorship (Doyle et al., 2006).

• **Determine targets of change:** Based on the information provided, work with the survivor to select the particular health behaviors that will be the focus of his or her efforts for change, along with those healthful behaviors for which he or she desires help in maintaining.

• **Appraise resources:** Resources for facilitating change should be assessed. Some of these resources may be the focus of intervention (e.g., bolstering familial social support). It may be useful to help the survivor identify resources that he or she finds useful in performing other health behaviors.

• **Appraise barriers:** Barriers both internal and external to the survivor should be assessed. In particular, barriers that can be modified should be noted. These may include a lack of skills, time, or resources, as well as pain, fatigue, or depression (Stolley et al., 2006).

• **Develop strategies to facilitate change and promote maintenance:** These strategies can take many forms, such as participation in formal lifestyle interventions specific to cancer survivors, involvement in facilitated or self-directed online efforts, acquisition of a lifestyle coach or personal trainer, or membership in a weight management group. Many strategies can involve drawing more deeply on identified resources and problem solving to handle the identified barriers. The survivor may need to learn new skills for implementing the new health behavior. Keep in mind that establishing new health behaviors requires different skills than maintaining habits already practiced.

• **Enhance motivation:** It is important that the motivation to change comes from the survivor; motivation cannot be “given” to another. However, certain strategies can help to capitalize on a survivor's current motivations, such as highlighting the reasons for making the change and providing information to help counter reasons for not making the change.

• **Monitor ongoing adherence:** Regular monitoring of health behaviors should be an aspect of the survivorship care plan. Many new health behaviors may lapse over time, and life situations will change. Therefore, it is important to continue monitoring health behaviors and to adjust strategies for living a healthy lifestyle over time and changing circumstances.

**REFERENCES**


“I’ve learned about ‘surfing’; about keeping myself anchored so that negativity can flow around me, not through me.”
—Cancer survivor, regarding Mindfulness in Motion

INTRODUCTION

Cancer survivorship is an important research and clinical practice area, as biomedical advances in cancer diagnosis and treatment have resulted in larger numbers of cancer survivors who are active, working members of society. The United States has an estimated 12 million cancer survivors (Horner et al., 2009). Despite these positive outcomes, cancer survivors are challenged with unique stressors that are not well understood (Morgan, 2009) and require innovative, biobehavioral interventions that could improve the survivorship experience.

Mind-body approaches that can enhance one’s daily life prove pivotal in maximizing health outcomes. Recent research has illustrated that newly diagnosed survivors who receive psychological intervention display biobehavioral, immune, and health benefits even after a recurrence (Andersen et al., 2010). Thus, interventions that seek to improve survivors’ mind-body wellness are timely, warranted, and can be incorporated into a comprehensive approach to cancer care. This chapter will describe Mindfulness in Motion, which is based on principles of mindfulness-based stress reduction (MBSR), a mind-body approach that has substantial research-based evidence for its efficacy in a variety of medical, social, educational, intercultural, and worksite settings (Kabat-Zinn, 2003).

Mindfulness in Motion is a mind-body wellness program that was developed specifically for cancer survivors who have returned to work or who are
capable of working. It is an adaptation of MBSR low-dose (MBSR-ld) (Klatt, Buckworth, & Malarkey, 2009) using yoga and meditation and addressing specific mind-body needs of cancer survivorship. Through affirmation of the whole person, Mindfulness in Motion is an example of an integrative medical approach that addresses psychosocial mind-body wellness for the cancer survivor in a multidisciplinary way.

INTEGRATIVE MEDICINE AFFIRMS THE WHOLE PERSON

Although the term complementary and alternative medicine (CAM) collectively is understood to represent approaches outside of conventional Western medicine, the term integrative medicine is not as well understood. According to the National Center for Complementary and Alternative Medicine (NCCAM) of the National Institutes of Health, integrative medicine is defined as “a practice that combines both conventional and CAM treatments for which there is evidence of safety and effectiveness” (NCCAM, 2010, “Defining CAM” section). This includes both preventive and therapeutic approaches. Integrative medicine is described as orienting the healthcare process to create a seamless engagement by patients and caregivers of the full range of physical, psychological, social, preventive, and therapeutic factors known to be effective and necessary for the achievement of optimal health throughout the life span (Schultz, Chao, & McGinnis, 2009).

Integrative health care refers to care that is integrated across conventional, traditional, alternative, and complementary domains, using scientific evidence as the barometer of inclusion. In 2009, the Institute of Medicine’s Summit on Integrative Medicine and the Health of the Public was convened to consider how integrative concepts fit within a number of initiatives for transforming the healthcare system, including patient-centered care; personalized, predictive, preventive, participatory medicine; mind-body relationships; and team-based care processes (Schultz et al., 2009).

Mind-body approaches are one of the five research domains outlined by NCCAM. Although overlap and “blurring of the lines” exists between the five research domains exploring the validity of CAM approaches, mind-body approaches typically refer to techniques designed to enhance the mind’s capacity to affect bodily function and symptoms (NCCAM, 2010). It is more accurate to view mind-body interventions as any treatments that address the interaction or the bidirectional flow (Monti, Sufian, & Peterson, 2008) between the mind (thoughts and feelings) and the body’s physical processes (Carlson & Bultz, 2008).

Survivorship is an optimal time in the continuum of care when mind-body techniques could be especially helpful, as these modalities serve as a potential means of connecting survivors to psychosocial supportive services and are a platform for oncology providers to discuss some CAM options with their patients (Monti et al., 2008). Survivorship is also a phase in the cancer continuum
in which the concern about conventional medicine and CAM interaction often is less than in active treatment, allowing the clinician to focus on the patient’s personal perception of health and well-being. Exploring evidence-based integrative approaches is an affirmation that the survivor is a whole person and can be an active participant in the journey forward.

Integrative oncology is a personalized and holistic approach to cancer care that considers each individual’s unique circumstances to customize treatment programs while using the best evidence-based interventions (Lawenda, 2010). The goals of integrative oncology, which incorporates mind-body approaches, include treating the cancer, preventing recurrence, and reducing side effects and symptoms. Some providers may not be confident discussing mind-body techniques because many research studies exploring their safety and efficacy are in their infancy. To aid in this process, the National Cancer Institute and the Agency for Healthcare Research and Quality have developed ranking criteria for levels of evidence. Stark, Hess, and Shaw (2005) have proposed a schema for ranking the weight of the evidence in integrative oncology. Helpful resources such as these provide evidence for clinicians and provide a starting point for a conversation with survivors about mind-body health and potential integrative interventions.

The assessment of CAM information has been shown to be a complex, personal process for people with cancer (Verhoef, Mulkins, Carlson, Hilsden, & Kania, 2007), depending on their previous CAM experience and their stage of disease. Research indicates that patients with less personal CAM experience depended on their physicians and other conventional health providers as authorities on CAM information (Verhoef et al., 2007). Thus, a provider-patient conversation about the potential integration of mind-body approaches for their overall well-being and health provides a necessary portal for patients to first consider, and possibly engage in, mind-body interventions that could affect their survivorship experience.

Carlson and Bultz (2008) described the current evidence for the use of mind-body approaches such as hypnosis, imagery, relaxation, meditation, yoga, art, music, dance, and journaling, which are commonly used by patients with cancer, and emphasized patient self-selection of these therapies as a primary benefit. Research has shown meditation and yoga to be helpful in addressing immune and sleep response, and specifically, meditation research has yielded significant results in stress reduction, mood improvement, and quality of life (Carlson, Speca, Patel, & Goodey, 2003; Hays, Brodsky, Johnston, Spritzer, & Hui, 2005). Creative therapies, including dance, visual arts, music, and journaling, help in the expression of feelings and are effective coping strategies in dealing with cancer (Carlson & Bultz, 2008).

Recent evidence has demonstrated that levels of inflammation are correlated with levels of stress and fatigue for patients with cancer (Miller, Ancoli-Israel, Bower, Capurorn, & Irwin, 2008). In a non-cancer population, yoga was associated with lower inflammation levels in women, suggesting that yoga and meditation and other integrative approaches may be useful in addressing
inflammation (Kiecolt-Glaser et al., 2010). Clinicians could use this information as evidence to support patients with self-selection. Patients need both the research information and the freedom of personal choice to be active participants in a comprehensive approach to survivorship.

The window of opportunity to address lifestyle issues currently is underutilized, as it is estimated that only 20% of oncologists provide information on CAM interventions for the reduction of complications associated with survivorship (Sagar & Lawenda, 2009). The UCLA Center for East-West Medicine provides a model for person-centered care for patients with cancer that acknowledges both patient preferences and the expanding evidence base for CAM therapies (Hui, Hui, & Johnston, 2006). This approach, which includes mind-body interventions, has demonstrated a positive impact on patients’ quality of life (Hays et al., 2005). Discussing CAM therapies provides an avenue to strengthen issues of identity and empower patients (Daykin, McClean, & Bunt, 2007) as contrasted with the limitations, isolation, and disempowerment often associated with a cancer diagnosis and treatment.

The use of mind-body approaches can address the behavioral symptoms that persist well into the survivorship period, including stress, depression, fatigue, sleep disturbances, and cognitive dysfunction (Miller et al., 2008). Yoga is one mind-body approach being studied to address these issues. Cohen (2005) studied 61 women with breast cancer who participated in yoga two times a week during radiation therapy. The women in the yoga group had improved physical and social functioning, better general health, less fatigue, and significantly lower levels of sleep-related problems as compared to the control group. In another study, Banerjee et al. (2007) reported that an integrated yoga program modulated the stress and DNA damage levels sustained by patients with breast cancer who were undergoing radiation. Discussions between patients and providers concerning mind-body wellness need to center on the patients’ goals and what they hope to achieve. If the goal is to improve pain tolerance, the provider should investigate the research evidence on imagery or hypnosis; if coping and quality of life are the goals, creative therapies are the best options to explore; and if stress reduction is sought after, MBSR should be reviewed.

**MINDFULNESS-BASED STRESS REDUCTION**

Cancer survivors have noted fear of recurrence as a central stressor in the survivorship experience. Well-documented symptoms experienced by survivors include disruptions in sleep and mood, stress, and fatigue (Carlson & Garland, 2005). A participatory holistic intervention, such as MBSR, is an effective modality to address these symptoms and stressors (Carlson & Garland, 2005). Jon Kabat-Zinn (2003) developed MBSR in 1979 at the University of Massachusetts Medical Center’s outpatient stress reduction clinic. Mindfulness meditation teaches nonjudgmental awareness of sensation, emotion, cogni-
tion, and perception and provides a method to observe the mind’s filtering of both internal and external experiences. Mindfulness encourages a state of mind in which one distances from one’s own mental noise. It allows for a new awareness of mind that permits focused attention on releasing stressful constructions and a more relaxed moment-to-moment awareness, and movement away from experiencing uncertainty as stressful to acceptance of the present moment (Kabat-Zinn, 2003).

MBSR is a participatory educational approach, exposing the power of internal resources in framing what a person experiences as stressful. MBSR refers to a change in one’s interior disposition toward awareness. Awareness of one’s affective response to external events is presented as the key to changing one’s internal experience of stress. Events are perceived positively or negatively and are within or beyond one’s control; becoming aware of one’s affective responses to internal and external events is the core activity of MBSR (Klatt et al., 2009).

In their examination of the use of MBSR with the breast cancer population, Shapiro, Bootzin, Figueredo, Lopez, and Schwartz (2003) concluded that MBSR was helpful for distress-related insomnia. In fact, the more days the participants practiced, the more the MBSR helped with sleep complaints, highlighting both a dose effect and the importance of daily practice. In another study with patients with cancer, Carlson and Garland (2005) reported that 90% of their participants struggled with sleep disturbances, yet it was possible to improve their sleep quality with MBSR. In their study, reductions in sleep disturbance were significantly correlated with reductions in symptoms of stress, and the yoga postures (included in MBSR) helped participants fall sleep.

MBSR has been recommended as a means to manage daily and long-term stress for cancer survivors (Carlson & Speca, 2007). Consistent benefits for cancer outpatients included improved psychological functioning, reduction of stress symptoms, and enhanced coping (Ott, Norris, & Bauer-Wu, 2006). The limitation of MBSR is that it is a time-intensive program requiring participants to attend a weekly 2.5–3-hour didactic meeting with an expectation of meditation practice of 45 minutes to 1 hour per day for the recommended eight weeks of the program. Pragmatic adaptations of MBSR are being developed to be more readily available for people who are unable to commit the time necessary for traditional MBSR (Kabat-Zinn, 2003). One such program, MBSR-ld, was originally designed as an adaptation of MBSR, a mind-body intervention for adults delivered at the worksite (Klatt et al., 2009). MBSR-ld was developed to retain the construct of mindfulness, as originally conceived and taught by Kabat-Zinn (2003), while adapting it for time-constrained adults.

Operationally, MBSR-ld is comparable to traditional MBSR programs, differing only in the amount of time both per day and week committed to the intervention. The shortened didactic educational component provides the contextual framework for the participants to begin to understand the connection between mindfulness meditation and the ability to effectively deal with stress. Experiential activities such as deep breathing, relaxation, body scans, and gentle yoga movement are used to facilitate a meditative state.
Two significant differences between MBSR and MBSR-ld are (a) yoga stretches are emphasized in the MBSR-ld protocol as a means to center the participant in one’s body, and (b) the relaxing background music played during the MBSR-ld weekly sessions is on each of the daily MBSR-ld practice tapes. In the MBSR-ld pilot study, using working adults at a large public university (faculty and staff), self-reported perceptions of stress, sleep quality, and mindfulness were significantly improved, resulting in a 10% decrease in perceived stress. Additionally, MBSR-ld significantly improved participants’ subsets of subjective sleep quality, sleep disturbances, sleep latency, and daytime dysfunction as compared to controls (Klatt et al., 2009). Given these results, MBSR-ld was adapted by the author for cancer survivors so that they could benefit from stress reduction and increase the quality of their sleep.

MINDFULNESS IN MOTION: A MIND-BODY APPROACH FOR CANCER SURVIVORS

Mindfulness in Motion was conceived as a mind-body approach to wellness for working cancer survivors, providing a pragmatic, low-dose version of MBSR. The intent was to provide an eight-week mind-body class that could fit into a survivor’s life as he or she reenters the workforce. Mindfulness in Motion is essentially MBSR-ld for the cancer survivor and requires a similar time commitment as the adapted MBSR program offered to survivors at Tom Baker Cancer Centre (Mindfulness-Based Cancer Recovery) in Calgary, Canada (Carlson et al., 2003). Modifications in their program were made in deference to the high levels of functional impairment, weakness, and fatigue of participants, many of whom were on active treatment. Similarly, the yoga poses in Mindfulness in Motion have been adapted from those used in MBSR-ld for survivors. These adapted poses accommodate those who do not have a full range of arm motion, yet the program still uses yoga movement as a portal for meditation.

Mindfulness in Motion uses music for relaxation, movement, cognitive restructuring, deep breathing, and mindful eating and sleeping techniques that address unique concerns of survivors. The program was developed and piloted by the author in two series of an eight-week program with 15 survivors who were enrolled in supportive classes offered by the cancer hospital at the university medical center. Nine survivors participated in the first eight-week program, and six were enrolled in the second program. The weekly sessions were one hour in length. Participants were given instructional CDs with eight 20-minute movement/meditation practices and were asked to record their daily practice on a provided form.

Overall, participants in both series of sessions reported similar benefits of participation, including learning new ways to deal with stress, finding pathways to positive emotions while learning how to deal with negative physical and mental states, becoming more aware of their bodies, learning how to relax, and enjoying a sense of shared camaraderie and connection with other participants. The
shortened time commitment of the program proved to be an important factor because reentering the workforce and juggling job and family demands was difficult for participants. A participant commented:

Coming from a stressful job to this class, I became aware that my blood pressure had been creeping up, and I now see how I am an active participant in this and that I can take control of it through relaxation and meditation. It is an excellent fit with my life.

The greatest benefit resided in the fact that the survivors fulfilled a need of connecting with other survivors who had returned to work. They often shared the relief they experienced in talking with someone else who could relate to their unique challenges. One participant noted:

Cancer survivors deal with anxieties others really can’t understand. We tend to keep them inside in order to not bore others. We mask our emotions! Once the mindfulness meditation process is understood and practiced, it is extremely beneficial as follow-up appointments approach or in our day-to-day discomforts.

**SUMMARY**

Integrative medicine, integrative oncology, and specifically mind-body interventions have the potential to enhance the mind-body wellness of survivors. The oncology population can benefit from discussions with healthcare providers about therapies to decrease symptoms, increase coping, and optimize wellness. Discussions about integrative oncology with a healthcare provider can serve as an invitation to the patient to expand the biomedical model to include mind-body techniques using self-empowerment, individual responsibility, and potential lifestyle changes (Sagar & Lawenda, 2009).

Emerging programs such as Mindfulness in Motion are needed to address the changing demographics and lifestyle needs of survivors. Future directions and strategies for healthcare professionals serving survivors include building a knowledge base of research evidence behind the available mind-body therapies and introducing and encouraging discussion about various available therapies that enhance the survivorship journey.

**REFERENCES**


INTRODUCTION

In the early 1970s, the National Cancer Institute designated psychosocial support as one of the four priorities for the rehabilitation of patients with cancer (Gerber, Vargo, & Smith, 2005). Early supportive outreach contained a strong didactic component designed to teach specific skills and competencies to patients and family caregivers to strengthen their self-confidence in coping with and managing cancer in their lives, particularly during diagnosis and treatment. A shift in psychosocial support occurred in the mid-1980s as patients were living longer.

Fitzhugh Mullan, MD, introduced the term cancer survivor in a medical journal and declared that patients experience distinct phases and what he termed seasons of survival beyond diagnosis and treatment (Mullan, 1985). His narrative paved the way for survivors to break the silence of cancer and share their stories in order to normalize the experience of cancer in their lives. Simultaneously, national survivorship coalitions, advocacy groups, and organizations started to emerge, heightening the visibility of the growing population of cancer survivors and bringing their needs to the forefront of public awareness. These developments were a precursor to new directions in psychosocial rehabilitation and signaled the growth of psychosocial care beyond traditional education and support modalities to integrative models of care emphasizing survivorship over the life span.

By the 1990s, increasing numbers of patients with cancer were beginning to augment their traditional care with complementary and alternative medicine (CAM) during active treatment as well as in the post-treatment survivorship phase (Monti, Sufian, & Peterson, 2008). CAM therapies represent person-centered approaches to health and well-being, and many patients began to actively engage in body-based therapies, mind-body interventions, and non-
pharmacologic modalities for stress management and optimal health (Barrett et al., 2003). Psychosocial rehabilitation continued to build upon an integrated, biopsychosocial model through a multimodal and multidisciplinary approach to care (Feuerstein, 2007). The range of innovative modalities for psychosocial support expanded in congruence with consumer expectations for survivorship, healing, and recovery.

In the past two decades, a growing dimension in mind-body therapies and psychosocial support has been the integration of expressive arts (Sonke, Rollins, Brandman, & Graham-Pole, 2009; State of the Field Committee, 2009). This chapter will discuss the role of expressive arts in cancer survivorship and will describe how artistic expression and art-making empower and support survivors as they ascribe meaning to the cancer experience. Additionally, research limitations will be addressed.

MOVING BEYOND TRADITIONAL PSYCHOSOCIAL SUPPORT

Levine (2009) described the experience of a traumatic life event such as cancer as one that leads to chaos and feelings of fragmentation and proposed that when this occurs, human beings will inherently strive to restore a sense of wholeness. Expressive arts facilitate this move to restoration of wholeness by helping individuals to find forms and shapes through art-making and creative self-expression. These artistic expressions enable survivors to contain and examine suffering and trauma, gain insight through introspection and reflection, and ultimately move from feelings of victimization to acceptance and self-empowerment (Levine, 2005; Malchiodi, 2005; McNiff, 1998). Limitations of traditional psychosocial support in facilitating this transformation of trauma include the structure of support groups themselves, the prominence of cognitive modalities in cancer support, barriers to access, and emphasis on the disease and patient role.

Traditional cancer support has maintained an emphasis on verbal, linear, and cognitive talk therapies offered primarily in disease-specific support groups. Some support groups may be time limited and involve specific interventions for the treatment of distress, while others offer open-ended sessions with participants determining the duration of their involvement. Although their emotional support needs may vary considerably over the cancer continuum, many individuals continue to participate in the same support group they joined upon diagnosis.

Cancer support groups have frequently been developed and facilitated by social work professionals. Cognitivism and behaviorism have been significant influences on the development of social work treatment approaches and have historically emphasized problem-solving and solution-focused care. Lee, Ng, Leung, and Chan (2009) proposed a new model for social work practice, described as integrative body-mind-spirit social work, which moves from the cognitive-behavioral to a reflective-expressive approach. This model incorporates
CHAPTER 31. EMPOWERING SURVIVORS THROUGH EXPRESSIVE ARTS

the cognitive (mind/thinking) with the emotive (mind/affect) and the spiritual (mind/soul) and facilitates client empowerment by connecting individuals with and in their larger environment.

Cancers with high incidence rates have been associated with the widest availability of psychosocial support. The most significant development of psychosocial support has occurred in the breast cancer population because of its high incidence, long-term survivorship, research efforts, and funding opportunities. On the contrary, individuals with rare or low-incidence cancers may find it difficult to locate a support group. Likewise, for individuals with cultural, language, geographic, or socioeconomic barriers, access to participation in traditional psychosocial support may be very limited.

Psychosocial support for individuals with cancer often has focused on immersion in the patient role while giving far less attention to reintegration with the life role (Schmitt, 2009). Rancour (2008) described the difficulties that patients encounter as they transition from active treatment to survivorship and begin the search for meaning of this life-transforming experience. Traditional cancer support groups often have emphasized the commonality of the disease over the uniqueness of the individual experience. Levine (2009) argued that in understanding and working through trauma, it is important to recognize that no universal story or narrative exists and that each person’s journey is unique.

TRANSFORMING TRAUMA AND EMPOWERING SURVIVORS THROUGH EXPRESSIVE ARTS

The influence of arts in healing has received recognition in recent years with the development of arts-in-medicine programs. Heightened attention to the role of arts in the healthcare environment has occurred through the development of expressive arts programs in visual, literary, and performing arts. The evolution of these therapeutic interventions began with the formation of professional disciplines and associations that established training standards, credentialing, and monitoring for expressive arts therapists in drama, dance, poetry, music, and the visual arts. These disciplines share common goals of integrating psychological, physical, and social functioning; reducing suffering; and promoting health (Malchiodi, 2005; Sonke et al., 2009). Although these therapeutic interventions have historically been associated with rehabilitation of motor, neurologic, and psychiatric conditions in acute and ambulatory rehabilitative facilities, they have only recently been applied to the oncology setting (Halprin, 2003).

The experience of being a patient with cancer leads to a narrowing of one’s life as immersion in the continuous journey through diagnosis, treatment, and ongoing surveillance can easily lead to both a physical and psychological preoccupation with the disease. The arduous demands and residua of cancer treatment, along with the psychosocial impact of cancer on all aspects of
life, can be consuming and overwhelming. The result of immersion in being a patient is the disengagement from “normal life.” As individuals begin to sort out what has transpired during this experience, they discover a need to create a “new normal.” Tedeschi and Calhoun (1995) suggested that increased self-reliance, strength, and psychological growth result from suffering when trauma can be addressed and confronted. Expressive arts are effective in helping individuals to confront crisis and access the source of their discomfort, and use this as the basis for transforming, reframing, and revisioning a new normal (McNiff, 1998).

Survivorship involves finding ways to make meaning of the life-transforming experience of cancer and reconstructing a personal identity after cancer (Harding, 2006; Luzzatto & Gabriel, 2000; Malchiodi, 2005; Rancour, 2008). Levine (2009) described art-making as a form of creative liberation that allows individuals to deconstruct and find understanding in trauma in order to release the fixation of the trauma experience and come to terms with what has happened. In direct contrast to the narrowing of one’s life that accompanies the patient experience, expressive arts emphasize a freedom of energy and expansiveness (Schmitt, 2009). Empowerment, mastery, and a sense of control occur as individuals learn to take risks, experiment, work through blocks, make choices, and trust the process while suspending judgment about the outcome (McNiff, 1998). This ability to tolerate ambiguity in the creation of art can support individuals as they deal with ambiguity and uncertainty in other aspects of their lives.

Participation in expressive arts requires giving oneself permission to let go of inhibitions and rigidity. Levine (2009), Malchiodi (2005), and McNiff (1998) all agreed that art-making is not limited to the seemingly talented. Rather, it is a process-oriented approach to creativity and self-expression where individuals step into the unknown and gain mastery over something that they did not know or did not think they could do. In the art workshops, groups, and retreats that we have conducted, participants repeatedly shared their joy and satisfaction with being able to create something. The sense of empowerment that accompanies their creativity gives them confidence and extends into other areas of their lives.

TRUSTING THE PROCESS AND DISCOVERING MEANING

The wide range of expressive arts modalities allows individuals to employ a personalized approach in selecting the type of modality that is most appealing to them or for which they may have a natural propensity. Participation in one modality frequently leads to participation in other expressive arts modalities. Individuals who use the creative process in their healing journey often find that the resulting artwork, image, poem, narrative, performance piece, or dance provides a direct connection to unconscious emotions. It is common for an individual who has expressed strong emotions through these modali-
ties to share, “I knew those feelings were in there. I just did not know how to get them out.” Art-making and creative expression bypass the usual channels of consciousness. What may have been filtered or censored is allowed to appear in its raw form as art to be experienced, expressed, and processed in a safe environment.

Expressive arts typically combine other mind-body interventions, such as breathing exercises, guided imagery, visualization, and relaxation techniques, with carefully chosen art experiences. The mind-body connection that occurs when working with expressive arts can produce specific physiologic changes that reduce stress and enhance well-being (Halprin, 2003). Sensory and perceptual by nature, art-making emphasizes being in the “here and now” that requires heightened levels of concentration, attention, and focus. Breathing may slow as individuals “tune out” the external environment, internal worries, or anxieties and become engrossed in the act of art-making. Accessing ways that reduce the fragmentation, chaos, and confusion of illness allows individuals to move away from the dissociation of mind and body and move toward integration and wholeness (Lee et al., 2009; Levine, 2009; McNiff, 1998).

An advantage of using expressive arts includes the active engagement of patients in their own recovery process. Unlike the cognitive and linear approach used in many cancer support groups, expressive modalities allow individuals with diverse cultural, learning, and perceptual styles and preferences to engage in psychosocial support that goes beyond “talk therapy.” Participants can select the type of support that is most appealing and comfortable to them. Additionally, individuals may participate in the same expressive arts experience regardless of their type of cancer, thus eliminating a barrier to access for someone with a cancer for which seemingly little or no support is available.

A goal of expressive arts is to support individuals as they reframe and integrate feelings into a larger gestalt (Harding, 2006; McNiff, 1998). Engagement and participation in expressive arts reconnects individuals with their life roles while allowing them to process and understand illness as part of the life experience. Visual, literary, and performing arts have historically shaped and defined cultures and serve as a bridge that reconnects individuals to their lives beyond the experience of cancer. Healthcare professionals may introduce these modalities into the cancer continuum at diagnosis and continuing through treatment, with offerings at the bedside or at the chairside in the clinic environment.

Increasingly, integrative psychosocial support through expressive arts occurs in group settings. The selection of group settings is very important for optimal benefit to the participants. Engaging participants in naturalistic settings where “normal life” occurs rather than in clinical settings can be a powerful way to empower survivors in their adaptation and adjustment (Schmitt, 2008). Innovative partnerships and collaborations with academic and community partners can lead to dynamic opportunities for the development and delivery of these modalities in settings that reacquaint cancer survivors with normal aspects of daily life. Participation in expressive arts modalities may
motivate survivors to return and reintegrate into their communities and become active participants in other creative and leisure activities that may have fallen away during treatment. They may develop new activities, acquire or build upon skills, or engage in new relationships as a result of their experiences with expressive arts.

CASE STUDY

P.L. is a 65-year-old Caucasian male who was diagnosed with oral cancer (squamous cell carcinoma) in 2005. Married with four adult children, P.L. was employed full-time as an insurance broker at the time of his diagnosis and was currently serving as a deacon in the Catholic Church. P.L.’s cancer surgery involved removal of the mandible, skin, and ligaments on the left side of his face; bone was taken from his left fibula for jaw reconstruction. During his inpatient stay, P.L. was reluctant to have his wife or children visit him because he did not want to appear weak or dependent. He said, “I felt I let them down as a strong father who was never supposed to be in a position of helplessness.” Leading up to and after surgery, P.L. consistently asked his healthcare team about what he was facing and if he would be all right. No one gave him the assurance he needed, and he felt hopeless. P.L. felt like a failure to himself and to his family, and he was angry at God for betraying him.

Following surgery, P.L. underwent radiation therapy that he described as “torture and like being burned alive” that left him with mouth sores, burning, pain in his face, and difficulty talking and eating. His emotional scars were far more complicated. P.L.’s metaphor for his cancer was “the bogey man” who was literally “scaring him to death.” The trauma of P.L.’s “consuming fear” caused him to be so anxiety-ridden that he did not go to church and could not preach or offer support to anyone experiencing illness or death. He became depressed and withdrawn.

Gradually, P.L. began the physical recovery from his significant side effects. Each phase of his survivorship propelled him further into healing, but he asked the same question, “Am I going to be all right?” He had trouble facing people, and upon returning to church, he did not want to speak, sing, or preach. He slowly emerged from “hiding” and began to make changes in his life that included retiring from his job, pursuing a master’s degree, and spending more time with family. But the cancer remained visible—it stared at him in the mirror as he started each day. He pushed his feelings about it down deep where they continued to frighten him.

Three years after diagnosis, P.L. participated in a collaborative project of the supportive services program at the cancer hospital with the university’s theater department. The project paired nine cancer survivors, ranging in age from 23 to 64 and with various types of cancer, with undergraduate students in a theater outreach program. Cancer survivors attended weekly class
sessions over a period of two academic quarters and learned theater arts and techniques as they developed original works about their cancer experience. In their roles as students, learners, and members of an ensemble, the survivors moved deeper in their understanding of the cancer experience through role play, improvisation, movement, acting, writing, narrating, and performing their own pieces. The project culminated in a live production performed by the survivors and aided by the students as other actors in their scenarios.

P.L. described this experience as an “eye opener” and a turning point, and one in which he found his voice and learned how to talk about his cancer without feeling embarrassed. He felt empowered by the experience because he could tell his story to the public. He enjoyed the camaraderie with the students and being with the other survivors and hearing their stories. P.L. felt “transported from the normal to the supernormal.” He said, “I didn’t feel sick or different during this experience.” Shortly after the live performance, P.L. stood before his congregation and told them the whole story of his cancer and started his transformation from fear to being able to wear his survivorship as a badge. P.L. summarized the experience:

With theater, you get to look at yourself as a whole person—all aspects of yourself, not just your cancer. It made me step back and look at my journey and what had happened to me. You create and pull from everything. You have to think about yourself. It brings out more emotion and I went deeper than I would have in other things—it forced a part of me to be exposed that I tried to keep hidden, but it needed to come out. I’m glad it came out. It makes you look at yourself as you never have before; it challenges you; it invigorates and enlightens you. I’ll never forget it. It was impactful. It made me look at life differently and look at cancer differently. It gave me confidence.

Since the project’s completion, P.L. has become a survivor advocate and mentor and a patient/family adviser at the hospital. He is also a public speaker and frequently shares his story in the hopes that it will help other cancer survivors and educate and inform healthcare professionals.

SUMMARY

The emergence of arts in cancer care and survivorship is relatively recent and is characterized primarily in programs such as creative arts therapies, group arts, environmental art, bedside activities, creative writing programs, healing gardens, art carts for patients or staff, music arts and music therapy, and performance groups. To date, published findings on the efficacy of expressive arts programs have been largely anecdotal and qualitative in nature, relying primarily on program and participant satisfaction. Music therapy is the exception that has most often been associated with systematic evaluation (Carlson & Bultz, 2008).
The multidisciplinary nature of the broad field of expressive arts and breadth of practice pose unique challenges to researchers. Many limitations and barriers exist, including access to funding agencies and sponsored competitions and inadequate expertise in research methodologies among artists and art practitioners, who often are viewed as ancillary to the healthcare team (Sonke et al., 2009; State of the Field Committee, 2009). Further limitations involve lack of clarity about what to measure, differing opinions between medical staff and therapeutic artists about what constitutes “healing,” competition for limited institutional resources, and attitudes of medical staff and administrators as to the value of integrating art or engaging in research outside of traditional scientific inquiry. Although significant evidence shows that the arts truly make a difference in people’s lives and their survivorship, the current evidence is anecdotal, observational, and subjective.

Medical, nursing, and allied healthcare programs in the United States and abroad have actively begun to incorporate arts courses in their clinical training programs that will encourage and foster collaborative relationships and partnerships in the future. Examination of the role of expressive arts in facilitating post-traumatic growth, resilience, and identity integration leading to positive health outcomes for cancer survivors are all areas of potential research and inquiry. Survivorship research in the future must encourage new interdisciplinary collaborations that will study these mind-body modalities that empower survivors to move through trauma and make meaning of the life-transforming experience of cancer.

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REFERENCES


Since the publication of the seminal report *From Cancer Patient to Cancer Survivor: Lost in Transition* by the Institute of Medicine in 2006, much has been accomplished internationally to identify and address the gaps in education, clinical care, and research for cancer survivors and the professionals who care for them. However, a tremendous amount still needs to be done, and done quickly. Key to growing this survivorship revolution is a refocusing that looks beyond survival to survivorship care.

The maturation of survivorship as a component within the continuum of care currently can be divided into three periods: early, middle, and late (future). The early period was almost exclusively focused on the research and care of survivors of pediatric cancers. The pediatric multidisciplinary “late effects” clinics and the research conducted as part of these clinics are still models of excellence from which we can learn because of the attention that was, and is, paid to the comprehensive needs of the survivor, including medical, psychological, economic, and social issues. Initially, this pediatric research focused on identifying long-term and late effects, but the focus then moved to the evaluation of interventions to treat the effects of therapy and even to study ways to reduce or eliminate these often serious sequelae. In addition, education about healthy living, such as diet, exercise, and smoking cessation, along with information about potential future risks has always been part of pediatric survivorship care.

Late in this early period, the oncology community began to concentrate on the survivors of adult-onset cancers, and things immediately became much more complex. The interest in developing formal programs and models of care
for adult survivors arose in academic health centers. Initial efforts focused on applying the pediatric model, although to a population that was much larger in terms of absolute numbers and types of diseases. However, most adult patients are treated in the community and not at academic health centers, requiring that any plans for care and services be simple to implement, widely distributed, and locally available. Furthermore, the pediatric multidisciplinary care model is expensive and time intensive, making it difficult to replicate for adults. Other significant differences exist between pediatric and adult cancer care. Treatment exposures for adult patients with cancer that result in long-term and late effects are much greater in number and are complicated by non-cancer comorbidities that can have tremendous impact on the survivor. Added to these many challenges are the limitations in adult survivorship research, which has, until recently, concentrated on descriptive research elucidating the problems facing adult survivors with little quantitative evidence to guide survivorship care.

We are now moving into the middle period of survivorship with a growth in interventional research and an increase in the number of investigators who are focusing their professional research careers on the challenges facing cancer survivors. In terms of clinical services, community hospitals, private practices, and healthcare systems are experimenting with ways to focus on the post-treatment care of patients with cancer. A growing number of innovative community programs have emerged that focus on recovery services of all types. A variety of clinical models now serve as useful prototypes and include the provision of a survivorship care plan to the patient and the primary care physician. Two significant outcomes have occurred during this middle period: (a) increased application of palliative care and symptom management services as part of survivorship, thus bringing symptom management into its rightful place in clinical care for common issues such as chronic pain and fatigue, and (b) the incorporation of navigation services to assist survivors in identifying and accessing information and services.

What does the future hold? As survivorship enters its mature phase, it takes a prominent place within the care continuum. Important opportunities are emerging as the healthcare system changes in ways that may benefit survivorship care, and as we begin to apply the lessons that others have already learned. We must better engage the patient, remembering that everything we do is in service of the health and well-being of our survivors. As the oncology community moves beyond survival as the ultimate goal, we need to better understand the values of survivors and focus on developing programs that add quality to this survival. We also must improve educational resources so that they reflect the cultural diversity of our nation. We should consider a “just in time” learning approach with the development of personalized education plans looking at what survivors want and need to know and when they want to know it.

The clinical care services related to survivorship must be linked into and occur in tandem with other healthcare system changes. The opportunities
for oncology nurses and other oncology professionals across the spectrum of clinical care are tremendous. A key member of this team is the nurse, who can, and should, provide the care related to the patient’s transition from active cancer treatment to the post-treatment period. In addition to taking the lead role in this provision of care, the nurse can provide the critical link between the oncology healthcare team and the primary care provider. Survivorship care is multidisciplinary in nature and requires leadership to knit together the elements of a survivorship plan. This coordination is analogous to an orchestra conductor who must bring together many different instruments, all working from the same score to achieve a common outcome.

With much time, effort, and money being spent on electronic medical records, untapped opportunities are awaiting the oncology nursing community to pilot and evaluate novel ways of providing survivorship care. For example, virtual visits for the confined, urban older adult and rural residents using telephone, e-mail, and Internet communication are possible. Consider how one might do a symptom assessment or deliver a psychosocial intervention in this manner. Also consider how many nurses and oncology professionals could be trained in survivorship care with the development and implementation of long-distance learning programs that are modeled on current university programs and utilize well-established education principles.

The future is now. The challenge is to creatively develop, use, reassemble, and share the resources in our communities and healthcare facilities and not be hampered by time or money. Let us remember the words of one survivor as we focus on making the future of survivorship care a reality: “The goal is to bring quality to the lives we fought so hard to keep.”

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Director, Survivorship Program
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New York, New York
INTRODUCTION

Survivorship care is a distinct phase of cancer that requires the educational preparation of healthcare professionals to address the quality-of-life issues that cancer survivors face (Institute of Medicine, 2006a). Because survivorship care is not currently taught in professional education programs, efforts are needed to raise awareness, knowledge, and skills of current professional staff in order to develop and implement appropriate survivorship care. This chapter addresses the content needed to prepare clinical staff for the provision of survivorship care, the principles of adult education, an overview of the steps involved in developing a survivorship education program, and a discussion of the evaluation methods used to measure results.

SURVIVORSHIP CARE CONTENT

Defining a cancer survivor and the components of a survivorship program provides the framework for the content of a survivorship education program. While the National Coalition for Cancer Survivorship (n.d.) defines an individual as a cancer survivor from the time of diagnosis through the balance of life, the distinct phase of survivorship care generally begins at the end of treatment. Survivorship care includes four components: prevention and early detection, surveillance, interventions for consequences of cancer and cancer treatment, and coordination of care. These components compose the essential content needed in a survivorship care education program (Institute of Medicine, 2006a).
PRINCIPLES OF ADULT LEARNING

Education is a key component that will facilitate a successful process change and implementation of survivorship care. The use of adult learning principles is essential to the development of healthcare professional education plans. Malcolm Knowles, a pioneer in the study of adult learning, identified five assumptions to effective adult learning (Knowles, 1990).

First, adults learn best when they understand why something is important to know or do (Knowles, 1990). Adult learners should know why they need to learn something before undertaking the learning. Often, the changes in survivorship care are an institutional initiative rather than initiated by an individual. Healthcare professionals, therefore, appreciate an educational program that is organized and has clearly defined elements that connect the institution’s goals to their own professional performance goals. Often this type of education is informal. Instructors must show participants how this new program, process, or action will help them attain their own professional goals so that alignment between the institutional goals and participants’ professional goals may be accomplished.

Second, adults have flexibility to learn with self-directed opportunities (Knowles, 1990). They need freedom to make their own decisions and need to be afforded the opportunity of self-direction. The survivorship education program must actively involve the participants in the learning process. Each health professional group will have different preferences for the educational content and delivery format. The educator must ascertain each participant group’s perspective about what topics to include in their session and which method of instruction to use. The participants should be allowed to assume responsibility for selecting their own educational session. The educator must show participants how the project, process, or action will help them reach their goals.

Third, adult learners have a variety of life experiences, which represent the richest resource for learning (Knowles, 1990). However, these experiences also can bring negative experiences to learning. Adults have a foundation of life experiences and knowledge that may include work-related activities, family responsibilities, and previous education. They need to connect the new program learning to their current knowledge and experience. The educator must recognize these past experiences and, when appropriate, include shared examples of similar project successes by program champions and process owners to help other participants recognize the value of learning the new process or action and implementing the new survivorship education.

Fourth, adults must be ready to learn those things they need to know in order to work effectively with current life situations (Knowles, 1990). Adults must see a relevancy for learning something. The education must be applicable to their current responsibilities and work to be of value to them. Therefore, educators of the survivorship education program must link the institutional, divisional, departmental, and personal professional objectives with the edu-
cational session invitation at the beginning of the educational session. All new components of survivorship care, processes, or activities must be related back to participants.

Finally, adults are motivated to learn to the extent that they perceive that it will help them perform activities in their current situation (Knowles, 1990). Adults are practical; focus the education on what they need to know to get their job done. They may not be interested in knowledge for its own sake. The educator must clearly demonstrate how the new project, process, or action will be useful to them on the job. The education provided should answer the question, “What is in it for me?”

These five assumptions are useful in designing and implementing a survivorship education program for professionals. It is best to customize the curriculum for each group of healthcare professionals based on their role and responsibility for survivorship care at their institution. The use of adult learning principles when developing survivorship care education will facilitate successful program implementation.

**DEVELOPING THE SURVIVORSHIP EDUCATION PROGRAM**

With adult learning principles in mind, several next steps are important in developing a program for an individual institution or setting. The program is best developed by someone in the education department of the institution or someone who has received training through a national training program on cancer survivorship. The first step is to identify the audience and assess their current understanding of survivorship care. More than one audience may be addressed, such as administrative staff, medical staff, and nursing staff. Current knowledge may be assessed by administering a short survey. Several surveys have been developed for this purpose and are available through the City of Hope Pain and Palliative Care Resource Center Web site at http://prc.coh.org.

The development of a grid of what content is needed for each of the audiences is a helpful next step in organizing the education program. Topic selection may be based on knowledge of an educational need or specific objectives of the program. Using this grid, the program planner’s next step is to identify the learning objectives for each audience. These objectives may address attitudes, knowledge, or psychomotor skills and should follow the format for sound educational objectives (Bloom, 1956). Examples of each kind of objective are found in Figure 32-1.

The next step is to identify the teaching methods. For objectives that are focused on changing attitudes, a lecture format including case studies is appropriate. For example, following beginning remarks that define a cancer survivor and a brief overview of the components of survivorship care, showing a video of cancer survivors provides an excellent way to introduce the concept of cancer survivorship to an audience (Institute of Medicine, 2006b).
Knowledge objectives fit well with the lecture format but also can be accomplished through self-study methods. The lecture method is most commonly used when presenting material at grand rounds or other continuing education settings. A Web-based learning module on survivorship care can provide broad foundational information appropriate for a variety of clinical staff. The advantage of this approach over a lecture is eliminating the necessity of a specific time frame or a large setting to provide the information.

Psychomotor skill objectives are best learned in small groups to allow an opportunity for the participants to demonstrate the new skill. Case studies, role play, and demonstration/return demonstration can be used to organize the material. The disadvantage of the small group approach is that it requires facilitator teachers in each group, and they may need preparation prior to the sessions. An example of a small group activity in a survivorship education program is to have nurses demonstrate teaching healthy living behaviors to survivors, practice filling in a treatment summary, or conduct an interview with a survivor during which they present a care plan to the patient.

In addition to matching teaching objectives to the method used, the program developer should spend time in planning to make the content interesting and keep the audience engaged. The teacher needs to be an expert in the content and allow time for questions and discussion. Slides, if used, should summarize, not provide detailed information. Video clips are especially valuable in demonstrating cancer survivors’ needs. Table 32-1 presents additional teaching tips.

Steps in developing the survivorship education program are designed to address individual audiences, identify appropriate content according to behavioral objectives, and plan teaching methods that capitalize on adult learning principles. An easy template to use that incorporates Knowles’ five adult learning assumptions for each specific healthcare professional group is described in Figure 32-2.

Research on how adults learn provides valuable information on how best to provide education to adults. As quoted in Pike (1994), adults generally stop retaining information after about 20 minutes. They will listen with understanding for 90 minutes but will retain information for the first 20 minutes. Learners retain 70% of what they learn within the first 10 minutes. Therefore,
it is crucial to put the main action points within the first 10 minutes. Adults retain only 20% of what they learn in the last 10 minutes, so it is a prime place to reinforce or recap main points (Pike, 1994).

### EVALUATING THE SURVIVORSHIP EDUCATION PROGRAM

A strong evaluation will provide information on how successful the program was in meeting the objectives. Different types of evaluations exist depending on the type of learning that was anticipated. The Kirkpatrick Model is a well-established and valid approach to evaluation (Kirkpatrick & Kirkpatrick, 2006). Four levels of assessment are defined. Level 1 refers to the reaction of the audience alone. It is a simple feedback questionnaire given at the completion of the session. A basic template states each objective that was given at the beginning of the lecture and asks the participant to rate if that was met. This is customarily on a 0–5 rating scale and allows evaluations to be tabulated to obtain an average score for each objective.

Level 2 evaluations are for learning objectives. This type of evaluation would provide the extent to which the participant increased his or her knowledge or skills. This level of evaluation would require a pre- and post-test comparison or an evaluation by a supervisor working with the participant that could document the extent of learning.

<table>
<thead>
<tr>
<th>Type of Objective</th>
<th>Point to Convey</th>
<th>Teaching Method</th>
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<tbody>
<tr>
<td>Attitude</td>
<td>Feelings, attitudes, and values; overview of information</td>
<td>Lectures—lunch and learn, grand rounds, Web-based learning modules, Case studies, Videos, Knowledge and attitude testing</td>
</tr>
<tr>
<td>Knowledge</td>
<td>Facts</td>
<td>Lecture—small groups, Games, Web-based learning modules with post-test evaluation, Handouts to reinforce facts</td>
</tr>
<tr>
<td>Psychomotor</td>
<td>Techniques or procedures</td>
<td>Small groups, Role play, Web-based learning modules with post-test or return method evaluation, Handouts to describe techniques or procedures</td>
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</table>
Level 3 evaluations focus on changes in behavior. Did the participants’ behavior change when they returned to the workplace as a result of the training? This level requires evaluation assessments from the participants as well as others who observe their work or are recipients of their expertise. Participants can complete a self-assessment questionnaire in addition to observation reports by appropriate managing staff. Satisfaction scores, such as Press Ganey® reports, can document patients’ and families’ responses to information provided by staff or a general understanding of, in this instance, survivorship information or plans for after treatment follow-up. (Press Ganey is a healthcare-focused performance improvement company that helps healthcare organizations col-
lect satisfaction data, and provides analysis and insights to improve clinical, operational, financial, and experiential outcomes [Press Ganey, n.d.]."

Level 4 documents the final results of the program and what the organizational benefits were as a result of the training. This level of evaluation is conducted anywhere from three months to one year or more after the program. This might include evaluating financial reports or quality inspections. For example, for a large National Cancer Institute–funded training program, participating teams were evaluated at baseline and at 6, 12, and 18 months after the course for achievements in survivorship care; institutional changes were also evaluated using a follow-up tool at the same time periods (Grant, Economou, Ferrell, & Bhatia, 2007). Although these methods of evaluation take time, the information gained is necessary to justify the money and efforts made to provide the educational program. The level of evaluation needed relates to the necessary outcomes.

Other methods used to describe evaluation approaches include formative assessments and summative evaluations (Scriven, 1967). Formative assessments, as indicated by the name, are evaluations that take place during the formation of the program or during the presentation of the program itself. They may be as simple as a question during the program asking if the participants understand the information being presented. It also may be referred to as “internal” evaluation and is considered a fluid way to primarily evaluate curriculum. New technology in keypad use during lectures has made this type of evaluation more streamlined and effective. Data can be tallied in the moment, and information reported on screen. Formative evaluations involve multiple assessments that are compared together to be sure a program is on track. This type of evaluation is especially important when teaching a new skill or procedure.

Summative evaluations are done at the end of a program and focus on the outcome. This is the primary evaluation method used by most educators (Scriven, 1967). This relates to level 2 of Kirkpatrick’s levels of evaluation. Post-test scores and general program evaluations are considered summative evaluations.

**SUMMARY**

Drawing these key components together when providing an educational program will help in providing successful survivorship education. As this body of knowledge increases, healthcare providers must provide this information to colleagues as well as patients, families, and caregivers. Integrating survivorship information into the care and education provided is necessary to improve the care of this growing population.

**REFERENCES**


CHAPTER 33

Theoretical Framework for Survivorship

Michael Feuerstein, PhD, MPH

INTRODUCTION

A great deal needs to be learned in order to effectively optimize the health, health care, function, and well-being of cancer survivors at both a population level and a personal level (Feuerstein, 2007b). These individuals experience a range of cancers and various long- and short-term effects. As with most scientifically based efforts in modern health care, innovations in knowledge and its ultimate test in terms of improvements in outcomes are facilitated by models that help to explain observations we see daily in our practices and research efforts. Models often are instrumental in developing knowledge and understanding the role of certain variables that contribute to specific outcomes. This process can help facilitate systematic efforts at improvement in prevention, evaluation, and management.

Comprehensive models in the area of cancer survivorship are needed to help drive innovation in the understanding and care of cancer survivors. Models help us take a step back and integrate our clinical knowledge and the available science to better understand the problems that face providers and cancer survivors, both now and in the future. Models can provide a useful framework for future research along with more effective practice and evidence-based societal response to a problem. Ultimately, if reliable and clinically valid, this information can help optimize the outcomes of those living in the aftermath of the diagnosis and treatment of cancer.

The validity of a model is determined by its ability to explain prior observations and its ability to predict new observations. When I was diagnosed with a grade 3 anaplastic astrocytoma eight years ago, the probability of survival given my age at the time (52 years old), my gender, and grade of tumor was very low. Did I somehow just “beat the odds”? Although this prediction is indeed a “moving target” given advances in early detection, new treatments, and less-invasive surgical techniques, maybe the model used to predict my survival was insensitive. This
appears to be the case with many patients with cancer who receive a diagnosis and prognosis. Perhaps the model used to predict survival is no longer valid, and different variables and algorithms (e.g., conditional probability) need to be considered (Davis, McCarthy, Freels, Kupelian, & Bondy, 1999; Lin et al., 2003).

MODELS RELATED TO CANCER SURVIVORSHIP

In order to provide a summary of current models in cancer survivorship, the literature was searched for models of cancer survivorship in the medical, psychological, and nursing literature over the past decade (1999–2009). Online search engines included PubMed, PsycINFO, and Google™ Scholar. Search terms included conceptual framework, conceptual model, and cancer survivor, which were combined with more specific search terms including quality of life, multivariate, chronic illness, health care, biobehavioral, and function.

Table 33-1 provides a concise overview of each model. These models were categorized into health systems, quality of life/overall well-being, diversity, psychological health/overall well-being, biobehavioral, and functional models. The outcomes of these models include concepts such as quality of life, health-related quality of life, improved health outcomes, changes in defined health behaviors, and symptoms and function. Many of the models cover similar elements, suggesting a certain degree of agreement as to the important variables to study. More emphasis has been placed on the individual, which includes important influences on the provision of personally relevant quality health care, with modest consideration to the broader public health perspective.

<table>
<thead>
<tr>
<th>Author</th>
<th>Model Components</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Systems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mandelblatt et al.,</td>
<td>Communication; patient/population; individual context</td>
<td>Outcomes of care</td>
</tr>
<tr>
<td>1999</td>
<td>Primary care providers; cancer care providers; medical care environment and context</td>
<td></td>
</tr>
<tr>
<td>Oeffinger, 2003</td>
<td>Survivor-related factors: cancer experience, internal and external modifiers, core health beliefs, health locus of control Health system-related factors: healthcare policies, healthcare system, medical insurance Provider-related factors: knowledge of late effects, core beliefs in benefits of prevention, organizational structure of practice, attitudes toward cancer survivors</td>
<td>Optimum longitudinal risk-based care</td>
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<tr>
<th>Author</th>
<th>Model Components</th>
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<tbody>
<tr>
<td><strong>Health Systems (Cont.)</strong></td>
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</table>
| Patrick et al., 2005        | Ecological factors contributing to cancer; genetic, biologic, and pharmacologic factors; cognitive and behavioral factors  
Interpersonal and micro-scale social, institutional, macro-scale social, natural and built environmental factors  
Reduction in risk and incidence; optimization of early detection and cancer care  
Web-based communication                                                                                                                                                                                                                                               | Health outcomes  
Cancer communication                                                                                                                                                                                                                                                                                                                                                                                                |
| Institute of Medicine, 2006 | Long-term care: Monitoring for long- and late-term complications, consequences, and quality-of-life (QOL) impairments  
Psychological, social, and financial  
Cancer and treatment–specific, general health–related                                                                                                                                                                                                                                                                                                                                                             | Outcomes not specified                                                                                                                                                                                                                                                                                                                                       |
| Institute of Medicine, 2006 | Prevention; early detection; diagnosis; treatment; survivorship; end-of-life care                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | Optimal cancer survivorship  
• Medical, psychosocial, and economic domains  
• QOL, survival                                                                                                                                                                                                                                                                                                                                                       |
| Oeffinger & McCabe, 2006    | Communication; multidisciplinary long-term follow-up program  
Stratified high-risk population  
Nurse practitioner–led shared care  
Primary care physician; oncology team and nurse practitioner  
Time course (pre-cancer, cancer diagnosis, completion of cancer therapy, 1–2 years after completion of cancer therapy, 5 years and beyond after completion of cancer therapy)                                                                                                                                                                                                                     | Optimal cancer survivorship healthy care  
• Monitoring for treatment complications, cancer recurrence, and late effects  
• Improvement in patient outcomes with quality, long-term follow-up                                                                                                                                                                                                                                                                                      |

**Quality of Life and/or Overall Well-Being**

| Wyatt & Friedman, 1996      | Interaction among physical, social, psychological, and spiritual categories  
Integration of the disease process into current life; change in relationship with others; restructuring of life perspectives; unresolved issues  
Somatic concerns; philosophical/spiritual view of life; health habits; social/emotional support, apparel issues; sensory changes                                                                                                                                                                                                                                           | Relative importance of QOL domains  
• Physical  
• Social  
• Psychological  
• Spiritual                                                                                                                                                                                                                                                                                                                                                   |
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<th>Author</th>
<th>Model Components</th>
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<tr>
<td>Ganz, 1997</td>
<td>Socioeconomic/cultural factors; social support; access to health care; other chronic illness; age-related functioning and well-being; menopause and reproductive factors; breast cancer</td>
<td>QOL</td>
</tr>
<tr>
<td>Wettergren et al., 2004</td>
<td>Disease stage; time since diagnosis; treatment modality; disease index; physical and mental health; nonmedical factors Coping capacity; environmental characteristics</td>
<td>QOL global index</td>
</tr>
<tr>
<td>Arora et al., 2007</td>
<td>Predisposing characteristics (patient characteristics, clinical characteristics) Enabling resources (social support, follow-up care experiences and attitudes) Mediating factors (cognitive health appraisal, health-related behaviors)</td>
<td>Health-related QOL Symptoms Functional status Health perceptions</td>
</tr>
<tr>
<td>Grant et al., 2007</td>
<td>Physical, psychological, social, and spiritual well-being</td>
<td>Physical well-being Symptoms Psychological, social, and spiritual well-being</td>
</tr>
<tr>
<td>Meier et al., 2007</td>
<td>Antecedents (person factors, social resources, illness-related factors) Mediators (appraisal of illness, coping effort: problem management/emotional regulation; electronic distribution list participation [Association of Cancer Online Resources], social support)</td>
<td>QOL Health behaviors</td>
</tr>
<tr>
<td>Paskett et al., 2008</td>
<td>Physical, social, psychological, spiritual, and economic well-being</td>
<td>QOL</td>
</tr>
</tbody>
</table>

**Diversity**

| Ashing-Giwa, 2005     | Psychological well-being; general health and comorbidity; health efficacy; cancer-specific medical factors Demographic, socioecologic, cultural, and healthcare context | Health-related QOL         |

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<th>Model Components</th>
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<td><strong>Diversity (Cont.)</strong></td>
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<tr>
<td>López et al., 2005</td>
<td>Stigmatizing beliefs about cancer; racial discrimination; cultural beliefs about African American women</td>
<td>QOL of rural African Americans</td>
</tr>
<tr>
<td></td>
<td>Role adjustment, seeking safe sources, serving the community as role models, and comfort with future</td>
<td></td>
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<td></td>
<td>Spiritual faith</td>
<td></td>
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<td></td>
<td>Maintaining social standing</td>
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<tr>
<td><strong>Psychological Health and Overall Well-Being</strong></td>
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<tr>
<td>Andrykowski et al., 2008</td>
<td>Cancer stress and burden; resources</td>
<td>Growth</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Distress</td>
</tr>
<tr>
<td>Stein et al., 2008</td>
<td>Cancer stress and burden; resources; coping</td>
<td>Psychological long-term effects (positive, negative)</td>
</tr>
<tr>
<td><strong>Biobehavioral</strong></td>
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<tr>
<td>Carpenter &amp; Andersen, 2008</td>
<td>Sociodemographics, prior health, social network/support, and other stressors</td>
<td>QOL of gynecologic cancer survivors</td>
</tr>
<tr>
<td></td>
<td>Disruptive signs/symptoms produced by disease</td>
<td>• Psychological impact</td>
</tr>
<tr>
<td></td>
<td>Extent of disease and treatment; early disease morbidity</td>
<td>• Sexual effects</td>
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<td></td>
<td>New health problems; risk-reducing intervention</td>
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<td></td>
<td>Onset of cancer; diagnosis, treatment, and recovery</td>
<td></td>
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<tr>
<td>Miller et al., 2008</td>
<td>Cancer and treatment (tumor, metastases, chemotherapy, psychological stress, surgery, radiation therapy)</td>
<td>Depression</td>
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<tr>
<td></td>
<td>Neuroendocrine system, sleep-wake cycle, inflammation, central nervous system</td>
<td>Fatigue</td>
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<tr>
<td></td>
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<td>Impaired sleep</td>
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<td></td>
<td></td>
<td>Cognitive dysfunction</td>
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<tr>
<td><strong>Functional</strong></td>
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<tr>
<td>Ness et al., 2006</td>
<td>Cancer diagnosis, treatment</td>
<td>Physical performance limitations; participation restrictions</td>
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<tr>
<td></td>
<td>Personal characteristics</td>
<td></td>
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<td></td>
<td>Organ system impairments</td>
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<td></td>
<td>Social and environmental factors</td>
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<td></td>
<td>Age, time</td>
<td></td>
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<tr>
<td>Gilchrist et al., 2009</td>
<td>Health condition; body functions; body structures</td>
<td>Activity and participation</td>
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<td>Environmental and personal factors</td>
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A BIOPSYCHOSOCIAL MODEL OF CANCER SURVIVORSHIP

In the concluding chapter of the *Handbook of Cancer Survivorship* (Feuerstein, 2007a), I described a conceptual framework with elements identified from my review of areas relevant to cancer survivorship outcomes. I constructed the proposed model based on the cancer survivorship literature, personal experiences as a cancer survivor, professional experiences as a healthcare professional (i.e., evaluating and managing psychological aspects of chronic illness), and careful consideration of the excellent published models (see Table 33-1) that were created to help explain the complexities involved in cancer survivorship.

The patient with cancer traverses through a set of stages (see Figure 33-1), including the early phases of diagnosis and treatment. Those two phases are connected by a bidirectional arrow, indicating that exposures during treatment may put the patient at risk for additional cancer diagnoses in the future (Brenner, Curtis, Hall, & Ron, 2000). After diagnosis and treatment, the individual moves into the phase of “cancer survivorship,” which includes the acute, subacute, and chronic stages, during which the individual may ex-
perience a complex set of late and long-term effects. If recurrence is observed or a second malignancy occurs, the individual returns to the diagnosis and treatment phases.

The model proposes that the cancer survivor’s health, health care, function, and overall well-being across the four phases of cancer survivorship can be influenced by four major types of factors: medical, individual, sociocultural, and environmental. At any phase—diagnosis, treatment, survivorship, and end stage—a variety of factors can influence outcomes. It is proposed that sociocultural, individual, and environmental factors can all influence medical factors, which can, in turn, have a reciprocal effect on the other three elements. As originally developed, this model conceptualizes the individual survivor or the personalized and public health perspectives. However, the original version (Feuerstein, 2007a) did not include specific outcomes or highlight the dynamic nature of the model in terms of its interactions. Although not explicit in the original figure of this model, the outcomes include the cancer survivor’s health, health care, function, and overall well-being (not simply the absence of pathology) across the four phases of cancer survivorship (see Figure 33-1).

SUMMARY

Models help us improve knowledge and its translation. As providers of health care for cancer survivors, we must be ever vigilant of challenges to survivors’ health, health care, function, and well-being. The goal is to assist survivors in tracking these outcomes and work toward their optimization. Cancer survivors of all types need quality, ongoing health care after diagnosis and treatment to manage the late and long-term effects of cancer and its treatment and their impact on long-term health, function, and well-being. This is no small task for providers, survivors, friends, families, or workplaces. Models can assist in the efforts to more effectively achieve these goals. They can help facilitate the development of unique evaluation methods to track and predict outcomes and identify variables that affect the emergence, reemergence, or exacerbation of many types of problems. Models can facilitate new interventions from the health, sociocultural, individual, and environmental levels that can improve outcomes at all levels, from molecular to societal.

The author would like to acknowledge Michael Moskowitz and Briana Todd for their contributions to this chapter.

REFERENCES


INTRODUCTION

The Institute of Medicine (IOM) published *From Cancer Patient to Cancer Survivor: Lost in Transition* in 2006 challenging healthcare providers to consider 10 recommendations for cancer survivorship care. The first recommendation stated that cancer survivorship care should be established as a routine part of cancer care; the second recommendation asserted that upon completion of their primary treatment, patients should receive a survivorship care plan. The remaining recommendations identified the foundation required to build a survivorship program, including the refinement of clinical practice guidelines, assessment instruments, and quality measures, and the development of a national infrastructure to support cancer survivorship care (IOM, 2006).

This national agenda for survivorship care was fueled by grassroots advocacy, special interest groups, the National Coalition for Cancer Survivorship (NCCS), and the surgeons generals’ *National Call to Action on Cancer Prevention and Survivorship* report (Cabe & Springer, 2008). Nursing and physician organizations were involved and subsequently began to prioritize survivorship care planning although in a diffuse manner. Multiple silo projects were initiated, all feverishly supportive of education, advocacy, and research yet somewhat lacking in collaboration and coordination (Haylock, Mitchell, Cox, Temple, & Curtiss, 2007). Several versions of a proposed survivorship care plan emerged, as well as numerous definitions of survivorship-related terms. Today, the interest to provide survivorship care persists, with the learned knowledge that the diffuse characteristics of cancer types may require varying approaches to survivorship care planning. This chapter will define key terms, describe the basic elements of a survivorship care plan, and discuss common barriers potentially encountered in providing a cancer survivorship care plan for all cancer survivors.
KEY TERMS

In discussing the terminology associated with cancer survivorship care planning, it is essential to review the basic definitions of (a) cancer survivor, (b) cancer survivorship care, (c) cancer survivorship care planning, and (d) the cancer survivorship care plan. These terms all surround care for the survivor (see Figure 34-1) and yet are distinctly different. The term cancer survivor, previously cancer “victim,” is the central focus of all survivorship activities. Cancer survivor has been defined as “five years out,” “two years after diagnosis,” “after treatment,” and “at the time of diagnosis” (Feuerstein, 2007). The definition has been further expanded to embrace anyone affected by cancer (i.e., any person involved in the cancer experience, including significant others, children, parents, and caregivers) (Lance Armstrong Foundation, n.d.; NCCS, n.d.). Arguably, while those individuals may be affected by the cancer, the biopsychosocial impact of the disease is different for the patient (Feuerstein, 2007), and perhaps they should not be identified in the same manner. NCCS maintains that a cancer survivor is identified “from the time of diagnosis and for the balance of life,” and includes family, friends, and caregivers (NCCS, n.d.). These definitions have one theme in common: a confirmed cancer diagnosis with related known and unknown challenges, and perhaps involving designated milestones.

Cancer survivorship care is a broad term that encompasses the unique issues of cancer care including prevention, screening, treatment, short- and long-term symptom management, rehabilitation, and well-being of survivors (Feuerstein, 2007; Morgan, 2009). Cancer survivorship care is a distinct phase
in the cancer trajectory (Lotfi-Jam, Schofield, & Jefford, 2009) that represents curative cancer treatment or managed chronic care (Horning, 2008). Ideal survivorship care (Lotfi-Jam et al., 2009) should include

- Comprehensive care with access for all cancer survivors
- Personalized, individualized care that empowers survivors with choices for a healthy lifestyle
- Multidisciplinary and collaborative care with inclusion of all people involved in the cancer experience
- Transitional support from the acute setting to the community with effective communication
- Holistic, proactive management with attention to psychosocial needs
- Evidence-based interventions with cost-effective, sustainable outcomes.

The key operational components of survivorship care include prevention of recurrence and new cancers, surveillance for recurrence and new cancers, interventions to manage cancer and related treatment, and coordination between specialists and primary care providers (IOM, 2006).

Cancer survivorship care planning is a less well-defined term that designates a subsection of cancer survivorship care. It is the operational process of developing and implementing the activities that support planned interventions in the cancer survivorship plan of care. It represents the actions of the oncology healthcare team to address the challenges that cancer survivors face, specifically the common late effects of treatment (Ganz, 2007). Additionally, it defines the expanding role of the primary care provider in early detection, as well as in post-treatment follow-up, health promotion, and surveillance (Ganz, 2009a, 2009b). Effective cancer survivorship care planning enhances communication between the oncology healthcare team and primary care provider, evaluates outcomes, and provides data for research initiatives.

The cancer survivorship care plan, a component of cancer survivorship care planning, is a document that summarizes the patient’s treatment and related experiences with a comprehensive plan for future care and follow-up. This synoptic document is intended to provide (a) a record of cancer treatment, (b) guidance for the patient/survivor and provider (Ganz, Casillas, & Hahn, 2008), (c) a plan to optimize health outcomes through healthy lifestyle behaviors, and (d) a monitor of ongoing quality of care. Additionally, when the survivorship care plan is intertwined with medical record documentation, it can provide a record of complex oncology care with appropriate verbiage linkages to reimbursement codes (Earle, Schrag, Woolf, & Ganz, 2007) and important survivorship data.

SURVIVORSHIP CARE PLAN

The cancer survivorship care plan is composed of two distinct sections: the treatment summary and the care plan. The treatment summary should include diagnostic test results, cytology/pathology reports, dates of treatment initiation and completion, and summary reports from the providers who managed the
treatments for the primary cancer, including surgery, chemotherapy, radiation therapy, biotherapy, angiogenesis therapy, hormonal therapy, transplantation, and other therapies (see Figure 34-2). Any complications experienced during treatment should be summarized with attention to those that may affect future care and long-term outcomes. Psychosocial, nutritional, and other supportive services that were provided should be included with a notation of the outcome of interventions.

Contact information detailing each treating institution and practitioner provides a directory for both the survivor and professionals (Ganz et al., 2008; Horning, 2008). An indication of current disease status and list of medications, over-the-counter and herbal preparations, the date, and practitioner signature should conclude the report. A copy of the treatment summary should be provided to the survivor and all primary care providers, such as the patient’s internist/family practice physician, gynecologist, and other pertinent providers identified by the survivor. This treatment summary is

<table>
<thead>
<tr>
<th>Figure 34-2. The Cancer Survivorship Care Plan: Treatment Summary</th>
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<tbody>
<tr>
<td>1. Diagnostic tests and results</td>
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<tr>
<td>2. Cytology and pathology reports</td>
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<tr>
<td>3. Initiation and completion dates of various cancer treatments; brief description including names and cumulative dosages of chemotherapeutic agents; radiation site and total cGy</td>
</tr>
<tr>
<td>4. Summary reports from providers:</td>
</tr>
<tr>
<td>• Surgical oncologist/general surgeon</td>
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<tr>
<td>• Medical oncologist (chemotherapy, biotherapy, angiogenesis, and hormonal therapies)</td>
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<td>• Radiation oncologist</td>
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<tr>
<td>• Interventional radiologist</td>
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<tr>
<td>5. Bone marrow transplantation (if applicable)</td>
</tr>
<tr>
<td>6. Complications encountered during treatment</td>
</tr>
<tr>
<td>7. Insertion of vascular access devices or other devices</td>
</tr>
<tr>
<td>8. Support services used:</td>
</tr>
<tr>
<td>• Psychology team</td>
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<tr>
<td>• Chaplain</td>
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<tr>
<td>• Social worker</td>
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<td>• Financial counselor</td>
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<td>• Dietitian</td>
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<tr>
<td>• Physical/occupational therapist</td>
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<tr>
<td>• Exercise physiologist</td>
</tr>
<tr>
<td>9. Contact information:</td>
</tr>
<tr>
<td>• Physician/nurse practitioner/physician assistant name</td>
</tr>
<tr>
<td>• Address and phone number</td>
</tr>
<tr>
<td>• Emergency contact numbers</td>
</tr>
<tr>
<td>10. Primary care provider’s name and contact information</td>
</tr>
<tr>
<td>11. Recent disease evaluation/date/findings</td>
</tr>
<tr>
<td>12. Current medications, including over-the-counter and herbal preparations</td>
</tr>
</tbody>
</table>

Note. Based on information from Ganz, 2009a, 2009b; Haylock et al., 2007; Horning, 2008; Lotfi-Jam et al., 2009.
intended to (a) provide survivors with a succinct and complete summary of their primary cancer treatment, (b) enhance communication between the oncology healthcare team and other oncology and non-oncology providers, and (c) provide a learning tool for the primary care team (Earle et al., 2007; Ganz, 2009a, 2009b; Horning, 2008).

The second component of the survivorship care plan is an individualized written plan with personalized evidence-based recommendations for future care (Earle et al., 2007; Ganz, 2009a, 2009b). This segment should provide a clear timeline for follow-up care with identification of the frequency of examinations and the responsible physician or nurse practitioner who will facilitate adherence and long-term management. The care plan can be used in subsequent follow-up visits with ongoing evaluation and revision (Haylock et al., 2007). Transdisciplinary healthcare professionals involved in the survivor’s care also should be noted, as survivorship care may be shared by multiple disciplines.

Several formats have been proposed that include information about a number of topics (see Figure 34-3). This information serves to educate the survivor and primary care provider about the short- and long-term effects of cancer and related treatment (Ganz, 2009a, 2009b; Haylock et al., 2007; Horning, 2008) and should be presented in a clear, easy-to-read format that summarizes the information discussion in the post-treatment visit.

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**Figure 34-3. The Cancer Survivorship Care Plan: Future Care and Follow-Up**

1. Ongoing and future treatment toxicities specific to cancer type/treatment
   - Marrow toxicities (e.g., neutropenia, thrombocytopenia, anemia) and infections
   - Sexual functioning (e.g., loss of libido, erectile dysfunction, ejaculation issues, premature menopause, urogenital atrophy, dyspareunia)
   - Cardiotoxicities (e.g., cardiomyopathy, hypertension, thromboembolism, peripheral vascular disease)
   - Pulmonary toxicities (e.g., interstitial pneumonitis/scarring, bronchitis)
   - Oral changes (e.g., mucositis, periodontal disease, xerostomia, radionecrosis, osteonecrosis, Sjögren syndrome)
   - Endocrine alteration (e.g., hypothyroidism, decreased gonadal hormones, infertility, pituitary failure, metabolic syndrome, diabetes mellitus, premature menopause, menopausal symptoms)
   - Gastrointestinal symptoms (e.g., liver dysfunction, malabsorption syndromes, gastrointestinal tract strictures, motility disorders, hepatitis, altered elimination/ostomy)
   - Genitourinary symptoms (e.g., nephritis, renal dysfunction, hematuria, bladder scarring, interstitial cystitis, altered elimination/ostomy)
   - Skin changes (e.g., dryness, scaling, itching, irritation, scarring, strictures)
   - Musculoskeletal disorders (e.g., osteoporosis, avascular necrosis, muscle atrophy, lymphedema, incisional hernias, fatigue)
   - Central and peripheral nervous system changes (e.g., peripheral neuropathy, cognitive changes [chemobrain], alterations in concentration)
   - Ear/eye changes (e.g., ototoxicity, hearing loss, cataracts)

(Continued on next page)
Figure 34-3. The Cancer Survivorship Care Plan: Future Care and Follow-Up (Continued)

2. Symptoms to report
   - New or persistent nodules or lumps
   - New or persistent pain
   - New or persistent cough
   - New or persistent nausea or vomiting
   - New or persistent bleeding or bruising
   - New or persistent limb swelling
   - New or persistent changes in elimination patterns (bowel and bladder)
   - Change in weight greater than 10 lbs, including gain or loss
   - Persistent or progressive weakness, fatigue; limitations in exercise

3. Health maintenance for treatment-related toxicities/frequency/responsible provider

4. Cancer screening recommendations/frequency/responsible provider
   - Annual mammogram, starting at age 40 or sooner if strong family history and genetic mutation; monthly breast self-examination
   - Periodic colonoscopy, starting at age 50 or sooner if strong family history and genetic mutation
   - Skin examination, including monthly self-examination
   - Prostate screening with annual serum prostate-specific antigen/digital rectal examination
   - Pap test every 1–3 years, determined by personal risk factors

5. Personal risks/screening for second cancers related to treatment side effects (specific to cancer type and treatment)

6. Recommended follow-up appointments for primary cancer, scheduled tests (specific to cancer type and treatment) with frequency and responsible provider

7. Potential long-term effects of treatment and related symptoms (specific to cancer type and treatment)

8. Signs and symptoms of recurrence from primary cancer

9. Existing and potential psychosocial needs
   - Functional loss in performing activities of daily living
   - Functional loss in performing instrumental activities of daily living
   - Adjustment problems, including anxiety, depression, other psychological symptoms
   - Adjusted school and/or work-related schedules
   - Alterations in body image, cosmesis, or self-esteem
   - Partner/relationship issues
   - Communication issues

10. Recommendations for healthy behaviors
    - Exercise/physical activity
    - Weight management
    - Stress reduction
    - Smoking cessation
    - Healthy diet
    - Prevention of osteoporosis
    - Heart health, cholesterol and triglyceride levels
    - Comorbid conditions
    - Immunizations

11. Rehabilitation needs, including reconstruction and lymphedema

12. Family cancer-related health history and genetic testing, as applicable

13. Recommended referrals

14. Cancer survivorship–related resources

Note. Based on information from Ganz, 2009a, 2009b; Haylock et al., 2007.
Multiple cancer survivorship care plan formats have been published for professionals to use as written guides or as online or computerized templates. A Prescription for Living (Haylock et al., 2007), written by nurses, was one of the first published care plans (see Appendix L) and remains key in the survivorship movement. Another leader in survivorship care, the American Society of Clinical Oncology (ASCO), has authored manual and online templates of cancer treatment plans and summaries (ASCO, 2009). Multiple versions of the ASCO care plan templates are available, including a generic cancer treatment plan and summary (see Appendix M); an adjuvant breast cancer treatment plan, summary, and care plan; an adjuvant colon cancer treatment plan and summary (see Appendix N) and survivorship care plan (see Appendix O); and lung cancer treatment plans and summaries for limited- and extensive-stage disease (ASCO, 2009). These formats enable documentation of common issues related to cancer survivorship care with personalization of concerns and problems specific to each survivor.

The LIVESTRONG™ Care Plan (LIVESTRONG, n.d.), powered by Penn Medicine’s OncoLink, is an innovative online resource that healthcare professionals or survivors can complete, resulting in a multipage cancer- and treatment-specific care plan (see Appendix P for sample breast cancer–specific care plan results). This option provides the easiest method to initiate a survivorship care plan although it lacks a more specific treatment summary and personalized attention to problems unavailable on the server list. The Cancer Survivorship Care Plan (see Appendix Q for a sample care plan for breast cancer) is the first computer-based program with features that allow application of provider preferences and personalization to the patient and practice (Journey Forward, n.d.). The program is downloadable and offers free technical assistance.

Several small studies have provided evidence for patient and provider satisfaction with survivorship care plans (Baravelli et al., 2009; Burg, Lopez, Dailey, Keller, & Prendergast, 2009; Gates & Krishnasamy, 2009; Hewitt, Bamundo, Day, & Harvey, 2007; Hill-Kayser, Vachani, Hampshire, Jacobs, & Metz, 2009; Mao et al., 2009). However, no studies have been conducted that provide validation for the development, use, and intended outcomes of survivorship care plans. Although it is doubtful at this time that prospective studies will be initiated, rigorous retrospective reviews must be conducted to evaluate the effects of survivorship care plans on various outcomes related to healthy survivorship.

**BARRIERS IN THE PROVISION OF SURVIVORSHIP CARE PLANS**

Across the country, academic institutions and community hospitals have initiated or maintained cancer survivorship care programs, developed elements of cancer survivorship care planning, and initiated survivorship care plans at their respective sites. This task—easy in theory but difficult in practice—of providing each survivor with a personalized care plan and treatment summary
at the end of active treatment has enlightened cancer care advocates on the barriers in establishing the routine use of survivorship care plans (Ganz et al., 2008). The most commonly reported barriers are retrieval of accurate information, real-time entry into the care plan, resources to gather and input data, choice of forms to use, provider and patient review of the treatment summary and care plan, and reimbursement issues in providing this complex care (Ganz, 2009a; Lotfi-Jam et al., 2009).

Retrieval of Accurate Information

Correct and concise information for the cancer treatment summary is dependent on primary source medical records that must be obtained from various departments, time periods, electronic document programs, and institutions. The task can be daunting for even the most experienced clinician or office associate and requires dogged persistence (Ganz et al., 2008). For creation of the most comprehensive treatment summary, all source documents should be placed in the primary medical record at the point of care. Oncology providers should prepare a summary treatment note (e.g., surgery, chemotherapy, biotherapy, hormonal therapy, radiation therapy) at the end of their respective primary treatment that includes the planned course of treatment, treatment received, ongoing treatment (e.g., biotherapy and hormonal therapy), encountered difficulties, and required interventions. These detailed summary notes are commonly provided by the surgical and radiation oncology teams but are less commonly observed from medical oncologists (Ganz, 2009a).

Real-Time Entry of Data Into the Care Plan

Prospective entry of data is preferred to retrospective retrieval (Ganz, 2009a). Electronic medical records can ease the task of obtaining this information, but their worth is only as good as the accuracy and completeness of inputted information. Electronic medical records that are linked to the cancer survivorship care plan template provide the most comprehensive and accurate means of prospectively entering data into the plan with prepopulated data fields. The progressive care plan can be reviewed at each clinic encounter during primary treatment to ensure the accuracy and completeness of data. Most importantly, the care plan can be personalized to each individual patient with information about treatment toxicities, complications, interventions, and outcomes.

Resources to Gather and Input Data

Each practice must prioritize its goals in the provision of cancer survivorship care, including survivorship care planning and the implementation of cancer survivorship care plans. The team may focus on one cancer type, typically
identifying a common and “easier” cancer with known multiple resources. Breast, prostate, colon, testicular, and pediatric cancers have been the focus of successful cancer survivorship care programs (Ganz, 2009a; Jacobs et al., 2009). Identification of individuals who can assist with data input is paramount. Members from the technology group in the institution may help simplify electronic data retrieval and input.

**Forms to Use**

Multiple paper, electronic, and computer-generated forms exist to create patient-specific survivorship care plans as detailed previously. At the minimum, providers can complete and instruct patients to use the LIVESTRONG online format and create a disease- and treatment-specific survivorship care plan, albeit minus specific characteristics of a personalized plan. One format does not work for all professionals, nor do all patient populations fit one format. The choice is up to each oncology healthcare team; the challenge is to choose one cancer, one form, one patient, and get started!

**Provider and Patient Review**

The follow-up clinic visit at the end of active primary cancer treatment is the designated time to review the cancer survivorship care plan with the patient. Typically, this visit focuses on residual, acute symptoms from treatment and offers little time to focus on the future with shared conversation about the survivorship care plan. Limited evidence is available to guide practitioners, although several academic institutions and community hospitals have established survivorship clinics that are managed by advanced practice nurses (Economou, Edgington, & Deutsch, 2010; Gates & Krishnasamy, 2009; Jacobs & Hobbie, 2002), thus freeing the oncologists to focus on acute oncology care. Experienced oncology RNs are also vital members of the survivorship care team (Gates & Krishnasamy, 2009). For a successful transition of care, the oncologist must reinforce the nursing role with the patient, relinquish control of care following active treatment, and approve the allotted time for this role (Baravelli et al., 2009; Hewitt et al., 2007; Kantsiper et al., 2009).

**Reimbursement Issues**

Reimbursement codes exist for the time spent with the patient to review and discuss the survivorship care plan, but they often are inadequate to cover the time required to both develop and administer the care plan (Hewitt et al., 2007). Oncology practices have creatively identified niches in the coding system to cover a 60–120-minute visit, including modification of “V” codes (Ganz, 2009a). Further work is needed to identify reimbursement codes that are workable for all.
SUMMARY

Cancer survivorship care, survivorship care planning, and implementation of the survivorship care plan are supported by clinical intuitive sense, although limited empirical data exist at present to support their efficacy. Based on survivor comments and suggestions, with the survivor being the core of survivorship activities (see Figure 34-1), IOM (2006) has delivered the challenge for comprehensive survivorship care. Each practice must identify the plan that is fiscally responsible yet directed to implementation of the IOM initiatives. Disease-free and disease-controlled survivorship is a reality with innovative treatments, but we must account for the short- and long-term side effects of these lifesaving interventions. The implementation of survivorship care plans will provide the basis for identification of needs and ongoing survivorship care.

REFERENCES


“Whenever or however the line from health to illness is crossed, we enter the realm of the soul.”

—From Bolen, 2007, p. 5

INTRODUCTION

The first hurdle confronting individuals with metastatic cancer is an overwhelming recognition that life prior to illness will never be recaptured and restored to its previous state of being. Mortality is no longer a distant imagination, but a reality that is imminent and tangible. Cancer, specifically metastatic cancer, brings uncertainty and an unwelcome life trajectory that alters one’s goals and dreams. Metastatic cancer creates a level of distress in proportion to the severity of threat to the integrity of the person (Cassel, 1982; Holland & Bultz, 2007). Physical symptoms and distress due to cancer are substantial for patients with metastasis (Mor, Masterson-Allen, Houts, & Siegel, 1992). Distress from metastatic cancer is amplified by spiritual burdens (Balboni et al., 2010), psychosocial stressors (Holland & Bultz, 2007), and disease-related life decisions (Maltoni et al., 2005).

This chapter will evaluate important limitations in existing survivorship models relevant to people with metastasis. Burdens are so unique for this subgroup of patients that we advocate for a comprehensive modification of survivorship care models to address the needs of patients with metastatic, recurrent, or progressive cancer using the principles of palliative cancer care (Ferris et al., 2009). In our practice at a U.S. cancer research hospital, palliative cancer care is a dynamic chronic disease management model for survivorship that embraces all patients with metastatic disease whether or not they are
actively receiving oncologic treatment. The paradigm of survivorship for metastatic, recurrent, or progressive disease should acknowledge that these conditions are now chronic illnesses and are not equated with an imminent death.

HEALTHCARE DISPARITIES AND PATIENTS WITH METASTASIS

Survivors with disease progression five years or more after initial diagnosis report inferior general health status on quality-of-life instruments and a lower cancer-specific health-related quality of life as compared to disease-free survivors. Short-term survivors with disease progression less than five years after initial diagnosis report even poorer health status and health-related quality of life (Thong, Mols, Coebergh, Roukema, & van de Poll-Franse, 2009). These and other studies demonstrate that survivors with metastatic cancer are a vulnerable population at risk for healthcare disparities, defined as “population-specific differences in the presence of disease, health outcomes, or access to health care” (U.S. Department of Health and Human Services, 2001). What is the size of this population?

A review of the survivorship literature raises more questions than answers for people with metastatic cancers. Although remarkable discoveries in the research, care, and treatment of cancer have occurred, for the 560,000 people (see Table 35-1) in the United States dying annually of cancer (Centers for Disease Control and Prevention, 2009a), and for the proportion of

<table>
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<tr>
<th>Table 35-1. Trends in U.S. Cancer Mortality Rates*</th>
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<tr>
<td>Measure</td>
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<tr>
<td>U.S. cancer mortality/100,000</td>
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<tr>
<td>Total U.S. population</td>
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<tr>
<td>Total cancer deaths (est.)</td>
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<tr>
<td>Total persons alive with metastatic disease</td>
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<tr>
<td>Total family members adversely affected</td>
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<td>Average life span with metastases</td>
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* All primary cancer sites combined

millions of cancer survivors living with metastatic disease, no cure for cancer exists. Although 3.5% of U.S. citizens today are cancer survivors (Hewitt & Ganz, 2006), no subgroup analysis has been performed on Surveillance, Epidemiology, and End Results (or SEER) data to identify people with prevalent metastases—perhaps the most vulnerable group of cancer survivors. The number could be as high as 2.3–6.2 million (Horner et al., 2009). Where does this proportion of people fit into survivorship models?

If those with metastatic disease are vulnerable patients, do available models of survivorship care (Ganz, 2007) address their needs? Fitzhugh Mullan’s (1985) original model shifted from an extended stage to a permanent stage with the assumption that remission and long-term survival were the only possible outcomes. Fiore (1990) introduced a model that designated a shift from termination of active therapy or rehabilitation to post-five-year survival status. Only one early model described by Mages and Mendelsohn (1979) included recurrence and death in the survivorship continuum. In 2004, the National Action Plan for Cancer Survivorship—Advancing Public Health Strategies emphasized control of long-term and late effects of treatment but did not address specific needs for patients with metastatic disease (Centers for Disease Control and Prevention, 2009b). Although Feuerstein (2007) acknowledged subacute, chronic, and end-stage cancer in his biopsychosocial model diagram, no long-term innovative approach to meet stage-based needs has been implemented. The development of new models of care delivery is encouraged by organizations such as the Lance Armstrong Foundation (2009), which supports survivorship clinics in its funded network centers. However, survivorship clinics are in the early phase of development (MacBride & Whyte, 1998).

“Shared care” models presume that cancer survivors have more office visits for cancer care with primary care physicians than with oncologists (Earle, 2007). However, in our practice, patients with new and chronic metastatic disease typically encounter their cancer hospital specialists more frequently than their primary care physicians. Discordance between oncologists’ and primary care physicians’ expectations of care during cancer treatment may be greatest for patients with metastatic disease (Cheung, Neville, Cameron, Cook, & Earle, 2009). For example, the Institute of Medicine (IOM, 2006) report From Cancer Patient to Cancer Survivor: Lost in Transition recommended that an “end of treatment summary and survivorship care plan” be sent to primary care physicians, implicitly excluding those whose treatment is not ending (as quoted in Ganz, 2007, p. 3, emphasis added).

Patients deserve a written survivorship care plan at the onset of treatment that can be modified along their journey and not solely triggered by treatment cessation. Current care plans emphasize the late and long-term effects of cancer treatments on long-term cancer survivors, defined as people who are five or more years beyond their initial diagnosis (IOM, 2006). Unfortunately, this qualification excludes patients who are less than five years from diagnosis who experience adverse effects, for example, having undergone second-, third-, or
thefourth-line chemotherapy. These at-risk individuals experience many problems (Chen & Tseng, 2005), including neuropathy, gonadal toxicity, lymphedema, fatigue, neurocognitive deficits, and financial distress (Meropol et al., 2009).

**A CHALLENGING NEW PARADIGM: PALLIATIVE CANCER CARE**

In 2009, the Board of Directors of the American Society of Clinical Oncology (ASCO) adopted recommendations of a consensus panel to deliver palliative cancer care for all patients with cancer from initial diagnosis to death, and following death by providing bereavement support for families (Ferris et al., 2009). The process begins with an assessment of symptoms, distress, and life decisions at the time of the initial oncology visit. Ferris and colleagues advocated an integration of palliative cancer care on a chronic basis throughout the cancer trajectory to include quality improvement initiatives and research. Training, advocacy, and education are warranted, as 90% of surveyed ASCO members reported that they learn palliative care principles through trial and error, and 38% reported that their learning occurs through a traumatic experience with a patient (Emanuel, Ferris, & von Gunten, 2002; Hilden et al., 2001).

This new paradigm challenges clinicians of all specialties. Clinicians may view chronic illness (particularly if patients are not currently receiving oncologic therapies) as an “overwhelming burden that has little likelihood of improvement despite one’s best efforts”; more worrisome is a traditional view from the behavioral health literature that professionals may develop strong negative feelings about people whom they feel impotent to help (Kane, Priester, & Totten, 2005, p. 209). On the other hand, palliative care specialists most familiar with end-of-life care may have little experience meeting the chronic care needs of ambulatory patients with metastasis who are undergoing oncologic therapies. How will this framework be implemented?

From a research perspective, best supportive care (BSC) may include the provision of palliative cancer care to those with advanced illness. In cancer chemotherapy research studies, BSC is delivered either in direct comparison to treatments or in conjunction with a new treatment. Cherny et al. (2009) reviewed BSC in cancer research trials and found problematic deficiencies. In a review of treatment plus BSC versus BSC alone, none of 20 eligible studies contained a description of contemporaneous standards for BSC. Sixteen of 20 studies did not present any details of the care actually delivered in the BSC arm. To protect human research subjects, the Declaration of Helsinki “explicitly rejects a ‘usual practice standard’ for control arms when usual practice is inferior to best practices and one that may result in significant untoward patient consequences” (Cherny et al., 2009, p. 5480). The authors concluded that a “lack of rigor in supportive care practices has contributed to a generation of research with ethical flaws and methodological shortcomings that may have contributed to biased outcomes” (p. 5480). This strong statement invokes a
call to question the ethical compliance and scientific validity for such studies frequently involving people with metastatic disease. Can BSC, as is described or not described in clinical trials, be translated to chronic survivorship care of patients with metastatic cancers? According to ASCO, survivorship care is interdisciplinary care, and interdisciplinary care is the best supportive care delivered on a chronic basis throughout the patient’s disease trajectory (Ferris et al., 2009).

PALLIATIVE CANCER CARE AS A CHRONIC DISEASE MANAGEMENT APPROACH

IOM (2001) recommended a redesign of the nation’s healthcare system to include improved management of chronic conditions such as cancer. Unfortunately, chronic disease management is not routinely taught in medical or nursing schools. It also is not the forte of large, traditionally acute-care inpatient facilities. New cancer treatments have achieved cures, as well as extended life for those not cured; now that metastatic cancer is a chronic condition, what guiding principles are available to enhance survivorship care?

Survival rates for nearly all cancers have increased in the past 30 years; however, the percentages of patients with regional (24%) and distant (21%) metastasis are substantial (see Appendix R and Appendix S) (Horner et al., 2009). For example, patients with stage IV non-Hodgkin lymphoma (NHL) comprise 47% of diagnosed patients with NHL and survive five years or more in 75% of cases (Horner et al., 2009). These longevity gains from oncologic treatment signify that ambulatory palliative cancer care is no longer an oxymoron for people with metastasis. In an 11-year period from 1995 to 2006, ambulatory care visits for cancer increased by 12%, and hospital discharges for cancer decreased by 26% (Decker, Schappert, & Sisk, 2009). The ambulatory setting is an ideal environment to deliver chronic survivorship care in a “palliative cancer care” approach. For example, investigators found improved survival (11.6 months versus 8.9 months; \( p \leq 0.02 \)) and improved quality of life (98.0 versus 91.5 on the Functional Assessment of Cancer Therapy–Lung scale; \( p = 0.03 \)) in patients with newly diagnosed metastatic lung cancer randomized to receive supportive care through an interdisciplinary palliative care clinic compared to control patients (Temel et al., 2010). For study patients, palliative cancer care in a clinic setting was delivered simultaneously while the patients were undergoing oncologic treatments (Temel et al., 2010).

Survivorship care for patients with metastatic disease may be best described by principles of chronic disease management and, at the appropriate time, end-of-life care. Patients and their clinicians alike face uncertainty; new therapies have made prognoses less predictable, and patients with advanced disease are living longer (Scitovsky, 2005). In our cancer research facility, we encounter a highly motivated group of patients with advanced cancer who are experiencing
the benefits of life-prolonging oncologic care. Our palliative cancer care ambulatory clinic has approximately 800 patients annually, with an average patient survival after initial clinic visit of 272 days, typically several years from initial diagnosis and one to two years from first metastasis. Considering these lengthy time intervals, it would seem reasonable that recognizing palliative cancer care needs at all points on the cancer care continuum may be a good organizational approach to integrate chronic survivorship care into clinical practice.

For example, given that patients with lung cancer often present with advanced disease identified at thoracotomy, we identified inpatients with substantial symptom burdens and supportive care needs at a postoperative juncture in their cancer trajectory. We organized a transdisciplinary approach where thoracic surgical oncologists and palliative care specialists performed daily palliative cancer care assessments at the point of care, managed symptoms, and developed care plans together. In a retrospective review of more than 1,100 patients, we found that this approach resulted in sustained improvements in pain relief, patient satisfaction, interdisciplinary care needs met, and healthcare costs (Adolph, Taylor, Ross, Vaida, & Moffatt-Bruce, 2009). Thereafter, patients and families were directed into a palliative cancer care continuum that included interdisciplinary ambulatory care. Remarkably, average monthly accruals in thoracic oncology clinical trials increased by 53% during the same period (James Cancer Hospital Clinical Trials Office, personal communication, April 25, 2010).

In our clinical experience with inpatient and ambulatory palliative cancer care for patients with metastasis, a care plan involving a time span of months to years most closely resembles chronic disease management (Kane et al., 2005). How is palliative cancer care delivered effectively for people with metastatic disease in a chronic disease management approach, if an ill-defined “best supportive care” misses the mark (Jack, Boland, Dickson, Stevenson, & McLeod, 2010)? A BSC approach as variably described in time-limited clinical drug trials is not adaptable to the chronic care of patients with metastatic cancer. Palliative cancer care implies a much broader focus: interdisciplinary chronic disease management (Ferris et al., 2009; Levy et al., 2009) and, when the time comes, a shift toward specialized end-of-life care (Ferris et al., 2009).

A system built with expert disease management nurses, a pharmacist, a psychologist, a chaplain, and a social work specialist is able to support patients in an ambulatory palliative cancer care survivorship practice providing personalized health care. Our psychologist and social worker provide counseling services and engage patient navigators to help match patients with community resources. Nurses and pharmacists educate patients and families in self-management strategies to achieve an acceptable quality of life. Integration of self-management is an important part of the care plan owned by an individual patient. Patients can attain a sense of transcendence in self-managing their chronic illness while living a personally meaningful life, including at the end of life (Block, 2001).
In chronic survivorship care, interdisciplinary clinicians can support outpatients and families experiencing a progressive or uncertain cancer trajectory. Transitions and handoffs to interdisciplinary experts are relatively seamless but may be limited by the patient’s travel distance or rural community resources. We formed partnerships with community organizations to facilitate survivorship care plans. Innovative ways to communicate effectively, promote patient safety, and reduce medication errors can be deployed when interdisciplinary palliative cancer care clinicians help build and maintain an ambulatory electronic medical record system. We have also applied technologic solutions to outpatient prescription management for chronic symptom control.

Interdisciplinary care plans are at the heart of survivorship care. Nurses, chaplains, and other clinicians can encourage this important work and contribute to a survivorship care plan. Mullan described that “the challenge in overcoming cancer is not only to find therapies that will prevent or arrest the disease quickly, but also to map the middle ground and minimize its medical and social hazards” (Mullan, 1985, p. 271). The survivor with metastasis encounters healthcare systems and personnel more frequently than any single group of patients with cancer (Farjah et al., 2009), thereby increasing his or her exposure to medical and social hazards. Access to interdisciplinary care is an approach to mitigate such hazards.

A person’s initial reaction to news of metastatic disease will be followed by fluctuating responses from diagnosis, to treatment, to end-stage cancer (Highfield, 1997). Illness brings about change; spiritual resources and strength are likely to ebb and flow over time. People with a new metastatic diagnosis will begin an inventory of their life and then work through the meaning of their life. They will review relationships, consider forgiveness, and identify new sources of hope. The answers to these life review processes form the patient’s perspective while proceeding through treatment and the realities of disease. Finally, our service has a well-developed decision support mechanism for complex case care. For example, substance abuse, psychopathology, and aberrant opioid use behaviors in survivorship are complex and unique issues for patients receiving controlled substances prescribed for chronic cancer pain (Whitcomb, Kirsh, & Passik, 2002). This comprehensive approach to cancer survivorship care in an ambulatory setting implements the principles described in Wagner’s Chronic Care Model originally published in 1996 (Wagner, Austin, & Von Korff, 1996).

**CASE STUDY**

M.J., an African American male in his mid-50s, visited his family physician for a routine examination and was diagnosed with stage IV prostate cancer that included painful bony metastasis at presentation. When offered treatment, he decided to pursue it because he felt he had more work to do in mentoring young people in his community and church. Bone metastases
in his shoulder limited his ability to lift heavy objects, including his Bible. Upon meeting him during a hospital stay, the chaplain made the following observations: the patient was a person of strong faith and was active in community and church; he had strong ties to family and was extremely positive and yet had realistic expectations and goals related to his cancer. At this point, the patient was still able to walk and planned on going back to doing God’s work once he was discharged from the hospital. However, with progressive disease, he experienced depression, lost his health insurance, and required home physical therapy while on second-line chemotherapy. M.J. should not have to wait until cessation of cancer therapy for a detailed written survivorship care plan. Having a well-designed plan in hand at initial diagnosis, adaptable at each clinical change, would ease some of his uncertainty and help him work through his personal life tasks during this phase of illness.

**SUMMARY**

Deficits in historical survivorship models and their implementation functionally exclude the vulnerable patient with metastatic disease. Chronic disease management is an innovation beginning to diffuse throughout the U.S. healthcare system; patients with metastatic cancer deserve inclusion in survivorship models of chronic illness that meet their specific needs. Interdisciplinary clinical survivorship care is best delivered in a chronic disease model where patients may be entered by assessment and recognition of palliative cancer care needs at all points across the continuum of care. This care can be delivered before, during, and after oncologic therapies. BSC predominantly applied in cancer therapeutics research has semantic and operational problems; this term should be abandoned in clinical survivorship practice. An expansion of expert nursing care and collaboration with interdisciplinary specialists are important components of chronic disease management as outlined in ASCO’s model of palliative cancer care. We endorse a written survivorship care plan at the time of diagnosis that is dynamic and can be modified by the patient and interdisciplinary specialists.

**REFERENCES**


INTRODUCTION

Cancer is the second leading cause of adult death in the United States (Centers for Disease Control and Prevention, 2009). Approximately 60% of people diagnosed with cancer are age 65 years or older (Carreca & Balducci, 2009). The median age of cancer diagnoses is 65 years of age, and the median age of cancer-related deaths is 73 years of age (Muss, 2009). Women age 70 and older are two times more likely to develop cancer than those age 50 or younger. Among the female population age 50 and older, breast cancer is the most common cancer in the United States (American Cancer Society, 2010). Although varying statistics exist about the anticipated number of cancer survivors in the United States, cancer survivors aged 50–85 years represent approximately 70% of all patients with cancer and that at least 6.5 million survivors are older than 65 (American Society of Clinical Oncology, 2004). As the population continues to grow older and life expectancy extends, these estimations have the potential to exponentially increase.

The term older adult has been defined in many ways: (a) government services arbitrarily designate senior citizen status at age 65; (b) geriatric specialists divide this population into three categories, young-old (age 65–74), old (age 75–84), and oldest-old (85 and older); and (c) a number of colloquial and coined definitions exist for people age 50 and older. Of note, in the population of people older than 65, the fastest growing subgroup are those age 85 and older (Centers for Disease Control and Prevention, 2009). Despite these varying definitions for older adult, it is important to note that chronologic age is not always indicative of physiologic age. Physiologic age takes into account functional status, comorbidity, frailty, and the presence of geriatric syndromes (Carreca & Balducci, 2009).
IMPACT OF AGING ON HEALTH STATUS

Advanced age in general is associated with inadequate cancer diagnosis and treatment and can translate into shorter survival time (Wedding, Röhrig, Klippstein, Pientka, & Höffken, 2007). Controversy exists among practitioners in regard to older adults and recommended treatment for cancer, including appropriateness for surgery, ability to tolerate chemotherapy, screening and prevention of other cancers, initiation of end-of-life care, and participation of older adults in clinical trials. As a result, the National Comprehensive Cancer Network (NCCN, 2009) established senior adult oncology recommendations for practitioners, estimating life expectancy based on function and comorbidities rather than chronologic age alone. The guidelines state that if the treatment diminishes an individual’s quality of life with no significant survival benefit, the treatment should be avoided (NCCN, 2009). Otherwise, older adults should be availed the same treatment and long-term follow-up options as their younger counterparts.

Several assessment tools are available to assist practitioners in determining risk for treatment. The most inclusive is the comprehensive geriatric assessment tool, which incorporates physical activity, comorbidity index, function, socioeconomic issues, and the presence of geriatric syndromes (Carreca & Balducci, 2009). A limitation of this assessment tool is the length and time it requires to complete, making it difficult to administer in an office setting.

Another important factor to consider is depression, which is a significant factor in the geriatric population and can increase the risk of death for older adults with cancer (Taira, Sawaki, Takahashi, Shimozuma, & Ohashi, 2010). As such, clinicians should routinely assess for and treat depression. The geriatric depression scale is a valid and reliable instrument in detecting depression in the older adult (Yesavage et al., 1982).

Other predictors can identify poorer outcomes in the older adult with cancer, such as increased age, increased pain, decreased physical functioning, and decreased appetite, which have all been shown to negatively affect survival (Quinten et al., 2009). Psychosocial factors can be predictors as well as mediators for survival. Adequate psychosocial screenings should be included in assessment prior to treatment. Additionally, assessment of an older adult’s access to social resources is vitally important.

SIDE EFFECTS OF CANCER TREATMENT WITH OLDER ADULTS

Common side effects of cancer treatment in the older adult include nausea, vomiting, and pain. These effects do not cease once treatment has stopped but often persist and can even become significant end-of-life issues. In a recent study of long-term survivors of breast, prostate, and colorectal cancers, 40% reported at least one symptom related to cancer or treatment, with pain
(21%) being the most commonly reported symptom (Deimling, Bowman, Sterns, & Wagner, 2004).

**Nausea and Vomiting**

The most common causes of nausea and vomiting in the geriatric patient with cancer include chemotherapy-induced nausea and vomiting (CINV), opioid-induced poor gastrointestinal tract motility, and malignant bowel obstruction. The mechanism behind CINV is multifactorial; however, it generally is believed that chemotherapy itself activates the chemoreceptor trigger zone (CTZ) (Wood, Shega, Lynch, & Von Roenn, 2007). Opioid-induced nausea and vomiting is typically generated by dopamine receptor stimulation in the gastrointestinal tract and the periphery. Poor gastrointestinal motility also can activate peripheral pathways. Bowel obstruction not only activates peripheral pathways but also stimulates the CTZ with inflammatory mediators. Therefore, the geriatric patient undergoing chemotherapy may face a number of physiologic challenges that induce, produce, or sustain nausea and vomiting.

As the mechanisms underlying nausea and vomiting become better understood for each individual geriatric patient, medications can be personalized. Medications that target the D$_2$ receptor (metoclopramide, prochlorperazine, and haloperidol) are the best drugs to initially prescribe because they work within the CTZ and in the gastrointestinal tract (Wood et al., 2007). If nausea is not relieved, it may be more beneficial to add a second medication rather than switch to another medication class (Wood et al., 2007). Adverse drug effects and individual comorbidities should be evaluated when choosing or adding medications because the geriatric patient may be more susceptible to side effects. Ondansetron and palonosetron are beneficial with CTZ activation but can cause constipation and prolonged QT interval. Promethazine can successfully treat nausea and vomiting associated with the CTZ; however, urinary retention and extrapyramidal side effects (tremor, slurred speech, sedation, and anxiety) make this drug a suboptimal choice in the older adult (Fick et al., 2003; Wood et al., 2007).

**Pain**

Pain is one of the most frequently reported symptoms in this age group regardless of survivorship stage (Beck, Towsley, Caserta, Lindau, & Dudley, 2009). At least 42% of older adult patients with cancer report unrelieved pain (Barford & D’Olimpio, 2008). Multiple factors can contribute to poor pain management in the older adult, including pain-related barriers and myths. Clinicians, as well as patients, may believe that pain is an expected effect of aging and may “accept” a certain level of pain without intervention. Clinicians may not adequately assess the older person’s pain, especially in patients with cognitive impairment who may not adequately understand the use of pain scales. Issues regarding polypharmacy and adverse drug effects in patients
with declining organ function are of added concern (Barford & D’Olimpio, 2008; Mercadante & Arcuri, 2007).

Pain treatment is an essential part of caring for a patient with cancer. Although older adults may be more sensitive to drug side effects, knowledgeable practitioners can provide appropriate treatment and safely achieve relief from cancer pain. Unrelieved pain can lead to depression, sleep and appetite disturbances, and an increase in healthcare utilization and cost (Mercadante & Arcuri, 2007). Cancer pain can present as both nociceptive (physical) and neuropathic (nerve) pain. Analgesics are commonly prescribed; however, antidepressants and newer GABAergic medications also may be effective agents in treating pain, especially neuropathic pain. GABA, or gamma-aminobutyric acid, is the most abundant inhibitory neurotransmitter in the brain. Although GABA is an amino acid, it is classified as a neurotransmitter and helps induce relaxation and sleep (Barford & D’Olimpio, 2008). Clinicians may consider initiation of short-acting interventions, with transition to longer-acting regimens with breakthrough medication once the patient is stable.

Acetaminophen or nonsteroidal anti-inflammatory drugs (NSAIDs) (e.g., ibuprofen, naproxen) often are the first-line agents in treating pain. If NSAIDs are contraindicated because of liver dysfunction, clotting disorders, renal insufficiency, or gastrointestinal ulcers, or when pain is no longer controlled, opioids are the analgesic of choice. Although hepatic function is a concern when dosing opioids, studies have indicated that renal function is equally as important (Fick et al., 2003), as most opioids are excreted via the renal system. If renal function is impaired, the patient will have a greater risk of overall side effects with oversedation.

Older adults may achieve pain relief at lower dosages than younger people who report the same pain severity (Sutton, Demark-Wahnefried, & Clipp, 2003). A good rule of thumb when initiating and titrating opioids is to start low and go slow. Short-acting agents (morphine, oxycodone, hydromorphone) are preferred to long-acting agents (methadone, fentanyl patches) when initiating therapy. Once patients are stabilized on a pain regimen, they can be converted to long-acting forms of similar medications. Methadone is an acceptable long-acting agent in older adults because it requires minimal renal clearance. However, methadone has an extremely long half-life and requires a slow titration by an experienced clinician (Mercadante & Arcuri, 2007). Fentanyl patches are an alternative long-acting pain medication with a 72-hour dosing schedule. Fentanyl patches can be considered in older adults, but clinicians must exercise caution related to differing fat distribution from that of younger patients.

Neuropathic pain often is described as a shooting or burning pain and can be difficult to treat. Older adults can be treated with common drugs such as gabapentin or pregabalin although clinicians should be aware that these medications require adjustment for renal function (Barford & D’Olimpio, 2008). Antidepressants also are useful in treating neuropathic pain. Serotonin norepinephrine reuptake inhibitors (venlafaxine and duloxetine) may be safer than tricyclic antidepressants, which can cause sedation and confusion.
Overall, these drug classifications should be prescribed with caution in order to maximize the older person’s safety related to falls and injury.

Polypharmacy

It is estimated that all people age 65 and older take two to nine prescription medications each day. Additionally, 50% take two to four over-the-counter medications daily, and 47%–59% ingest vitamins or minerals daily (Flood, Carrol, Le, & Brown, 2009). The most common cause for the overprescription of medications is the recommendation of a medication without a true indication (Hajjar, Cafiero, & Hanlon, 2007). Polypharmacy in the older adult is an issue due to habitual, social medications as well as the necessary treatment of comorbid conditions. In an effort to avoid polypharmacy, each medication should be examined for its indication, side effects, potential drug interactions, and overall benefit to the patient.

The ability of clinicians to avoid drug-drug interactions has become more difficult because of the cumbersome number of medications on the market and the widespread use of multiple pharmacies for one patient. Most patients with cancer, including older adults, have multiple physicians/prescribers, such as a medical oncologist, surgical oncologist, radiation oncologist, primary care provider, and other specialists related to their comorbidities. It is a common dilemma for one provider to treat a side effect of a medication with an additional medication rather than stopping the original offending agent. The primary care provider is the key coordinator and should be included in the overall oncologic management of the geriatric patient.

Polypharmacy is a significant risk factor in the exacerbation of common geriatric syndromes such as dementia, delirium, depression, malnutrition, falls, or urinary incontinence (Flood et al., 2009). Older adults have demonstrated altered medication adherence rates, with adherence to only three out of every four prescribed medications (Hajjar et al., 2007). In an attempt to clarify all medications and their prescribed schedules, healthcare providers should update, print, and explain medication lists at each visit and with each change of medication.

The effects of polypharmacy are not only clinical but economic as well. Thirty percent of hospital admissions within the older adult population can be attributed to drug-related causes (Hajjar et al., 2007). The Institute of Medicine estimated the financial burden of polypharmacy at nearly $8 billion nationally (Fick et al., 2003). This situation can be especially difficult for those individuals older than age 65 who live on a fixed income. Many patients must decide between paying for medications versus purchasing food and maintaining their utilities and household. This economic burden has been reduced with the introduction of $4 medication programs and pharmaceutical company-sponsored hardship programs. The surge of these medication programs within large chain pharmacy and grocery stores has led to a greater understanding of the costs of drugs, as well as a coordinated effort to prescribe and provide economic pharmaceutical agents.
GERIATRIC SYNDROMES

The term _geriatric syndromes_ has been embraced to highlight the unique features of common health conditions in older adults. Often, a clustering of symptoms composes the syndrome, including dementia, failure to thrive, delirium, and falls. The multidisciplinary team should routinely conduct diligent assessment, prevention, and treatment of these syndromes.

Dementia

Dementia can be defined as an impairment of global intellectual and cognitive function characterized by memory loss, difficulty with problem solving, organization difficulties, and abstract thinking (Knopman et al., 2001). Three major types of dementia exist: Alzheimer dementia, vascular dementia, and Lewy body dementia. Patients with dementia who are hospitalized or undergoing cancer treatments are more likely to experience increased confusion with delirium and increased fall rates (Lyketsos et al., 2002). Accurate assessment of the older adult patient’s cognitive status is imperative to the prevention of negative outcomes. The Mini-Mental State Examination is the most frequently used tool to diagnose dementia.

Failure to Thrive

Failure to thrive in an older adult is a syndrome with symptoms of weight loss, decreased appetite, poor nutrition, inactivity, potential dehydration, depression, and impaired immune function. It is estimated that failure to thrive affects 5%–35% of community-dwelling older adults and 25%–40% of those residing in nursing homes (Knopman et al., 2001). Malnutrition itself is an independent predictor of mortality in older adults. Treatment of suspected or actual failure to thrive should focus on any identifiable causes (e.g., chemotherapy, radiation, surgery, medications) with a comprehensive plan to prevent or treat symptoms. Assessment of dietary habits, metabolic markers, and physiologic processes is inherent to the prevention and treatment of malnutrition. Nutritional supplementation is a vital intervention and should be routinely implemented in the older adult patient’s diet (Huffman, 2002). Dietary supplements should be given between meals rather than with meals to help decrease early satiety and maximize caloric intake.

Delirium

Delirium is defined as an acute disorder of attention with onset in hours to days, characterized by confusion and disorientation (Inouye, 2000). Risk factors for the development of delirium include age, dementia, frailty, comorbidities, infection, dehydration, polypharmacy, sensory impairments, and sleep deprivation. Older adults presenting with infection often exhibit symptoms
of delirium without accompanying increases in white blood cell count or fever. Treatment of delirium is based on identifying the cause and providing appropriate treatment with an eventual return to baseline.

Falls

Thirty percent of older adults who live at home experience at least one fall annually (Day et al., 2002). This is a critical issue to consider in older adult cancer survivors who may live alone at home. Injurious falls also are the primary cause of accidental deaths in this age group (Tinetti, 2003). Commonly, falls result in hip fractures, which can lead to multiple complications and a significant reduction in the pre-fall level of independent activities. Complications related to falls are the leading cause of death in patients age 70 and older (Tinetti, 2003).

Multiple methods exist to assess the risk for falling at home, in a nursing facility, or in the hospital. The “get up and go” test is perhaps the easiest and most time efficient way to assess for fall risk (Podsiadlo & Richardson, 1991). This test involves asking a patient to rise from a seated position, stand for 15 seconds, and then walk. Any difficulty indicates a risk for falls. A home assessment is also crucial to ensure safety from environmental hazards in the older adult.

SUMMARY

Older adults with cancer have unique needs during all aspects of their survivorship. It is safe for older adults to receive treatment for cancer; however, proper assessment and careful consideration of all options are paramount. The ultimate goal of treatment is a preservation of physical and psychosocial function. Function can be limited if common symptoms such as nausea, vomiting, and pain are not addressed. It is vital that clinicians continually assess geriatric cancer survivors for the presence of geriatric syndromes, as these syndromes can limit treatment and quality of life. As the worldwide population continues to grow older, the quality of geriatric cancer survivorship will depend on the ongoing assessment and interventions for geriatric cancer survivors across the survivorship continuum.

REFERENCES


INTRODUCTION

In a small, crowded room on a brutally hot day in Washington, DC, five cancer survivors took their places at the front of a basement conference room on Capitol Hill and nervously flipped through their notes. In a few minutes, they would share the floor with world experts on cancer treatment and address a group of congressional staffers on the deficiencies of their own cancer care. Two had relationships with their senators and representatives; three had never spoken publicly as advocates before. One had been told repeatedly that she had only months to live over the past 11 years, but through her own dogged persistence in getting new and better treatments, she was still here. Another, whose recurrence was missed by her doctor until she went back and demanded an x-ray, died just a few months after the briefing.

Survivorship advocacy by cancer survivors, their loved ones, and their healthcare providers is a cornerstone in the fight to improve the way that health care is delivered, research is funded, and illnesses are prevented, screened for, and treated (Clark & Stovall, 1996). Advocacy by patients and healthcare providers has led to some of the most important advances in cancer care delivery, from the National Coalition for Cancer Survivorship’s (NCCS’s) insistence on changing the very terminology used to talk about people with cancer (Stovall, 2005) to efforts to eliminate discriminatory insurance practices against people with cancer histories. Survivor- and provider-advocates have already achieved many successes. They have (a) opened the door to allow pediatric cancer survivors to serve in the armed forces, (b) allowed use of compendia to describe acceptable off-label uses for drugs, and (c) used the Americans with Disabilities Act to combat discrimination against people with cancer (Monaco, 1992).

This chapter will define survivorship advocacy, examine how advocacy skills can be employed across a continuum from self-advocacy to public interest efforts, and explain why survivorship advocacy is so important. It also will look at the role that healthcare professionals can play in fostering
advocacy skills with their patients and engaging them in opportunities to share their experiences.

THE SIX BASIC ADVOCACY SKILLS

Advocacy is defined as “active support, which includes directly representing, defending, intervening, or recommending a course of action” (Hoffman & Stovall, 2006, p. 5154). Empowerment has been described as “a process of increasing personal, interpersonal, or political power so that individuals can take action to improve their life situation” (Gutiérrez, 1990, p. 149). Combining these concepts, empowered survivor-advocates know and understand their choices and have the ability to act upon them, and gain familiarity with and access to important resources (O’Hair et al., 2003).

When a person is diagnosed with cancer, the person and his or her loved ones (or “co-survivors”) often face a crisis for which the individual’s usual problem-solving skills and coping mechanisms may not be adequate or may simply be forgotten (Clark & Stovall, 1996). In addition to the feeling of being psychologically paralyzed after hearing the three words “You have cancer,” people diagnosed with cancer must quickly adapt to their new situation as they face serious decisions about treatments, finances, end-of-life planning, and other issues that could affect their own lives and the lives of those around them. The current healthcare delivery system is extremely complex and difficult to understand or navigate, and affords patients very little personal control (Clark & Stovall, 1996; Hoffman & Stovall, 2006).

In their article, “Advocacy: The Cornerstone of Cancer Survivorship,” Clark and Stovall (1996) suggested that people with cancer need to learn basic advocacy skills to adapt successfully to their new lives as survivors, defined as beginning at diagnosis and continuing through the balance of life. When experts from NCCS, the Oncology Nursing Society, and the National Association of Social Workers began developing the Cancer Survival Toolbox®, a self-learning audio program, they surveyed cancer survivors and found that fewer than half of the 569 respondents reported that they could communicate their needs effectively, negotiate with providers, insurers, or employers, or felt they had the skills necessary to make important decisions (Walsh-Burke & Marcusen, 1999). Less than one-third of the 833 healthcare professionals who responded to the survey felt that their patients had necessary self-advocacy skills (Walsh-Burke & Marcusen, 1999).

Individuals can learn and apply the basic advocacy skills recommended by Clark and Stovall (1996) throughout the cancer experience at multiple levels. Advocacy skills also are transferable: the same strategies that work for self-advocacy can be used to help others in the community or to effect system-wide change for the benefit of the public. In developing the Cancer Survival Toolbox, the creators identified six key abilities that allow cancer survivors to successfully advocate for themselves: (a) communicating, (b) finding infor-
mation, (c) making decisions, (d) solving problems, (e) negotiating, and (f) standing up for one’s rights (see Appendix T).

**Communicating**

Communication skills allow survivors to effectively share information and emotions with their healthcare professionals, loved ones, employers, and others. At its essence, communicating means one person letting someone else know clearly what he or she thinks and feels, and learning what that person thinks and feels. It includes such facets as information sharing, rapport building, and trust. For example, survivors may talk to a doctor about treatment options or their partners about changes in their relationships. Both participants in the communication share responsibility for the interaction and its outcome (Clark & Stovall, 1996).

**Finding Information**

Information-seeking skills, essentially a form of “medical consumerism” (Clark & Stovall, 1996), enable survivors to use many of the different resources available to understand their kind of cancer and its treatment. For example, survivors may need to find reliable and accurate information about their disease, select healthcare providers whom they respect and trust, or know when and how to seek a second opinion. Knowing they have good information at hand can help survivors feel confident in the many decisions they need to make.

**Making Decisions**

When a person has cancer, decision making can be very difficult. The survivor may need to select doctors, choose from different courses of treatments, or even decide whether to end a treatment. Some people may be tempted to leave choices to the oncologist or surgeon, but studies show that cancer survivors who are active in making decisions tend to manage side effects and treatment better than those who are less involved (Gattellari, Butow, & Tattersall, 2001; Zafar, Alexander, Weinfurt, Schulman, & Abernethy, 2009). Decision-making styles vary from person to person. Some individuals like to gather information from many sources, while some prefer to trust in an authority or two, and others rely on their own sense of what is best. Still, all individuals can benefit from weighing the pros and cons of each choice and come to a decision they feel confident in and avoid second-guessing themselves once they have made the decision (Gattellari et al., 2001; Zafar et al., 2009).

**Solving Problems**

Problem-solving skills are mechanisms that help survivors think through a situation carefully and reach a resolution. These skills include identifying
and defining the problem, gathering information to help resolve the issue, planning and carrying out an action, and being able to go back and make changes to that plan as needed (Walsh-Burke & Marcusen, 1999). Survivors, for instance, may face the problem of deciding whether and how to tell family members, friends, and coworkers about their diagnosis, determining ways to balance their treatments with other responsibilities, or choosing a path for treatment when family members have very different opinions.

**Negotiating**

Having cancer often means that survivors must be able to advocate for appropriate medical care, insurance coverage, and legal rights. They may have to work out solutions with an employer for a new work schedule or come up with a more reasonable treatment schedule at a cancer center that is far from home. Agreeing on solutions and resolving conflicts requires negotiating skills, such as being able to identify values and principles and set boundaries, as well as learning how to set aside emotions and imagining more than one solution to a problem (Walsh-Burke & Marcusen, 1999).

**Standing Up for One’s Rights**

The last skill identified by Clark and Stovall (1996) is the ability to stand up for one’s rights. This means that survivors (and their loved ones) learn to take action in their own best interests. Self-advocacy helps survivors feel more in control of their lives, gain confidence to face challenges, and learn how to reach out to others for help and support. Self-advocacy helps survivors feel hopeful rather than helpless. For example, cancer survivors who are self-advocates may feel entitled to seek second opinions or may choose to make action plans for getting through treatment. They might communicate and share this with family members and providers and tell them how they can be of assistance to them in staying with their plan.

**USING ADVOCACY SKILLS ACROSS A CONTINUUM**

NCCS organizes its advocacy across a continuum that stretches from personal or self-advocacy, to community or advocacy for others, to public interest advocacy (NCCS, 2009). Personal or self-advocacy develops as a result of being an informed healthcare consumer (Hoffman & Stovall, 2006). Self-advocacy means speaking up to get what one needs and arming oneself with the tools and skills necessary to feel comfortable in doing that. It requires collecting accurate medical information, seeking out second opinions if needed, finding and using support resources, and speaking up for one’s rights regarding finances, insurance coverage, employment, and privacy. Self-advocacy also means taking responsibility and assuming some control of one’s life circumstances with cancer.
Clark and Stovall (1996) pointed out that advocacy may begin at a personal level when survivors must learn the basic skills to ensure their own health and well-being. But as the survivors’ paths of survivorship change and develop over time, they grow comfortable with their skills and may want to transfer these skills to help others. As a result, their efforts may broaden to include advocacy on behalf of other people or members of a local support group or organization, and eventually may grow to include public advocacy efforts.

Many people who have lived through cancer, either directly or as a loved one, want to use their experiences and the skills they have learned to give back to their communities. Vachon (2001) noted that some cancer survivors consider their experience to be a major part of their self-definition and may “use the experience constructively, working for improved care, treatment, and research funds for other cancer patients” (p. 281). This is what Clark and Stovall (1996) called “advocacy for others” or community advocacy. Activities might include mentoring newly diagnosed cancer survivors, participating in support groups, or raising funds for a local or national cancer charity. Studies have shown that the act of helping is associated with better mental health because it can help survivors to feel more empowered and offers them a positive external focus (Schwartz, Meisenhelder, Ma, & Reed, 2003; Thoits & Hewitt, 2001). Survivors have reported finding friendship and support among fellow advocates who share similar experiences (Zebrack, 2001; Zebrack, Oeffinger, Hou, & Kaplan, 2006) and exercising a strong desire to help others (Kovtun, Engh, & Jatoi, 2008).

Some cancer survivors, their families, and providers may choose to use their advocacy skills in the interests of the public at large by influencing public policy decisions around cancer research, treatment, and care. Public interest advocacy can take place at the local, state, federal, or international level and can be used to make changes in legislation, regulatory policy, and corporate policy, as well as in the private sector within specialty societies and standard-setting bodies. Survivor-advocates are instrumental in informing policy decisions through legislative efforts, marches and rallies, speaking out and educating decision makers and the public at large, speaking to the media, participating in review boards that oversee funding and research priorities, and evaluating and testing patient education materials.

For example, a group of 25 advocates succeeded in convincing the National Cancer Institute to develop its Specialized Programs of Research Excellence (SPORE), garnering $20 million in funding for the program, and, in California, convincing Kaiser Permanente to pay the costs of patients enrolled in SPORE research (Kovtun et al., 2008). Survivor-advocates contributed to the creation of the National Action Plan for Cancer, a joint project between the Centers for Disease Control and Prevention and the Lance Armstrong Foundation (2004), to study and address cancer survivorship issues. Advocates also provide a much-needed consumer perspective on research funding review boards on programs through the U.S. Food and Drug Administration, the U.S. Department of Defense, and the National Cancer Institute. In the lead-up to
the passage of healthcare reform legislation in 2010, survivor-advocates shared their stories about severe deficits in current insurance practices, helping to push through many reforms that would particularly affect people diagnosed with cancer, such as ending preexisting condition exclusions and lifetime caps.

Over the past 40 years, numerous organizations have formed specifically to bring people together to advocate for cancer survivors. These include the American Childhood Cancer Organization (formerly the Candlelighters Childhood Cancer Foundation), the American Cancer Society, Susan G. Komen for the Cure, the National Breast Cancer Coalition, NCCS, and the Lance Armstrong Foundation. Hundreds of organizations now exist that provide education, resources, financial aid, and advocacy. Because of the proliferation of these organizations, the National Cancer Institute has developed specific criteria for inclusion in their database of resources. These groups and many others have helped cancer survivors to be heard by policy makers who influence critical issues such as funding for research at the National Cancer Institute, regulations for how drugs are tested and made available by the U.S. Food and Drug Administration, and what treatments must be covered by insurers. Many of these organizations organize lobby days, hearings, or congressional briefings, such as the one the five NCCS advocates took part in. They also help advocates to learn more about particular bills and issues and connect them with their own lawmakers, review boards, and other decision makers.

THE IMPORTANCE OF BEING AN ADVOCATE

Cancer affects millions of Americans every year. Today, nearly 12 million cancer survivors are alive in the United States, and 1.5 million join their ranks every year (American Cancer Society, 2010). The stakes are high for cancer survivors and their loved ones; improving the quality of care means improving the quality of life for those who experience a cancer diagnosis. Yet, survivors’ voices still are not heard enough, especially regarding issues related to healthcare quality and delivery and long-term survivorship.

Meaningful changes in the cancer care delivery system must include survivor and provider voices. These are the populations with the most intimate knowledge of how cancer affects the body, the mind, the family, the workplace, and the healthcare system. At the same time, they bring different viewpoints, concerns, and loyalties to the table, a new perspective that other policy makers may never have considered (Niles, Myrhaug, Johansen, Oliver, & Oxman, 2006). Survivors can offer useful advice and input regarding policy, research, healthcare practice and delivery, and patient education. Indeed, as Gray, Doan, and Church (1990) pointed out, inclusion of the survivor voice in decisions at the system level may enhance patient empowerment by providing the opportunity for survivors to “define their healthcare needs and priorities” (p. 44).

Engaging in self-advocacy can be helpful, even lifesaving, for the survivor. People who have cancer often experience a loss of personal control as a result
of their illness (Gray et al., 1990). The diagnosis and treatment of cancer creates a high level of uncertainty and anxiety that can last well beyond treatment and into survivorship. Survivors may find they can no longer do the things they want or need to do for themselves as a result of their illness. They may have to give up familiar roles and responsibilities at home and at work, and later may have difficulty resuming or obtaining those roles back. Furthermore, people with cancer may find they can no longer maintain some of their relationships as a result of the stigma and discomfort some people associate with cancer (Gray et al., 1990). Becoming a skilled self-advocate is a powerful way to overcome the loss of control that comes with cancer because it gives survivors the necessary tools to make their own decisions about treatment and other issues related to their cancer (Gray et al., 1990).

Cancer survivors may find that participating in community and public interest advocacy helps them personally for many other reasons, too. For some, becoming a survivorship advocate means acceptance. It is a way to find meaning in an unwanted experience. Likewise, some survivors find confidence. Once they have dealt with cancer, they feel they have the wherewithal to cope with whatever life brings their way. For those who reach out and advocate for others, survivorship advocacy offers a chance to share experiences, sympathize with another person, and offer support and advice. Finally, becoming an advocate is a way to give back to the people and institutions that helped them and to “pay it forward” to other people who have recently begun fighting cancer (Zebrack, 2001).

THE ROLE OF HEALTHCARE PROFESSIONALS IN ADVOCACY

Healthcare professionals, and oncology nurses in particular, have special roles to play in survivor advocacy. Many institutions are beginning to recognize the value of advocacy training for healthcare professionals. Several, such as Montefiore Medical Center in New York and University of California, San Francisco, now offer electives in healthcare advocacy and policy to medical students (Bein, 2010). Nurses, as healthcare providers, are deeply involved in frontline patient care and have distinct insights into the experiences of cancer survivors navigating the healthcare system. They often are the provider whom the patient reaches out to when in distress or in need of assistance. Nurses are knowledgeable about how cancer care is currently delivered, where gaps in the system create difficulties for patients and for providers, and where barriers and obstacles prevent them from providing the kind of patient care they would want to give or receive.

Because nurses often are the healthcare providers who have the most interaction with patients and survivors, and with whom survivors often have a trusting relationship, they are in an excellent position to provide advocacy skills training as part of their care. Gray et al. (1990) advocated that healthcare
professionals facilitate survivor empowerment by offering the opportunity to consider “all the relevant dimensions of their life situation in making treatment decisions” (p. 38). Clark and Stovall recommended that healthcare practitioners be creative and assertive in teaching advocacy skills to build coping strategies that will prevent or overcome psychosocial limitations and promote a more positive future outlook (Clark & Stovall, 1996; Walsh-Burke & Marcusen, 1999).

INTEGRATING ADVOCACY TRAINING INTO PRACTICE

Training cancer survivors in advocacy skills can empower them to better take care of themselves and to help others at all levels of the cancer experience (Monaco, 1992). This sort of training can take place in a multitude of ways, including one-on-one sessions with healthcare professionals, support groups, referrals to local and national organizations, workshops, conferences, and through patient education products such as the Cancer Survival Toolbox. In creating training programs, it is important to keep in mind certain goals. First, programs should empower cancer survivors and caregivers to feel confident in their abilities to advocate for themselves with regard to cancer and be able to find solutions to the everyday problems that come up when dealing with the disease (Monaco, 1992). Second, advocacy training should offer survivors a route to taking charge of their lives, whether that is through self-advocacy, community advocacy, or public interest advocacy. It is important to ensure that opportunities for survivor-advocate input are meaningful to avoid minimizing their views or tokenism (Niles et al., 2006). When survivors do speak up, it is paramount that they are listened to and heard.

SUMMARY

In their analysis of patient advocacy in cancer politics, Gray et al. (1990) stated that “if patients are to have optimal control over the conditions of their care, then they require input not only about their individual treatment but also about the policies that guide the daily functioning of institutions and the broader healthcare system” (p. 42). Advocacy skills training is vital to ensuring that the current and future population of cancer survivors, their loved ones, and their providers are equipped to understand and navigate the complex world of cancer they must live in and stand up for their rights and the rights of others. The skills, once learned, can be applied at all levels. But the experience and knowledge that comes from living with, through, and beyond cancer are what makes trained survivor- and provider-advocates so effective in changing the system for the millions of people who will be diagnosed with cancer in the future.
REFERENCES


A cancer diagnosis is a frightening experience, plunging patients into a world of new terminology, endless questions, and countless medical visits. The result is that many patients feel as if they have entered a “foreign territory” without an “interpreter.” For many years, lay health workers, termed community health workers, lay health advisers, or promotoras (Rhodes, Foley, Zometa, & Bloom, 2007; Zuvekas, Nolan, Tumaylle, & Griffin, 1999) have helped community members with various aspects of health care (e.g., obtaining mammograms or Pap tests). Freeman, Muth, and Kerner (1995) coined the term patient navigator to describe a person not on the medical cancer care team who “navigates” patients through the cancer experience.

Navigators are gaining approval and popularity in various healthcare settings to provide assistance to patients across the continuum of cancer care. This chapter reviews the history of patient navigation, presents evidence for the success of patient navigation programs across the spectrum of cancer control, and provides recommendations for future uses of patient navigators across the continuum of cancer care.

**HISTORY OF PATIENT NAVIGATION**

Patient navigation for cancer care emerged in 1990 under the direction of Dr. Harold P. Freeman in response to the poor outcomes observed in African American women with breast cancer in the Harlem neighborhood of New York City (Freeman, 2006). The idea for the program originated from a 1989 report from the American Cancer Society (ACS) titled *Report to the Nation: Cancer in the Poor*, which indicated that poor people with cancer faced significant
obstacles to obtaining appropriate cancer care such as financial, logistical, and sociocultural barriers (ACS, 1989). In addition, patient navigators follow the rationale for using other “natural helpers,” such as community health workers, lay health advisers, and promotoras, who are from the community and provide social support to the patient (Dohan & Schrag, 2005). Patient navigators, however, focus on removing barriers to care (see Figure 38-1).

In 2001, the President’s Cancer Panel recommended that funding be provided to support patient navigation programs in communities to help individuals obtain the entire spectrum of cancer care from information to screening, treatment, and supportive services (Freeman, 2001). Since that time, patient navigation programs have sprung up throughout the United States, sponsored by national organizations such as ACS (2007), the Avon Foundation, and the Lance Armstrong Foundation, as well as local community organizations (Hede, 2006). In 2005, the National Cancer Institute’s Center to Reduce Cancer Health Disparities funded the national Patient Navigator Research Program (PNRP) in conjunction with ACS (National Cancer Institute, 2005b), and in 2006, the Centers for Medicare and Medicaid Services funded a demonstration program using patient navigators for minority beneficiaries. Given this interest in patient navigation, evidence for the usefulness of navigators must be reviewed.

EVIDENCE FOR PATIENT NAVIGATION

In reviewing the evidence for patient navigation, a definition of patient navigation will be provided, followed by a description of what navigators do and a review describing outcomes of patient navigation studies.

Definition of Patient Navigation

Many definitions of patient navigation exist (Freeman, 2004; Newman-Horm, 2005). However, what all definitions have in common is that navigators provide barrier-focused interventions with the following characteristics: navigation is provided to an individual patient for a defined episode of cancer-related care; navigation has a defined end point; navigation focuses on a certain set of health services to complete an episode of cancer-related care; navigation focuses on barriers to accessing care; and navigation aims to reduce delays in the receipt of treatment services (Wells et al., 2008).

Services Provided by Patient Navigators

Patient navigators typically provide services in four barrier areas across the cancer continuum of care: (a) overcoming health system barriers, including coordination of care among multiple providers, completing paperwork, scheduling appointments, and facilitating doctor-patient communication; (b)
Figure 38-1. Cancer Care Barriers

Note. Figure courtesy of National Institutes of Health/National Cancer Institute, Center to Reduce Cancer Health Disparities.
providing health education, including written information and responses to questions; (c) addressing barriers to care, such as transportation, financial barriers, language translation, and low literacy; and (d) providing psychosocial support either directly or by coordinating referrals (Wells et al., 2008) (see Figure 38-2).

Navigators come from a variety of backgrounds, from lay community members, to clinic personnel, and even cancer survivors (Giese-Davis et al., 2006; Steinberg et al., 2006; Wilcox, 2007). They are mostly paid employees, not volunteers. Training programs for navigators have recently been initiated; however, the training that most navigators have received has not been evaluated in terms of quality and quantity. Within the national PNRP, a formal training program was developed and is in the process of being evaluated (Calhoun et al., 2007). Navigation programs serve underserved populations (National Cancer Institute, 2005a) as well as patients in medical centers and managed care organizations (Nash, Azeez, Vlahov, & Schori, 2006; Rahm, Sukhanova, Ellis, & Mouchawar, 2007). Thus, these programs can potentially benefit all patients with cancer.

Outcomes of Patient Navigation

Previous patient navigation programs have primarily focused on a single cancer site while few have targeted multiple cancer sites (Wells et al., 2008). Outcomes as reported in published studies have demonstrated the efficacy of patient navigation programs in the following areas.

**Cancer screening:** Either alone or in combination with other interventions such as outreach strategies, patient navigation appears to improve adherence to breast, cervical, and colorectal cancer screening by 11%–17% as compared to groups not receiving navigation (Dignan et al., 2005; Jandorf, Gutierrez, Lopez, Christie, & Itzkowitz, 2005; Nash et al., 2006; Tingen, Weinrich, Heydt, Boyd, & Weinrich, 1998).

**Adherence to follow-up after an abnormality is detected:** In all studies in which navigation has been evaluated in terms of adherence to follow-up after an abnormal test or timeliness of follow-up, patient navigation improved both outcomes (Battaglia, Roloff, Posner, & Freund, 2007; Ell, Padgett, et al., 2002; Ell, Vourlekis, Lee, & Xie, 2007; Ell, Vourlekis, et al., 2002; Ferrante, Chen, & Kim, 2008; Freeman et al., 1995; Nash et al., 2006; Psooy, Schreuer, Borgaonkar, & Caines, 2004; Weinrich et al., 1998). Improvements in adherence ranged from 21% to 29% when compared to a comparison group. Limitations of these data include that only two of the studies included randomization of patients to study arms (Ell et al., 2007; Ferrante et al., 2008).

**Stage of cancer diagnosis:** One study examined the effect of patient navigation on stage at diagnosis as part of a multimodal intervention (Oluwole et al., 2003). Reductions in late-stage diagnosis were reported.

**Cancer treatment:** This outcome has mixed reports of efficacy in terms of timeliness of initiating cancer treatment. One study reported that patients
CHAPTER 38. PATIENT NAVIGATION ACROSS THE CONTINUUM OF CARE

Figure 38-2. Patient Navigator Possible Roles

Note. Figure courtesy of National Institutes of Health/National Cancer Institute, Center to Reduce Cancer Health Disparities.
with breast cancer who received navigation and counseling started treatment sooner than those randomized to receive usual care (Ell et al., 2007). A second study found no significant improvements in timeliness of care (Ell, Padgett, et al., 2002). In both of these studies, navigation was combined with psychosocial counseling services provided by a social worker with a master’s degree for patients displaying significant mental health symptoms.

Treatment recovery: One descriptive study utilized patient navigators across the cancer continuum from breast cancer screening through treatment recovery among Native American women (Dignan et al., 2005). A second study reported that cancer-related trauma symptoms decreased and emotional well-being increased over time among women diagnosed with breast cancer who received services from a patient navigator (Giese-Davis et al., 2006).

Palliative care: This area of the cancer care continuum has not been evaluated in terms of the efficacy of patient navigation. One study evaluated the efficacy of patient navigation for advance planning, pain management, and hospice utilization among older Latinos (Fischer, Sauaia, & Kutner, 2007).

RECOMMENDATIONS FOR USE OF PATIENT NAVIGATORS ACROSS THE CANCER CARE CONTINUUM

In general, most evaluations of patient navigator programs have demonstrated that patients benefit from navigation. There is, however, a paucity of well-designed, randomized controlled trials that evaluate navigation alone, and even fewer trials evaluate the effect of patient navigation further along the cancer control continuum. Thus, the following recommendations pertaining to patient navigation are proposed.

• Conduct rigorous, well-designed studies that evaluate the efficacy of patient navigation among a variety of cancer types across the cancer care continuum.
• Find ways to incorporate patient navigators into existing programs, as evidence exists that demonstrates the benefit of patient navigation in improving the use of cancer screening and adherence following an abnormal screening test.
• Develop training programs for patient navigators, and assess them for quality, quantity, and coverage of issues across the cancer care continuum.
• Explore ways to pay for patient navigation services as well as the cost-effectiveness of patient navigation.
• Once data on the efficacy and cost-effectiveness of patient navigation are available, enact legislation allowing public and private insurers to cover the costs of navigation.
• National organizations and independent entities sponsoring patient navigation programs should work collaboratively to provide evidence about the efficacy of patient navigation along the entire cancer curriculum using similar evaluation tools and training programs.
SUMMARY

Patient navigation clearly has a niche in the cancer care continuum. More information is needed about the implementation of these programs, including evaluation of patients with more types of cancer throughout the cancer care continuum. Additionally, data on the costs of these programs and training programs must be obtained. Patient navigators can be especially beneficial in minority, underserved, or poorer populations where more intense cancer disparities exist. Efforts to expand and assess navigation programs among these populations should be a top priority. Until then, the promise of patient navigation has yet to be fully realized.

REFERENCES


CHAPTER 39

The Promise of Healthy Survivorship

Wendy S. Harpham, MD

INTRODUCTION

While celebrating the burgeoning population of long-term survivors, primary care clinicians face the challenge of integrating each patient’s cancer history into a comprehensive wellness program. The obstacles are great. Diagnoses can remain enigmatic when aftereffects alter the expression of clinical disease. Routine care now demands scrutiny because ongoing medical problems and the risk of late effects shift the risk-benefit ratio for many methods of disease prevention, screening, and treatment. In addition, the Internet and the rise of patient advocacy have transformed how patients obtain and process medical information. And a variety of forces—economic, social, and logistical—are stressing the clinician-patient bond. Not surprisingly, the many dilemmas unique to 21st century patient care are accompanied by ethical concerns. For example, what are clinicians’ obligations to patients regarding the provision of information about alternative therapies for curing cancer? What about regarding patients’ hopefulness or their pursuit of happiness?

This chapter will offer clinicians a simple framework for translating the growing literature on post-treatment cancer survivorship into personalized care of individual patients. From my perspective as an internist who, since 1990, has experienced innumerable diagnostic tests and procedures, most types of antineoplastic therapy, a variety of aftereffects, the terror of a terrible prognosis, and the hope of clinical trials, I have developed a concept called Healthy Survivorship (Harpham, 1993, 2005). The notion of Healthy Survivorship arose as a response to the fact that there is no one right way for all patients to deal with cancer, but there are best ways for each individual. This chapter outlines how clinicians can empower each of their patients to embark with them on a shared mission of forging and following the best path
at each point in time. These healing efforts can begin right now. This is the promise of Healthy Survivorship.

HEALTHY SURVIVORSHIP

*Survivor* has become the standard label for people who have ever been diagnosed with cancer. As path-breaking as the term was when the National Coalition for Cancer Survivorship (n.d.) introduced it in 1986, *survivor* falls short in the context of modern personalized medicine because it does not take into account patients’ role in their recovery or their quality of life. In contrast, *Healthy Survivor* captures the physical and psychosocial dimensions of illness and healing: “[A healthy survivor is] someone who is (1) getting good medical care while (2) living as fully as possible” (Harpham, 2005, p. 25). The benefit of this two-criteria label is that patients can be Healthy Survivors no matter how sick they are or how long they live because Healthy Survivorship is not defined by biology or medical outcome. Rather, Healthy Survivorship revolves around making life the best it can be and then accepting and adjusting to what is. It is about embracing life—whatever the circumstances—and finding happiness today while hoping for a better tomorrow.

Healthy Survivorship is an art based on science, involving factors such as patients’ needs, desires, strengths, weaknesses, goals, values, and circumstances. These factors can be difficult to assess, let alone to quantify. Consequently, what constitutes good medical care and what it means to live fully are specific to each patient. One useful three-step approach to the personalized care implicit in Healthy Survivorship is for clinicians to help patients to (a) obtain sound knowledge, (b) find and nourish hope, and (c) take effective action (Harpham, 1993, 2005). What follows are insights and suggestions for guiding and supporting these efforts on both sides of the stethoscope. Note that in many cases, clinicians’ obligations do not necessitate personally tending to the issues in question, but only to ensuring that qualified members of the extended healthcare team address these issues adequately.

THE THREE-STEP APPROACH TO PERSONALIZED CARE IN HEALTHY SURVIVORSHIP

Knowledge

Sound knowledge is essential for patients to make wise decisions—about all aspects of survivorship, not just treatment—and to live as fully as possible every day. A variety of obstacles can make it difficult for patients to obtain sound knowledge. For one thing, cancer care is complicated. Patients may not have the necessary scientific background and vocabulary. For another, emotions (like shock, fear, and grief) and physical problems (such as pain, fatigue, and
cancer-related cognitive deficits) can interfere with patients’ ability to hear what is said or to process teaching materials. In addition, patients’ mistaken preconceptions about illness and healing or any unsolicited advice based on junk science, such as that offered by some blogs and Web sites, friends, family members, and even strangers, can lead patients to become confused or to question and possibly dismiss clinicians’ assertions and advice.

Clinicians can determine the receptivity of each patient before imparting information. For patients who cannot handle medical information but need urgent treatment, their families can assign surrogates or proxies to fill in until the patients can take over. In the typical situation, clinicians have time to optimize patients’ ability to benefit from information by providing only that which is needed immediately and then scheduling a follow-up visit to review the situation in depth and make decisions. They can advise patients to come to doctor visits with a “listener”—a family member, friend, or patient navigator—who can review later what was said and done. And physicians can address physical and emotional factors that can interfere with cognitive clarity, such as pain, sleep deprivation, anxiety, grief, and depression.

As increasing numbers of patients obtain medical information from a wide variety of sources (Fox & Jones, 2009), it becomes essential that clinicians refer patients to quality resources that reinforce and supplement the information provided by the healthcare team. By encouraging patients to ask about any information obtained elsewhere that contradicts information provided by members of the healthcare team, clinicians create opportunities to ensure that their patients appreciate the critical differences among conclusions drawn from anecdote, observation, and scientific studies (Harpham, 2005).

Alternative therapies, clinical trials, and decision-making tools deserve special mention. Physicians who are not talking to patients about alternative therapies are like parents who are not talking to teenagers about sex; these clinicians are making errors of omission, as many patients have considered or already are using them. Along with offering guidelines on alternative therapies, clinicians who provide information about clinical trials and decision-making tools empower their patients to ask useful questions and thus to make informed treatment decisions. From then on, no matter what happens, these patients can enjoy the confidence that comes from knowing they have entertained all options and are doing the best they can. This stance strengthens the physician-patient bond and minimizes the chance of patients ever saying with regret, “I wish I knew then what I know now.”

A common source of distress for patients who feel vulnerable and helpless is the uncertainty surrounding conventional and investigational medicine. Clinicians can remind patients that cancer does not make life uncertain; it simply exposes the uncertainty of life. Along with reassuring patients of the certainty of the diagnosis and the approach to treatment, they can emphasize the power of wise decisions in all spheres of life to enable patients to affect outcomes positively and regain a measure of control. Clinicians can refer patients to resources that teach them not only how to adjust to the uncertainty that remains,
but also how to embrace this uncertainty in healing ways (Harpham, 2005, 2009). For example, many patients in remission wish to know, “Am I cured?” by which they mean their cancer will not come back. Two circumstances enable them to know: (a) if their cancer recurs, or (b) if they die while their cancer is in remission. When patients see that in some situations certainty comes at a terrible price, they can enjoy the benefits of not knowing.

Embracing uncertainty can be a liberating—if novel—concept for patients. Clinicians can help transform uncertainty from a source of fear to one of hope by reminding patients who are undergoing evaluation, “We are doing these tests because we don’t know what is causing this problem. While we are taking the right steps to find answers, keep in mind you may be fine.” When discussing prognoses when no known curative treatments are available, clinicians can remind patients, “We can determine the likely outcome, but nobody can predict your future with certainty. Unexpected, inexplicable recoveries happen.” Knowledge is the first step to Healthy Survivorship, but only if patients have hope that knowledge makes a difference.

Hope

Hope is the centerpiece of Healthy Survivorship (Harpham, 2005). From the first suspicion that patients might have cancer, hope is a driving force behind their obtaining good care and living as fully as possible. Thus, clinicians have an obligation to discuss patients’ hope throughout the survivorship trajectory. I offer here a new and useful definition of hope in the context of survivorship, one drawn from an amalgam of definitions found in the philosophical and psychological literatures: the pleasurable feeling associated with the belief that a future good can happen. Such hope is neither static nor all-or-nothing. Patients’ hope for a wide variety of things fluctuates over time, reflecting ever-changing circumstances. And the hope for these various ends can interact, such as patients’ hope for a cure, a durable remission, pain relief, reconciliation with a loved one, participation in a life-cycle event, spiritual peace, maintaining dignity, and leaving a meaningful legacy.

Clinicians’ mission of healing is inextricably intertwined with their obligation to help patients nourish “healthy hope,” namely, whatever hope helps patients get good care and live as fully as possible. In general and with all other things being equal, nourishing hope of recovery is more difficult when patients feel sick or are in pain (physical or emotional). Patients who harbor little hope of pain relief may let go of their hope of recovery, while patients in similar situations but with high hope of pain relief may hold on to their hope of controlling the disease. This example, in addition to illustrating the dynamic interdependence of specific hopes, highlights how clinicians’ obligation to hope demands that they include palliative care as an essential element of comprehensive cancer for all patients throughout their survivorship, whatever the prognosis.

Patients often look to their physicians for insight into how hopeful they can be, seeing these professionals as their link to the science and technology
of healing. Consequently, physicians’ tone and word choices shape patients’ hope of benefiting from modern medicine. For instance, patients may feel more hopeful of recovery if their physicians describe their cancer as “treatable” instead of “incurable,” or if they are told that “80% of patients with this type of cancer are cured” instead of “20% of patients are not cured.” In either case, also telling patients directly, “You have good reason to be hopeful,” may decrease the chance of patients misinterpreting clinicians’ explanations and erroneously concluding that their situation is hopeless or their healthcare team feels hopeless regarding their case.

A host of problems involving hope can arise when patients’ prognoses are not good. Clinicians’ obligation to be truthful may seem in conflict with their obligation to help patients nourish hope. In the short run, hiding the truth protects patients from the distress of learning bad news. But the price is high: withholding the truth denies patients the benefits of guidance, comfort, and support that could ease their adjustment to what is happening and help them prepare for tomorrow. In the setting of terminal disease, noble lies about the prognosis deprive patients of their autonomy and the life-enhancing services offered by hospice or other end-of-life care.

Some clinicians choose to delay sharing the truth about terminal disease until their patients are feeling sick, fearing that to do it sooner might take away patients’ hope (Keating et al., 2010). Not so. First of all, clinicians cannot give or take away patients’ hope; hope is an emotion that arises from within, like faith and love. Second, in every situation—even those where the prognosis is grim—clinicians can both tell the truth and nurture hope. This can be accomplished by separating expectation from hope, discussing both, and helping each patient find a balance of acceptance and hope that helps him or her to obtain good care and live as fully as possible (Harpham, 2009).

Expectations reflect what people think will happen; they are beliefs in the likely outcomes based on statistics. In contrast, hope reflects desired outcomes, whatever their likelihood. People can expect one outcome while hoping for another. In all spheres of life, this so-called hopeful acceptance empowers patients to benefit from accepting and preparing for the likely outcome while also benefiting emotionally from hoping for the best possible outcome. Simple phrases enable clinicians to fulfill their obligation to be truthful about patients’ situations and prognoses while leaving room for hope. When, for example, the chance of recurrence is high but not 100%, physicians can say, “If the cancer recurs” instead of “When the cancer recurs.” At the difficult juncture when treatment options run out, physicians can say, “If things progress as expected” instead of “When things progress.”

Physicians and nurses can advocate for their patients by helping family members respect and support whatever outlook helps patients. Clinicians can explain that patients’ hope often is different from that of family members or the members of the healthcare team. And that is all right. Caring for patients and loving patients means helping them find that balance of acceptance and hope that works well for them, whatever levels of acceptance and hope that
might be. When transferring patients to hospice or another end-of-life setting, clinicians can crack open the door for hope by explaining that some patients do unexpectedly well when the toxicity of chemotherapy or radiation is removed. Not uncommonly, patients live longer than predicted. On occasion, patients are discharged from hospice to resume an active lifestyle or active treatment for their disease.

As an aside, the exercise of separating expectation from hope in one’s own mind can benefit healthcare professionals, too. Because clinicians have professional obligations to ascertain and then prepare everyone for the likely outcome, physicians and nurses tend to focus most or all of their attention on expectations. But if they stop for a moment and remind themselves, “I can completely expect one outcome while still hoping for the best possible outcome for this patient,” they naturally tap into their sense of possibility. By nourishing hope for the unlikely recovery, even if short lived, clinicians may strengthen their sense of purpose—that intoxicating blend of desire and determination that led them to choose medicine as a career.

Clinicians also help patients by respectfully sharing their concerns about hope that is not healing. Patients who hang their hope on a quack remedy may not put enough energy into effective measures of healing. Patients who use their hope that worrisome symptoms mean nothing or will disappear spontaneously to justify keeping these symptoms secret are allowing hope to interfere with their obtaining good care. Knowledge and hope help patients become Healthy Survivors by leading them to actions that help them to receive good care and live as fully as possible.

**Action**

Knowing what to do and doing it are two different matters. Having all the knowledge and hope in the world does not help patients obtain high-quality care unless patients take effective action. Yet, while vast resources are devoted to developing and distributing sound information, relatively little is devoted to helping patients overcome the many obstacles to acting on this knowledge in healthy ways. Emotions often keep patients from doing what they know to be the right thing. Fear, for example, can keep people from reporting worrisome symptoms or following through on effective treatments: fear of pain or injury from tests or treatments; fear of being hospitalized or otherwise separated from loved ones; fear of appearing impatient, hypochondriacal, or wimpy to family or the healthcare team; fear of learning their situation is grave; and fear of dying, even if patients are not in immediate danger. Other emotions that can become obstacles to effective action include anger, embarrassment, confusion, impatience, inflexibility or stubbornness, denial, and despair.

Clinicians play a vital role in helping patients recognize when emotions are keeping them from effective actions. At the bedside and with printed handouts, clinicians can help patients mitigate unpleasant emotions and then act properly despite whatever uncomfortable emotions remain. For example, they
can acknowledge and clarify patients’ specific fears, anxieties, anger, and other unpleasant emotions. While reassuring patients that heightened emotions are normal, common, and manageable, clinicians can encourage patients to stay focused (at least for now) on the overall goal: getting better. Clinicians also can ask patients to assign a friend or family member to accompany them to medical visits and procedures, a step that can offer an added measure of accountability along with calming companionship.

If patients miss appointments, take medications incorrectly, or otherwise demonstrate poor compliance, clinicians can use the errors as teachable moments. To set the stage, especially for first-time problems, clinicians can preserve patients’ dignity by accepting and forgiving the lapse. Then clinicians can offer sound information, compelling stories, useful insights, and inspiring mantras to help these patients to act properly if the same situation subsequently arises. To illustrate, if patients skip appointments clinicians can (a) acknowledge the obstacles (“I know it is difficult to keep track of appointments, to take time off from work, to come back to the cancer center . . .”), (b) forgive the lapse (“No worries! It can happen to anyone. I’m just glad you returned.”), and (c) emphasize the power of proper action (“You regain some control of your life by faithfully coming for follow-ups, and so on.”). Clinicians who praise patients for complying with therapies, especially when patients had to overcome known obstacles, can boost patients’ confidence in the “action” aspect of Healthy Survivorship and may help prevent noncompliance.

**MEANING AND HAPPINESS**

Clinicians and researchers are scientists, not theologians or philosophers. But cancer often thrusts “meaning” and “happiness” center stage for patients. While the disease can threaten patients’ life and limb, the illness experience can threaten patients’ sense of self and ability to pursue happiness. Consequently, physicians, nurses, and other members of the healthcare team cannot afford to cordon off philosophical and spiritual issues when addressing their patients’ medical concerns.

Unlike the gradual effects of aging, cancer-related losses can occur almost overnight. Physical changes that impair people’s ability to fulfill usual roles threaten their sense of self as independent and responsible adults. Difficulties with mobility or communication can stifle patients’ sense of self as social beings. Alterations in sexuality can destroy patients’ sense of self as sexual partners. Clinicians’ words and actions can help patients preserve that sense of self that is so essential to recovery. Obvious examples include looking patients in the eye when listening or talking to them, addressing patients with proper greetings at the beginning and end of visits, and asking permission before doing anything to patients, such as positioning them, sticking them with needles, or asking emotionally charged questions. Acknowledging patients’ notes and gifts of thanks bolsters patients’ sense of self while relieving their
sense of debt. Participating in patients’ celebrations, even if only by taking a few moments to enjoy patients’ photographs or dropping by a hospital-room party, strengthens the clinician-patient bond through shared joy.

Ultimately, the purpose of providing medical care is to free patients as much as possible from the physical and emotional constraints on living well. When patients have activities or travel plans that conflict with the proposed treatment schedule, clinicians have an obligation to guide patients to wise choices that balance patients’ need to proceed with medical care and desire to pursue a life-enhancing activity or trip.

In the setting of wise decisions and high-quality care, some patients and their caregivers may feel a sense of failure if the patients’ treatments do not go smoothly or the patients do not get well. Clinicians can help everyone by sharing the truism that the best we can do is the best we can do, and that we can only affect—not control—the outcome. Then clinicians can applaud patients’ efforts, share in and recall the small victories along the way, and emphasize the notion that triumph over cancer can be measured by how one lives, instead of how long.

SUMMARY

Medicine is an art based in science. The challenge for clinicians has always been to do the best they can with what they have, while looking for better interventions. Comprehensive care of patients with cancer demands that the same expertise, energy, empathy, and support that were provided during the crises of diagnosis and treatment are provided throughout survivorship (Harpham, 2010). By helping each patient obtain sound knowledge, find and nourish hope, and take effective action, clinicians help patients to receive good care and live as fully as possible from the moment of diagnosis to their final breath.

REFERENCES


Cancer Survivorship Care in the Future

Joanne L. Lester, PhD, CRNP, ANP-BC, AOCN®, and Patricia Schmitt, MA, CRC

INTRODUCTION

Healthcare professionals and cancer advocates have worked tirelessly for more than two decades to establish a routine system of cancer survivorship care. Although a great deal has been accomplished, an extraordinary amount of work remains to be done to ensure equitable cancer survivorship care, including the establishment of personalized cancer survivorship care plans for every survivor. The preceding authors have expertly described the evolution of cancer survivorship care, physical and psychosocial challenges that may occur as results of cancer diagnoses and related treatments, practical issues that confront survivors, intended ideal healthy outcomes with guidelines to empower survivors, and discussions of critical elements of a successful comprehensive cancer survivorship care program. This final chapter will summarize some key points that are crucial for successful survivorship care planning and discuss the challenges that persist.

Cancer rehabilitation and survivorship care are dependent on an understanding and conceptualization of cancer as a chronic disease, rather than as a unilinear trajectory aimed at a predictable death (Rowland, 2008). The changing demography of cancer survivors, aging of the population, and diversity in the range and type of issues that survivors will experience as a result of cancer treatment necessitate a paradigmatic shift in oncology care. Inclusion of survivors with metastatic disease imparts additional challenges although is obligatory as we observe potential decades of survival in this subgroup. The exponentially increasing cohorts of cancer survivors must systematically be directed into a biopsychosocial model of cancer survivorship with a transdisciplinary approach to personalized care. The goal is to empower all individuals involved in the cancer experience and promote healthy survivorship.
PARADIGM SHIFTS IN CANCER SURVIVORSHIP CARE

Several paradigm shifts are essential to understanding the transformation to a survivor-based program of care. The population of cancer survivors is expected to continue to increase in the decades to come, in part because of improved delivery of quality cancer care, the baby boom generation reaching age 65 (the median age for cancer occurrence), and the decline of deaths from comorbid conditions (Rowland, 2008). The human cost of survival with accompanying persistent and late effects of the diagnosis and related treatments must be addressed. The view of cancer as a death sentence is valid in few cancers and should be dismissed for the vast majority of cancer diagnoses.

The demographics of cancer survivor groups must be understood, specific to each clinic setting. For example, a lung cancer clinic may have different goals and objectives for survivors than a breast cancer clinic, based on anticipated length of survival and characteristics of the cancer and host. The American Society of Clinical Oncology (n.d.) has recognized these differences and has designed multiple care plans, including generic, breast cancer, colon cancer, and limited-stage lung cancer (small cell), and extensive-stage lung cancer (small cell). Yet to be determined is the format of a survivorship care plan for survivors with metastatic disease, who may have many months to years of survival depending on their disease and cancer trajectory. Survivorship care plans for metastatic, recurrent, or progressive cancer perhaps should incorporate palliative care principles, as well as agreed-upon healthy outcomes.

The other paradigm shift that is rapidly encroaching upon oncologists and cancer programs is the need to transfer long-term survivorship care to other members of the oncology healthcare team, specifically advanced practice nurses (APNs) and RNs, with eventual inclusion of the primary care physician (PCP). This is a difficult shift, as oncologists and survivors alike often build emotional relationships that persist for years (Kantsiper et al., 2009).

SUCCESSFUL SURVIVORSHIP CARE PLANNING

The success of survivorship care planning is institutionally driven and will be measured, in part, by the accuracy of symptom and problem assessments and the intended outcomes of interventions. The goal is to provide personalized care while empowering survivors to assume an active role and responsibility in their own health management (Lotfi-Jam, Schofield, & Jefford, 2009). A number of institutions ranging from academic cancer research centers to community hospitals have incorporated cancer survivorship care plans into their programs of care. It has been noted that provider-driven (i.e., the practitioner who provided acute treatment) programs have received the highest marks from survivors, as components of trust and familiarity remain intact (Baravelli et al., 2009; Mao et al., 2009). Many institutions that once provided centralized survivorship care (minus the provider-driven model) have shift-
ed to a decentralized, clinic-driven model utilizing active treatment providers (e.g., oncologist, APN, RN) that are familiar to the survivor (Ganz, 2009; Jacobs et al., 2009; Morgan, 2009), or provide both models to accommodate all survivors. Participation of dedicated APNs, RNs, transdisciplinary colleagues, and PCPs in peri- and post-treatment care is necessary to enhance cancer survivorship care and relieve the increasing burden on surgical, medical, and radiation oncologists.

The variety of cancer survivorship care plans that are available supports the notion that one size does not fit all (Rosenthal, 2009). As institutions embark on the inclusion of cancer survivorship care plans, it is important to realize that multiple versions exist (see Appendices L, M, N, O, P, and Q) or one can create a care plan with incorporation of the basic principles as described in Chapter 34. Use of electronic-based medical record systems enhances the ability to quickly and accurately build the individualized survivorship care plan with the added capability to personalize the plan to each survivor.

CANCER REHABILITATION AS THE FOUNDATION FOR CANCER SURVIVORSHIP CARE

Prevention, early detection, and advanced therapeutics for the treatment of cancer have resulted in significant increases in survival rates. This extended survival has increased the potential for long-term and late effects of cancer treatment, including a broad and diffuse range of possible physical sequelae as well as social, psychological, economic, and vocational issues. Cancer rehabilitation efforts have historically provided the foundation for cancer survivorship care, with a focus on physical rehabilitation and function. Initially, rehabilitative interventions were targeted at hospitalized patients undergoing physically disfiguring or disabling surgical procedures in order to reduce morbidity leading to functional deficits and disability. As cancer rehabilitation efforts evolved, a more comprehensive and integrative approach to care occurred with an expanded emphasis on psychosocial issues.

Early psychosocial rehabilitation focused on the immediacy of diagnosis and treatment as the focal episode of cancer support. Long-term adaptation and adjustment following treatment has emerged as a rehabilitative priority, particularly as a result of the advocacy and demand from survivors themselves who view the psychosocial concomitants of cancer as often more problematic than the physical impact. New modalities in psychosocial support and rehabilitation integrate mind-body interventions and use a skills-based approach to actively engage survivors in learning specific strategies to optimize their overall well-being and manage stress.

Vocational rehabilitation of patients with cancer has been supported through the passage of a number of federal laws, including the Americans with Disabilities Act, the Rehabilitation Act of 1973, and the Family and Medical Leave Act, which were designated to protect individuals with a cancer history
from discrimination in hiring or discrimination in the workplace. Survivors, survivor advocacy groups, and organizations continue to play an active and highly visible role in legislative efforts related to insurance and employment.

Another inherent principle of rehabilitation is that the family is the unit of care. This is certainly a focus for family members and “co-survivors” of cancer. Until recently, the literature has primarily explored the role of caregiver support and adjustment during diagnosis and the acute phase of cancer treatment (Kim & Given, 2008). However, with extended survival, the impact of cancer across the life trajectory is becoming an increasingly important quality-of-survival issue. Additionally, with the aging of the population, co-survivors are not only at risk for psychological, sexual, or social distress due to a loved one’s cancer, but they are at increased risk for the development of age-related disease and chronic conditions themselves. Screening and assessment of psychosocial health and well-being should involve both survivors and co-survivors. Health promotion efforts should likewise strive to involve family caregivers to optimize health and well-being for survivors and their families.

A primary goal of cancer rehabilitation is intended to help patients restore and achieve maximum levels of function in these multidimensional domains of life while minimizing the limitations imposed by the disease or cancer treatment. It is estimated that nearly two-thirds of individuals diagnosed with cancer will survive for more than five years and will require ongoing and continuing care (Shulman et al., 2009). Improved efforts must focus on incorporating the fundamental principles of rehabilitation into cancer survivorship care with the promise of reducing morbidity and, possibly, mortality.

### Reducing the Burden of Unmet Psychosocial Needs Through Survivorship Care Planning

In 2007, the Institute of Medicine (IOM) released a report focused on the psychosocial health needs of cancer survivors, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, and concluded that the integrated delivery of psychosocial care does not exist (IOM, 2007). The report recommended a model of care that (a) identifies the psychosocial needs of patients, (b) links patients and families to needed services, (c) supports patients and families in managing illness, (d) coordinates psychosocial and biomedical care, and (e) follows up on care delivery to monitor the effectiveness of services (IOM, 2007).

Special challenges occur with the coordination of psychosocial survivorship care, particularly if providers do not routinely screen for psychosocial risk (Jacobson, 2009). Many providers underestimate distress among survivors or are unfamiliar with resources that may be available to treat distress. Providers may feel more comfortable in their ability to address the biomedical aspects of survivorship and lack the knowledge or competencies to discuss key survivorship issues, such as work and employment concerns, financial issues, role and relationship changes, altered identity and body image problems, and spiritual
concerns. Additionally, the coordination of resources to address these issues is a key concern.

The potential for persistent psychological vulnerability is unique to each patient and is related to age, gender, socioeconomic status, family support, reaction to illness, cultural views, and community resources. Low participation in clinical trials by adults that would yield helpful data about psychological risk factors and long-term adjustment to cancer further complicates our understanding about long-term psychosocial health risks. Additionally, financial concerns may prohibit survivors from accessing needed services for their long-term health and well-being (Weaver, Rowland, Bellizzi, & Aziz, 2010). With the introduction of patient navigation programs in 2001 (Freeman, 2001), individuals at increased risk of vulnerability have been able to link to community resources and ongoing support. Survivor advocacy groups and organizations continue to prioritize patient navigation as essential to ensure access to survivorship care, particularly for at-risk and underserved populations.

Although many survivors report psychosocial adjustment and even psychological growth as a result of their cancer experience, the majority of cancer survivors will experience some level of psychosocial distress, particularly related to uncertainty and fear of recurrence. Wide variability exists in prevalence estimates for the psychological long-term effects of cancer because of multiple issues, including lack of definitional consensus, variability in case mix within and across study samples, inconsistent use of reliable and valid instruments to define and document long-term effects, and length of time from treatment (Stein, Syrjala, & Andrykowski, 2008). Survivorship care planning must include a proactive rather than reactive approach to the prevention and management of distress through early assessment and continued screening.

EMPOWERING SURVIVORS THROUGH HEALTH PROMOTION

Recent efforts in survivorship have recognized the benefits of the “teachable moment” in promoting healthy lifestyles and behavior change (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005). Survivors need encouragement from their healthcare providers to follow recommendations for lifestyle change. Partnerships between survivors and their healthcare practitioners in a transdisciplinary model of patient-centric and personalized care must be emphasized for improving the health and functioning of survivors.

Health promotion efforts such as lifestyle modifications in diet, weight management, physical activity and exercise, tobacco cessation, and stress management are all important rehabilitative interventions that focus on the adoption of long-term behaviors and habits. Not only do these modifications in lifestyle reduce the risk for recurrence, but they also reduce the risk of morbidity from other health conditions and complications that increase in incidence as one becomes older.
One of the early psychological and often spiritual tasks associated with a diagnosis of cancer is working through and coming to terms with the betrayal of one’s health. Survivors often view this reversal from health to illness as a feeling of “losing control.” Patient empowerment and encouragement of individual responsibility for regaining and optimizing one’s health through health promotion and lifestyle modification offer survivors a way to restore a sense of control (Sagar & Lawenda, 2009).

**ENHANCED CANCER SURVIVORSHIP CARE**

The increasing number of individuals who will require ongoing care and surveillance following active cancer treatment threatens to overwhelm an already burdened healthcare delivery system. With the projected shortage of oncology professionals occurring simultaneously with the aging of the population, the debate continues as to who will provide the long-term care for the complex, continuous, and chronic needs of cancer survivors. Complicating these challenges are the changing demography of the country and healthcare system, lack of cultural competencies among healthcare providers, disparities in access to care, and the poor representation of survivors, including adults older than 65, in clinical trials (Rowland, 2008). Additionally, survivors with extended periods of disease-free or disease-controlled survival who have fended for themselves are seeking help as they read or hear about the cancer survivorship care movement. Their personal psychological struggles or persistent long-term physical side effects of treatment likewise will require attention. Are we to only offer survivorship care plans to patients completing active treatment? How will we enhance the care and optimize healthy outcomes for this remaining large group of survivors?

As oncologists and other healthcare providers fully realize the necessary paradigm shift of care that must occur, greater attention will focus on successful survivorship care programs that utilize APNs and RNs, as well as members of the transdisciplinary care team that can attend to multiple physical and psychosocial needs (Economou, Edgington, & Deutsch, 2010; Ganz, 2009; Gates & Krishnasamy, 2009; Jacobs & Hobbie, 2002). Nurses are champions for holistic care, a cornerstone of survivorship care planning, and are uniquely positioned to be involved in extended survivorship care (Rowland, 2008). Ferrell, Virani, Smith, and Juarez authored a white paper in 2003 that delineated the role of oncology nursing to ensure quality care for cancer survivors. Nearly 10 years later, we are still woefully behind in implementing the goals and directives in this commissioned initiative.

The collaborative model in which the oncologist partners with the APN enables the oncologist to see additional new patients, initiate primary neoadjuvant or adjuvant treatment, and manage complex issues, especially in the metastatic population. The APN can follow patients receiving primary treatment, facilitate the application of cancer survivorship care plans, and manage the long-term
care of survivors. This same model of care can be effective in the PCP’s practice, with APNs providing the long-term care of cancer survivors based on the practice standards exemplified in the cancer survivorship care plan (Shulman et al., 2009). APNs, especially those in oncology care, are educated in the foundations of primary health care and are uniquely positioned to assume the role of the long-term cancer survivorship care provider (Economou et al., 2010).

Primary care providers will need to play an expanding role in the follow-up care, health promotion, and surveillance of cancer survivors. Models of survivorship care implemented in oncology practices have recently been challenged, as studies report that it is more efficient and cost-effective to follow survivors in primary care (Bowman, Rose, Deimling, Kypriotakis, & O’Toole, 2010). Conversely, in a study of the delivery of survivorship care by PCPs for breast cancer survivors, patients reported less confidence in their PCP’s ability to deliver cancer-specific care than their oncologist, although they rated general care, psychosocial support, and health promotion with high marks (Mao et al., 2009). Improved education and collaboration between the oncology healthcare team and the PCP must occur, with inclusion of valuable components from the survivorship care plan.

SUMMARY

Advocacy groups and patients will continue to demand that survivorship be recognized as an important phase and component in the cancer continuum. A shortage of oncology professionals is imminent, as is an anticipated doubling of the number of cancer survivors by 2050 (Yabroff, Lawrence, Clauser, Davis, & Brown, 2004). Health promotion and disease prevention will be important components of survivorship care in the future. A one-size-fits-all approach to planning for survivorship does not exist, particularly in examining the myriad and unique needs of survivors.

REFERENCES


APPENDICES
## APPENDIX A

### Progress Toward Identifying and Meeting Cancer Survivors’ Needs, With a Focus on Nursing

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1964</td>
<td>The American Society of Clinical Oncology is founded.</td>
</tr>
<tr>
<td>1967</td>
<td>The American Cancer Society publishes <em>Nursing Care of the Cancer Patient</em>.</td>
</tr>
<tr>
<td>1971</td>
<td>President Nixon signs the National Cancer Act into law, launching America’s newest War on Cancer.</td>
</tr>
<tr>
<td>1973</td>
<td>The Association of Pediatric Oncology Nurses, later renamed the Association of Pediatric Hematology/Oncology Nurses, is incorporated.</td>
</tr>
<tr>
<td>1975</td>
<td>The Oncology Nursing Society (ONS) is incorporated.</td>
</tr>
<tr>
<td>1978</td>
<td>The Association of Pediatric Oncology Social Workers is incorporated.</td>
</tr>
<tr>
<td>1979</td>
<td>The journal <em>Cancer Nursing</em> is launched.</td>
</tr>
<tr>
<td>1984</td>
<td>The Association of Oncology Social Work is incorporated.</td>
</tr>
<tr>
<td>1986</td>
<td>The National Coalition for Cancer Survivorship is founded.</td>
</tr>
<tr>
<td>1989</td>
<td>ONS forms the Survivor Focus Group with 58 members. The name is changed to Nurse Survivors in 1990. A second focus group called Survivorship with 92 members is formed in 1990. The Survivorship Special Interest Group (SIG) is approved in 1991 with 29 members. In 2003, the Survivorship SIG name is changed to Survivorship, Quality of Life, and Rehabilitation. Current (2010) membership is 376.</td>
</tr>
<tr>
<td>1996</td>
<td>The National Cancer Institute establishes the Office of Cancer Survivorship.</td>
</tr>
<tr>
<td>2003</td>
<td>The Institute of Medicine publishes <em>Childhood Cancer Survivorship: Improving Care and Quality of Life</em>.</td>
</tr>
<tr>
<td>2003</td>
<td>The <em>Oncology Nursing Forum</em> publishes “The Role of Oncology Nursing to Ensure Quality Care for Cancer Survivors: A Report Commissioned by the National Cancer Policy Board and Institute of Medicine” (Ferrell et al., 2003).</td>
</tr>
<tr>
<td>2005</td>
<td>The <em>American Journal of Nursing (AJN)</em> sponsors “State of the Science on Nursing Approaches to Managing Late and Long-Term Sequelae of Cancer and Cancer Treatment” (Curtiss &amp; Haylock, 2006).</td>
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</tbody>
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(Continued on next page)
## APPENDIX A (Continued)

Progress Toward Identifying and Meeting Cancer Survivors’ Needs, With a Focus on Nursing

<table>
<thead>
<tr>
<th>Year</th>
<th>Event/Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006</td>
<td>Institute of Medicine, cosponsored with the American Society for Clinical Oncology and the National Coalition for Cancer Survivorship, publishes <em>From Cancer Patient to Cancer Survivor: Lost in Transition</em>.</td>
</tr>
<tr>
<td>2006</td>
<td><em>AJN</em> holds “Coming Together to Improve Care for Survivors of Adult Cancers,” a stakeholders’ summit, at the National Academy of Sciences (Haylock et al., 2007). <em>AJN</em> publishes “Improving the Care of Cancer Survivors” (Curtiss et al., 2006).</td>
</tr>
<tr>
<td>2007</td>
<td>Institute of Medicine publishes <em>Implementing Cancer Survivorship Care Planning: Workshop Summary</em>.</td>
</tr>
<tr>
<td>2007</td>
<td><em>AJN</em> publishes “The Cancer Survivor’s Prescription for Living” (Haylock et al., 2007).</td>
</tr>
<tr>
<td>2008</td>
<td>ONS holds Cancer Survivorship Task Force meeting to develop the Survivorship Initiative Roadmap.</td>
</tr>
</tbody>
</table>

## REFERENCES


# APPENDIX B

**Recommendations From the State of the Science on Nursing Approaches to Managing Late and Long-Term Sequelae of Cancer and Cancer Treatment**

Develop a research agenda for long-term survivor issues that includes categories of the nature and scope of the problem, issues and needs of survivors, access to care, outcomes, and education and dissemination of information.

1. Shift the paradigm in cancer care to a wellness model incorporating health promotion and disease prevention in all aspects of care.
2. Support the development of a comprehensive national database of cancer survivors to facilitate comprehensive follow-up and surveillance.
3. Develop and disseminate guidelines in evidence-based practice, education, and policy for all site-specific cancers. Until evidence-based guidelines are developed, create consensus-based guidelines.
4. Improve access to care focused on the needs of long-term survivors regardless of socioeconomic level or healthcare setting.
5. Conduct educational outreach for the healthcare providers, survivors, and the general public using culturally sensitive language and approaches.
6. Expand research on survivor outcomes, focusing on quality of life and quality of care across all socioeconomic groups, across the life span, and inclusive of all cancer diagnoses.
7. Improve interdisciplinary and multidisciplinary collaboration and communication to deliver seamless, coordinated care.
8. Advocate for increased research funding, particularly for translational research to apply in clinical practice.
10. Encourage consultations with cancer survivors and frontline providers at every level, from the development of research priorities to clinical decision making and design of delivery systems.

<table>
<thead>
<tr>
<th>Goal 1</th>
<th>Build the capacity to educate all nurses, caregivers, patients, and the public on cancer survivorship issues, including undergraduate and graduate curricula and continuing education.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goal 2</td>
<td>In collaboration with patients and families, develop a jointly crafted, interdisciplinary, evidence-based wellness plan as part of a comprehensive cancer survivorship care plan.</td>
</tr>
<tr>
<td>Goal 3</td>
<td>Develop and prioritize a multinational research agenda related to cancer survivorship and translate the findings into clinical practice and policy.</td>
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### APPENDIX D

**Multidimensional Cancer Survivorship Agenda for Nursing**

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<thead>
<tr>
<th>Education Agenda</th>
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<tbody>
<tr>
<td>• Educational needs assessment</td>
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<td>• Public education</td>
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<tr>
<td>• Media education</td>
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<tr>
<td>• Patient and family education</td>
</tr>
<tr>
<td>• Basic professional education</td>
</tr>
<tr>
<td>• Faculty education at basic and advanced levels</td>
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<tr>
<td>• Continuing education</td>
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<th>Health Policy Agenda</th>
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<tbody>
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<td>• Social justice</td>
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<tr>
<td>• Vulnerable populations</td>
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<tr>
<td>• Fiscal resources/allocations</td>
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<td>• Nurses’ and other professional and lay providers’ scope of practice</td>
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<table>
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<tr>
<th>Research Agenda</th>
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</thead>
<tbody>
<tr>
<td>• Wellness and risk reduction</td>
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<tr>
<td>• When to screen</td>
</tr>
<tr>
<td>• Who follows</td>
</tr>
<tr>
<td>• How to follow up</td>
</tr>
<tr>
<td>• How to pay for follow-up care</td>
</tr>
<tr>
<td>• Programs</td>
</tr>
<tr>
<td>• Health policy</td>
</tr>
<tr>
<td>• Identification and study of the needs of cancer survivors</td>
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<tr>
<td>• Role of nutrition</td>
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<tr>
<td>• Role of physical activity</td>
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<tr>
<td>• Survivors’ family issues</td>
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<tr>
<td>• Cultural influences and issues</td>
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<table>
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<th>Communications Agenda</th>
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<tr>
<td>• Media collaboration</td>
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<tr>
<td>• Nongovernmental organizations</td>
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<tr>
<td>• Academic centers, regional centers, community centers, rural centers</td>
</tr>
<tr>
<td>• Community service organizations</td>
</tr>
</tbody>
</table>
APPENDIX E
Organizing Framework for Understanding Cancer-Related Fatigue in Cancer Survivors

CANCER

Impairments in Neuromuscular Metabolism and Function

DISTRESSING SYMPTOMS (e.g., pain, dyspnea)

PsycHological and Coping Responses

IMBALANCED Neuroendocrine-Immune Stress Response

MECHANISMS

Anemia
Anorexia/Cachexia
Asthenia
Malnutrition
Cytokine Dysregulation (including second messengers such as nitric oxide and prostaglandin)

Vagal Afferent Nerve Inhibition
Dysregulation of hypothalamus-pituitary-adrenal (HPA) axis and hypothalamus-pituitary-thyroid (HPT) axis
Serotonin and Dopamine Dysregulation
Disrupted Circadian Rhythms

CANCER-RELATED FATIGUE

Inactivity
Adverse Changes in Body Composition (overweight/obesity, sarcopenia)
Sleep/Wake Disturbances
Mood

Health-Related Quality of Life
Long-Term Survival Outcomes

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APPENDIX F
Fatigue Survivorship Care Plan

DEFINITION
- Fatigue is one of the most common side effects of treatment, and almost 50% of cancer survivors report fatigue that persists for months and even years after treatment.
- Fatigue is a feeling of weariness, tiredness, or exhaustion that can include a loss of physical and/or emotional energy.
- Fatigue is felt on different levels, with some survivors experiencing low energy, others feeling totally wiped out or unable to concentrate, and some feeling depressed or frustrated.

EVALUATE ALL PATIENTS FOR FATIGUE
- Screen all patients for fatigue at regular intervals: On a scale of 0–10, where zero is no fatigue and 10 is the worst fatigue imaginable, how would you rate your fatigue over the past 7 days?
- If moderate (4–6) or severe (7–10), evaluate onset, pattern, duration, change over time, contributing factors, interference with function, and self-management strategies, and develop a tailored fatigue plan.

INTERVENTIONS TO MANAGE FATIGUE
- Exercise
  - With permission from your healthcare team, begin a program of physical activity such as walking, stretching, and cycling. Begin with 5 or 10 minutes twice daily, and increase the time by 1 minute a day. Do not be tempted to overdo it in exercise, but rather strive for consistency.
  - Consider referral to physical therapy, occupational therapy, exercise physiologist, or physiatrist to develop, tailor, or sustain an exercise program.
- Gain Information About Fatigue
  - Offer anticipatory guidance about possible patterns of fatigue onset occurrence (e.g., in association with muscle weakness/deconditioning, boredom, excess activity, impaired sleep quality, sedating medications, stress).
  - Differentiate facets of the fatigue experience (fatigue, tiredness, weakness, cognitive slowing).
  - Keep a journal or diary of activities, fatigue severity, associated feelings/symptoms, and evaluation of self-care actions.
- Improve Sleep Quality
  - See care plan for managing sleep-wake disturbances (Appendix G).
- Seek Help in Managing Stress, Mood Disturbances, and the Ups and Downs of Survivorship
  - Maintain open communication among patient, family, and healthcare professional about fatigue and its effects on daily life.
  - Offer information and referrals to counseling or support groups.

(Continued on next page)
Fatigue Survivorship Care Plan

**APPENDIX F (Continued)**

**Fatigue Survivorship Care Plan**

**PHARMACOLOGIC INTERVENTION:** ___________________________________

**FOLLOW-UP ASSESSMENT:** REPEAT 6–8 WEEKS LATER; IF NO IMPROVEMENT, CONSIDER REFERRALS:

- Advanced Practice Nurse  Social Worker/Psychologist/Counselor
- Rehabilitation (PT, OT, Physiatry)  Sleep Center

**FOR FURTHER CONSIDERATION**
- Optimize the management of concurrent symptoms (pain, depression, dyspnea).
- Offer relaxation, massage, acupuncture, mindfulness-based stress reduction, or levo-carnitine supplementation.
- Consider treatment with an antidepressant or psychostimulant.
- Consider referral for rehabilitation, physical therapy, polysomnography, psychotherapy, or cognitive-behavioral therapy for sleep.
- Encourage attention-restoring activities, such as exposure to natural environments, and pleasant distractions, such as music.
- Teach diversional and relaxation techniques.
- Provide information concerning the importance of a balanced diet with adequate intake of fluid, calories, protein, carbohydrates, fat, vitamins, and minerals to achieve or maintain a healthy weight.

Patient: _____________________  Clinician initials: _________  Date: ____________

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APPENDIX G

Insomnia Survivorship Care Plan

DEFINITION
- Insomnia is a complaint of difficulty initiating sleep, difficulty maintaining sleep, or waking up too early or sleep that is chronically nonrestorative or poor in quality. Insomnia is prevalent in cancer patients, most likely due to changes in the body’s function and presence of other symptoms.

SCREEN ALL PATIENTS FOR SLEEP-WAKE DISTURBANCES
- Insomnia Severity Index (ISI)*
  Circle the number that best describes your current (last 2 weeks) sleep pattern:

<table>
<thead>
<tr>
<th>Item</th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Very Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Difficulty falling asleep</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Difficulty staying asleep</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Problem waking too early</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

4. How satisfied/dissatisfied are you with your sleep pattern?
   Very Satisfied 0 1 2 3 4 Very Dissatisfied

5. To what extent do you think your sleep problem interferes with daily functioning (daytime fatigue, ability to function at work or daily chores, concentration, memory, mood, etc.)?
   Does Not Interfere 0 1 2 3 4 Significant

6. How noticeable to others are your sleeping problems in terms of impairing the quality of your life?
   Not at all Noticeable 0 1 2 3 4 Very Noticeable

7. How worried/distressed are you about your current sleep problems?
   Not at all 0 1 2 3 4 Very Distressed

Add the scores for all items = _____________total score**

0–7 = No clinically significant insomnia
8–14 = Subthreshold insomnia
15–21 = Clinical insomnia (moderate severity)
22–28 = Clinical insomnia (severe)

** If ISI score = 8 or higher, initiate interventions.

## APPENDIX G (Continued)

### Insomnia Survivorship Care Plan

#### INTERVENTIONS TO IMPROVE SLEEP
- Go to bed only when sleepy and approximately the same time each night.
- Get out of bed and go to another room whenever unable to fall asleep; return to bed only when sleepy again.
- Use the bedroom for sleep and sex only.
- Maintain a regular rising time each day.
- Avoid daytime napping. If needed, limit to <1 hour and complete 4 hours before bedtime.
- Create a bedtime routine. Start by winding down 1–2 hours before bedtime. Use a preferred relaxation technique, such as taking a warm bath or shower, reading, listening to soft music, or receiving a massage.
- Avoid stimulants such as caffeine after noon and nicotine or alcohol prior to bedtime; complete dinner 3 hours before bedtime; do not go to bed hungry (a protein snack is preferred).
- Create a comfortable sleep environment. Replace mattress every 10–12 years and pillows more frequently; keep the bedroom dark, cool, and quiet, and use light covers; do not watch television in the bedroom.
- Ensure at least 20 minutes every day of exposure to bright, natural light, preferably in the morning.
- Visit the National Sleep Foundation: www.sleepfoundation.org or the National Cancer Institute Physician Data Query (PDQ®) on sleep disorders: www.cancer.gov/cancertopics/pdq/supportivecare/sleepdisorders.

#### PHARMACOLOGIC INTERVENTION:
__________________________________________________________

#### FOLLOW-UP ASSESSMENT: REPEAT 6–8 WEEKS LATER; IF ISI SCORE = 8 OR HIGHER, CONSIDER REFERRALS:
(circle most appropriate)

<table>
<thead>
<tr>
<th>Advanced Practice Registered Nurse</th>
<th>Primary Care Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal Medicine</td>
<td>Sleep Center</td>
</tr>
</tbody>
</table>

#### FOR FURTHER CONSIDERATION
- With permission from your healthcare team, begin a program of physical activity such as walking, stretching, and cycling. Avoid exercising within 2 hours of bedtime.
- Consider mindfulness-based stress reduction, relaxation and guided imagery, progressive muscle relaxation, supportive-expressive group therapy, expressive writing, massage, yoga, and music therapy.

Patient: __________________________  Clinician initials: _______  Date: ____________________

---

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# APPENDIX H

## Fertility Options

### FEMALE OPTIONS

**CRYOPRESERVATION (Freezing)**

- Approximate cost per procedure = $12,000
- Additional costs for storage/pregnancy/reimplantation and intrauterine insemination (IUI)
- In vitro fertilization (IVF)—extra

<table>
<thead>
<tr>
<th>STANDARD</th>
<th>EXPERIMENTAL</th>
<th>EXPERIMENTAL</th>
<th>STANDARD</th>
<th>STANDARD</th>
<th>EXPERIMENTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Embryo freezing (post-puberty before treatment)</td>
<td>Egg freezing (post-puberty before treatment)</td>
<td>Ovarian tissue freezing (pre-puberty before treatment)</td>
<td>Donor egg (from woman)</td>
<td>Donor egg (from couple)</td>
<td>Sperm</td>
</tr>
<tr>
<td>Harvesting unfertilized eggs to freeze for future fertilization and implantation</td>
<td>Freezing ovarian tissue prior to cancer treatment for later reimplantation</td>
<td>USE OF A SURROGATE</td>
<td>Sperm obtained through masturbation for freezing and future impregnation of female</td>
<td>Spem extracted from testicular tissue or obtained from electro-ejaculation under sedation for freezing and future impregnation of female</td>
<td>Individual sperm obtained from testicular tissue through biopsy for freezing and future impregnation of female</td>
</tr>
</tbody>
</table>

### MALE OPTIONS

**CRYOPRESERVATION (Freezing)**

- Average storage cost is approximately $500 per year.
- Costs for IUI and IVF—extra

<table>
<thead>
<tr>
<th>STANDARD</th>
<th>EXPERIMENTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sperm</td>
<td>Testicular</td>
</tr>
<tr>
<td>Sperm banking (post-puberty before treatment)</td>
<td>Sperm banking (post-puberty before or after treatment)</td>
</tr>
<tr>
<td>(pre- or post-puberty before treatment)</td>
<td></td>
</tr>
</tbody>
</table>

### UTILIZING DONORS & SURROGATES

- $5,000–$10,000 per egg
- $5,000–$7,000 per embryo
- $4,000–$16,000
- $500–$2,500 for surgery;
- $300–$1,000 for freezing

<table>
<thead>
<tr>
<th>STANDARD</th>
<th>EXPERIMENTAL</th>
<th>STANDARD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donor egg (from woman)</td>
<td>Donor embryo (from couple)</td>
<td>Sperm donated by a man for artificial insemination via IUI or IVF</td>
</tr>
</tbody>
</table>

### IVF EXTRA

APPENDIX I
Practice and Selected Treatments for Lymphedema

Recommended for Practice

COMPLETE DECONGESTIVE THERAPY (CDT)
Evidence at the highest level supports CDT for the treatment of lymphedema (LE). CDT is a two-phase therapy that involves 5 key components:
- Skin care*
- Manual lymph drainage*
- Compression*: Low-stretch compression bandaging (phase I)* and compression garments (phase II)*
- Movement therapies including remedial exercise*
- Patient education.

CDT aims to decrease swelling and prepare patients for self-management and maintenance. In addition to reducing interstitial lymphatic fluid, CDT improves shoulder range of motion and decreases pain. Intensive therapy lasts 10–20 days.
- Intensive CDT should begin when LE is moderate to severe.
- Modified CDT (excluding one or two components) is indicated for mild to moderate LE.
- CDT is administered by a specialty-trained therapist.
- Early intervention with CDT is less costly and less burdensome and has better outcomes (than later interventions for more severe LE).**

COMPRESSION BANDAGING (CB)*
To reduce swelling and prepare limb for** gradient compression garments (sleeves, gloves, and gauntlets) to maintain reductions or prevent fluid accumulation. Specialized expertise is required for the initiation and monitoring of CB.
- Short-stretch, multilayer bandages reduce the volume of LE during the intensive treatment phase when used alone or in conjunction with other therapies.
- Maintenance therapy using nightly CB and compression garments decreases the risk of LE recurrence and can stabilize limb volume.

TREATMENT OF INFECTIONS
People with LE are at increased risk for infection. Criteria for hospitalization include:
- Hypotension, tachycardia, fever, confusion, or vomiting
- Continuing symptoms despite oral antibiotics for 48 hours
- Unresolved local symptoms.

Early detection and treatment are critical to minimizing the risk for systemic infection. Oral penicillins should be started early and continue for at least 14 days or until signs have resolved. For penicillin allergy, clindamycin or other appropriate antibiotic may be used.

Simple and manual lymph drainage should be avoided during acute infection with fever. If tolerated, reduced-level compression garments or CB may be applied.

Recurrent infections occur in up to 20% of patients.

Likely to Be Effective

MAINTAINING OPTIMAL BODY WEIGHT*
Although isolating patient factors from treatment factors is not possible, evidence supports a body mass index score > 30 as a risk factor for LE.

(Continued on next page)
**APPENDIX I (Continued)**

**Practice and Selected Treatments for Lymphedema**

### MANUAL LYMPH DRAINAGE (MLD)*
Systematic reviews and individual studies support the use of MLD for LE treatment. MLD practitioners require training at the specialist level.

### SKIN CARE*
Impeccable skin care is a cornerstone of LE therapy.

### Benefits Balanced With Harms

#### EXERCISES*
Exercise and movement therapies play an important role in CDT by supporting cardiovascular health, muscle strength, and functional capacity. Integrating exercise requires an individualized approach. *Note: Evidence is moving toward Likely to Be Effective.***

#### PROPHYLACTIC ANTIBIOTICS FOR RECURRENT INFECTIONS
Recurrent infection occurs in nearly one-quarter of people with LE who experience an initial cellulitis. For people who experience 2–3 infections per year, evaluate the benefits and risks of antibiotic prophylaxis.

#### Effectiveness Not Fully Established as Stand-Alone Therapies**
- Compression garments*
- Hyperbaric oxygen
- Low-level laser therapy
- Nanocrystalline silver dressing on lymphatic ulcers
- Pneumatic compression pump
- Simple lymph drainage*
- Surgical intervention

### Not Recommended for Practice

#### DRUG THERAPY
- Diuretics
- Benzopyrenes

---

* Indicates components of CDT
** Additions by authors are italicized.

APPENDIX J
Follow-Up Resources for Survivors With Psychological Distress

A list of services and organizations can be found in a report by the Institute of Medicine (IOM, 2007) on the psychosocial needs of patients with cancer. Practitioners will need to update and supplement these with local resources. Resources specifically for survivors with suicidal thoughts are listed separately. These resources are not a substitute for mental health treatment, and survivors should be referred to them after appropriate screening and assessment.

<table>
<thead>
<tr>
<th>Organization</th>
<th>Web Site</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Resources for Feelings of Isolation and Depression</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lance Armstrong Foundation</td>
<td><a href="http://www.livestrong.org">www.livestrong.org</a></td>
<td>866-673-7205</td>
</tr>
<tr>
<td>National Coalition for Cancer Survivorship</td>
<td><a href="http://www.canceradvocacy.org">www.canceradvocacy.org</a></td>
<td>888-650-9127</td>
</tr>
<tr>
<td><strong>Mental Health Advocacy Groups</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression and Bipolar Support Alliance</td>
<td><a href="http://www.dbsalliance.org">www.dbsalliance.org</a></td>
<td>800-826-3632</td>
</tr>
<tr>
<td>Mental Health America</td>
<td><a href="http://www.nmha.org">www.nmha.org</a></td>
<td>800-969-6642</td>
</tr>
<tr>
<td><strong>Organizations Offering Survivor Support Groups</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CancerCare</td>
<td><a href="http://www.cancercare.org">www.cancercare.org</a></td>
<td>800-813-HOPE</td>
</tr>
<tr>
<td>Cancer Hope Network</td>
<td><a href="http://www.cancerhopenetwork.org">www.cancerhopenetwork.org</a></td>
<td>800-552-4366</td>
</tr>
<tr>
<td>The Wellness Community</td>
<td><a href="http://www.thewellnesscommunity.org">www.thewellnesscommunity.org</a></td>
<td>888-793-WELL</td>
</tr>
<tr>
<td><strong>Disease-Specific Programs</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living Beyond Breast Cancer</td>
<td><a href="http://www.lbbc.org">www.lbbc.org</a></td>
<td>888-753-LBBC</td>
</tr>
<tr>
<td>Support for People with Oral and Head and Neck Cancer</td>
<td><a href="http://www.spohnc.org">www.spohnc.org</a></td>
<td>800-377-0928</td>
</tr>
<tr>
<td><strong>Information on Depression From the National Institutes of Health</strong></td>
<td><a href="http://www.nimh.nih.gov">www.nimh.nih.gov</a></td>
<td>800-421-4211</td>
</tr>
</tbody>
</table>

(Continued on next page)
### APPENDIX J (Continued)

**Follow-Up Resources for Survivors With Psychological Distress**

<table>
<thead>
<tr>
<th>Organization</th>
<th>Web Site</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local Mental Health Professionals for Evaluation and Treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>American Psychiatric Association</td>
<td><a href="http://www.psych.org">www.psych.org</a></td>
<td>888-35-PSYCH</td>
</tr>
<tr>
<td>American Psychological Association</td>
<td><a href="http://www.apa.org">www.apa.org</a></td>
<td>800-347-2721</td>
</tr>
<tr>
<td>American Psychosocial Oncology Society</td>
<td><a href="http://www.apos-society.org">www.apos-society.org</a></td>
<td>866-276-7443</td>
</tr>
<tr>
<td>National Association of Social Workers</td>
<td><a href="http://www.helpstartshere.org">www.helpstartshere.org</a></td>
<td>800-742-4089</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Additional Resources for Feelings of Hopelessness or Suicide</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Suicide Prevention Hotlines</td>
<td></td>
<td></td>
</tr>
<tr>
<td>National Hope Line</td>
<td><a href="http://www.hopeline.com">www.hopeline.com</a></td>
<td>800-SUICIDE</td>
</tr>
<tr>
<td>National Suicide Prevention Hotline</td>
<td><a href="http://www.suicidepreventionlifeline.org">www.suicidepreventionlifeline.org</a></td>
<td>800-273-TALK</td>
</tr>
<tr>
<td>Suicide Prevention Organizations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>American Foundation for Suicide Prevention</td>
<td><a href="http://www.afsp.org">www.afsp.org</a></td>
<td>888-333-2377</td>
</tr>
<tr>
<td>Samaritans USA</td>
<td><a href="http://www.ncsp.org/samaritans">www.ncsp.org/samaritans</a></td>
<td>212-677-3009</td>
</tr>
<tr>
<td>Suicide Awareness Voices of Education</td>
<td><a href="http://www.save.org">www.save.org</a></td>
<td>952-946-7998</td>
</tr>
<tr>
<td>Suicide Prevention Resource Center</td>
<td><a href="http://www.sprc.org">www.sprc.org</a></td>
<td>877-438-7772</td>
</tr>
</tbody>
</table>

**Reference**

Mental Health Teaching Sheet for Depression and Suicide Risk

Mental Health Services for Cancer Survivors

Why would I need a mental health professional?
Many people who experience problems in their lives seek a mental health professional for some kind of therapy or counseling. They may look for treatment for a specific symptom, such as panic attacks, or they may want to learn a new way to manage problems in a relationship or at work. Cancer survivors may look for a mental health provider for these same reasons, as well as for issues related to their cancer.

What can I expect if I see a mental health professional?
There are several kinds of mental health providers and many kinds of treatments. Your experience will depend on the provider you see and the problem you want help with. You can expect the provider to listen to your experiences and ask questions about your personal history. You will need to talk about your difficulties and your goals for treatment. Most therapists see patients once a week for 45–50 minutes. Some types of therapy will last only a few sessions, while others will continue for months or longer.

Finding the Right Mental Health Professional
1. Mental health services can be expensive, often $90–$200 a visit, so most people use insurance to help pay for therapy. Contact your insurance provider for information about mental health services. Find out:
   - What services are covered, if you have a co-pay, and how many sessions are covered.
   - Can you use your insurance with any mental health provider, or do you need to see a provider who is part of the insurance network?
   - Does the insurance plan have a list of providers in your area? Some insurers will fax you a list or let you search a Web site of affiliated providers.
2. Talk with your primary care provider (PCP) about your concerns and ask about mental health professionals in your area. If your insurer provides a list, ask if your PCP recommends any of the listed professionals. You may want to ask your PCP about possible medical causes of your current symptoms.
3. You may get helpful recommendations from trusted sources in your community. Friends and family, clergy, and local hospitals or community centers may be able to recommend a mental health professional.
4. When you find the names of two or three providers, contact them by telephone. When you call:
   - You will typically need to leave a message and ask the provider to return your call.
   - Tell providers about your concerns and ask about their experience in helping people with similar issues.
   - Ask about availability, fees, insurance, and if they are licensed. You may want to ask about their education, expertise, and number of years in practice.
   - If you are satisfied with the answers, make an appointment.
5. During your first visit, plan to describe the reasons that led you to seek help. The provider may ask you detailed questions about your personal and medical history. Ask the provider what kind of treatment he or she recommends, and what other kinds of treatment might be available. Ask about expected benefits, length of treatment, and any side effects.

(Continued on next page)
6. It is important to find someone with whom you have rapport and feel you can trust. It may take a few visits to be sure you have a good “fit” with the provider and for him or her to get to know you. Talk to the provider about your questions or concerns. If you do not feel you have a good fit with the provider, talk to him or her about that, too. Be honest—it is your treatment and the provider’s job is to help you. The provider may be able to change his or her approach to your therapy, or help you to find a therapist who is a better match for you. Recontact your insurer or PCP if you need further assistance.

Types of Mental Health Providers

- **Clinical social workers** have a master’s degree in social work (MSW) and are trained to make diagnoses and provide therapy.
- **Clinical psychologists** have a doctoral degree (PhD) in psychology and are trained to make diagnoses and provide psychological testing and therapy.
- **Psychiatrists** are medical doctors (MDs) who have specialized training in mental illness and treatment. Psychiatrists can prescribe medications, and may also provide therapy.
- **Psychiatric nurse specialists** are nurses with a master’s degree in mental health nursing who may prescribe medications as well as provide therapy.
- **Certified alcohol and drug abuse counselors** are counselors with a variety of educational backgrounds who have specialized training in substance abuse.

Types of Treatment

Medication can be used to treat emotional disorders and symptoms of distress. Treatment usually involves identifying some target symptoms and trying a medication to improve them. Some medications take several days or even weeks to take effect, and the provider may need to see you several times to adjust the medication. Medication is often combined with psychotherapy. Psychotherapy involves talking face-to-face with a therapist to help understand and resolve problems. The following are the most common types of psychotherapy available:

- **Behavior therapy** focuses on trying to change patterns of problem behavior. Treatment often includes keeping records of problems or symptoms, learning new behaviors, and learning relaxation and stress management. Behavior therapy may be used with cognitive therapy.
- **Cognitive therapy** focuses on identifying thought patterns that lead to troublesome feelings and behaviors. Treatment often involves recording problematic thoughts and developing new thought patterns.
- **Psychodynamic therapy** focuses on understanding how past experiences influence present behaviors and feelings. Treatment involves talking about problems in detail to better understand the motivations and emotions involved and to develop better ways of expressing those feelings.
- **Family or couples therapy** involves treating the couple or family to help resolve problems that arise in family relationships. The therapy often involves family members discussing problems together to develop better communication and identify problem interactions.
- **Group therapy** brings together individuals with similar problems to work together for change. Treatment often includes group members discussing their problems and getting feedback and support from each other.

(Continued on next page)
### APPENDIX K (Continued)

#### Mental Health Teaching Sheet for Depression and Suicide Risk

**What resources are available for people without insurance?**
- Medicaid and Medicare cover mental health services for older adult, disabled, and low-income individuals.
- Free care at a local hospital may also cover mental health services.
- Community mental health centers, listed in the yellow pages of the phone book, have reduced-fee services based on income.
- Individual therapists may provide some reduced-fee services based on income.

#### Additional Referral Resources
- American Psychiatric Association: 888-357-7924; www.healthyminds.org
- American Psychological Association: 800-964-2000; www.apa.org/about/contact.html#R
- CancerCare: 800-813-4673; www.cancercare.org/get_help/telephone.php
- Social Work Therapy Referral Service: 800-242-9794; www.therapymatcher.org

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*Note. This mental health teaching sheet was developed by Christopher Recklitis, PhD, at the Perni Family Survivors' Center, Dana-Farber Cancer Institute, Boston, MA, as a resource to help educate cancer survivors about mental health services and assist them in finding appropriate referrals. It may be downloaded from www.cancernetwork.com/cancernetwork/Recklitis-Mental-Health-Teaching-Sheet.pdf and reproduced at no charge. Copyrighted by Christopher Recklitis, PhD.*
## APPENDIX L
### A Prescription for Living

**Date of first preparation:**

**Updated:**

<table>
<thead>
<tr>
<th>Name:</th>
<th>Date of birth:</th>
<th>Sex:</th>
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<tbody>
<tr>
<td>Cancer diagnosis:</td>
<td>Date of diagnosis:</td>
<td></td>
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</tbody>
</table>

| Symptoms of presentation: |

| Date completed therapy: | Initial stage: | Initial disease site(s): |

### History of Cancer Treatment

#### Surgery

<table>
<thead>
<tr>
<th>Surgeon's name/phone:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date:</td>
</tr>
</tbody>
</table>

#### Radiation therapy

<table>
<thead>
<tr>
<th>Radiation oncologist's name/phone:</th>
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<tbody>
<tr>
<td>Date range:</td>
</tr>
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</table>

#### Chemotherapy, biotherapy, hormone therapy, targeted therapies

<table>
<thead>
<tr>
<th>Medical oncologist's name/phone:</th>
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<tr>
<td>Regimen 1:</td>
</tr>
<tr>
<td>Regimen 2:</td>
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<td>Date range:</td>
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<table>
<thead>
<tr>
<th>Agents received (include cumulative doses for anthracycline, cyclophosphamide, cisplatin, or high-dose therapy)</th>
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<td>Agents received (include cumulative doses for anthracycline, cyclophosphamide, cisplatin, or high-dose therapy)</td>
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<tr>
<td>Allogeneic stem cells</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Other interventions:</th>
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</thead>
</table>

<table>
<thead>
<tr>
<th>Vascular access device:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Significant events during treatment:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight gain &gt; 10 lbs. (4.5 kg)</td>
</tr>
<tr>
<td>Weight loss &gt; 10 lbs. (4.5 kg)</td>
</tr>
<tr>
<td>Cardiopulmonary event:</td>
</tr>
<tr>
<td>Hemorrhagic cystitis</td>
</tr>
<tr>
<td>Psychosocial event requiring treatment:</td>
</tr>
<tr>
<td>Major depression</td>
</tr>
<tr>
<td>Anxiety disorder</td>
</tr>
<tr>
<td>CTCARE grade III or IV toxicities:</td>
</tr>
<tr>
<td>Other:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other active health problems:</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recent disease evaluation:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date:</td>
</tr>
</tbody>
</table>

| Findings: |

(Continued on next page)
### APPENDIX L (Continued)

**A Prescription for Living**

<table>
<thead>
<tr>
<th>Primary cancer care provider:</th>
<th>Follow-up Plan</th>
<th>Symptoms to report:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer evaluation</td>
<td>Frequency</td>
<td>□ New lumps</td>
</tr>
<tr>
<td>□ Imaging</td>
<td></td>
<td>□ New pain (bone, abdomen, head and neck)</td>
</tr>
<tr>
<td>□ Laboratory</td>
<td></td>
<td>□ Bleeding</td>
</tr>
<tr>
<td>□ Physical exam</td>
<td></td>
<td>□ Cough that doesn’t resolve</td>
</tr>
<tr>
<td>□ Other</td>
<td></td>
<td>□ Loss of appetite</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Change in bowel habits</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Weight loss &gt; 10 lbs. (4.5 kg)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Persistent nausea and vomiting</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Persistent fatigue</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Other</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Persistent effects</th>
<th>Plan</th>
<th>Persistent effects</th>
<th>Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td></td>
<td>□ Anorexia</td>
<td></td>
</tr>
<tr>
<td>□ Fatigue</td>
<td></td>
<td>□ Weakness</td>
<td></td>
</tr>
<tr>
<td>□ Pain</td>
<td></td>
<td>□ Neuropathy</td>
<td></td>
</tr>
<tr>
<td>□ Sleep problems</td>
<td></td>
<td>□ Continuing blood product and cytokine support</td>
<td></td>
</tr>
</tbody>
</table>

**Other**

- □ Onset of symptoms or signs that may affect daily living or functional ability
  - □ Adjustment problems □ Anxiety □ Depression □ Psychosocial dysfunction □ Other:
  - □ Other:

### Possible late effects of treatment

- □ Cardiovascular disease
  - □ Oral dentition, mucosa, bony structures
- □ Second cancer
  - □ Renal
- □ Hearing loss, tinnitus
  - □ Neurologic
- □ Pulmonary dysfunction
  - □ Graft-versus-host disease
- □ Cardiomyopathy
  - □ Infection risk
- □ Infertility
  - □ Osteoporosis
- □ Hepatic dysfunction
  - □ Ocular: cataracts
- □ Psychosocial distress

### Other health care problems

- □ Plan (include provider)

### Wellness

- □ Smoking cessation
  - □ Colonoscopy Frequency:
- □ Screening for and prevention of osteoporosis
  - □ PSA test and digital rectal exam Frequency:
- □ Nutrition and healthy weight management
  - □ Skin examination Frequency:
- □ Physical activity
  - □ Papanicolaou test Frequency:
- □ Safe sex
  - □ Other individualized plan Frequency:
- □ Limiting sun exposure

<table>
<thead>
<tr>
<th>Patient's signature and date:</th>
<th>Clinician's signature and date:</th>
</tr>
</thead>
</table>

APPENDIX M
Sample Cancer Treatment Plan and Summary

[Insert Practice Name/Info Here]
The Treatment Plan and Summary is a brief record of major aspects of cancer treatment. This is not a complete patient history or comprehensive record of intended therapies.

<table>
<thead>
<tr>
<th>Patient name:</th>
<th>Patient ID:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical oncology provider name:</td>
<td>PCP:</td>
</tr>
<tr>
<td>Patient DOB:</td>
<td>Age:</td>
</tr>
<tr>
<td>Support contact name:</td>
<td>Support contact phone:</td>
</tr>
</tbody>
</table>

BACKGROUND INFORMATION

Symptoms/signs:

Family history/predisposing conditions:

Major co-morbid conditions:

Tobacco use: No □ Yes, past □ Yes, current □ (If current, cessation counseling provided? □ Yes □ No)

Cancer type/location: Diagnosis date: ______/_____/_______

Is this a new cancer diagnosis or recurrence?: □ New □ Recurrence (date: ______/_____/_______)

Surgery: □ None □ Diagnosis only □ Palliative resection □ Curative resection

Surgical procedure/location/findings:

Tumor type/histology/grade:

<table>
<thead>
<tr>
<th>Study</th>
<th>Date</th>
<th>Findings</th>
</tr>
</thead>
</table>

T stage: □ T1 □ T2 □ T3 □ T4 □ Not applicable
M stage: □ M0 □ M1 □ Not applicable

Location(s) of metastasis or recurrence (if applicable):

TREATMENT PLAN

<table>
<thead>
<tr>
<th>ECOG performance status at start of treatment:</th>
<th>ECOG performance status at end of treatment:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ 0 □ 1 □ 2 □ 3 □ 4</td>
<td>□ 0 □ 1 □ 2 □ 3 □ 4</td>
</tr>
</tbody>
</table>

Chemotherapy Drug Name | Route | Dose mg/m² | Schedule | Dose reduction | # cycles administered |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Yes ___ % □ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Yes ___ % □ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Yes ___ % □ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Yes ___ % □ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Yes ___ % □ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Major side effects of this regimen: □ Hair loss □ Nausea/Vomiting □ Neuropathy □ Low blood count □ Fatigue □ Menopause symptoms □ Cardiac □ Other

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Important: This is a summary document whose purpose is to review the basics of the cancer treatment for this patient. This does not replace information available in the medical record: a complete medical history provided by the patient, examination and diagnostic information, or educational materials that describe strategies for coping with cancer and cancer therapies in detail. Both medical science and an individual's health care needs change, and therefore this document is current only as of the date of preparation. This summary document does not prescribe or recommend any particular medical treatment or care for cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.

(Continued on next page)
### Sample Cancer Treatment Plan and Summary

[Insert Practice Name/Info Here]

The Treatment Plan and Summary is a brief record of major aspects of cancer treatment. This is not a complete patient history or comprehensive record of intended therapies.

<table>
<thead>
<tr>
<th>Non-chemotherapeutic Agents</th>
<th>Route</th>
<th>Purpose/Goal</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Reason for stopping treatment:**
- ☐ Completion
- ☐ Toxicity
- ☐ Progression
- ☐ Other: __________________________

**Response to treatment:**
- ☐ Complete
- ☐ Partial
- ☐ No response
- ☐ Progression
- ☐ Not measurable

**Serious toxicities during treatment (list all):**
- __________________________

**Ongoing toxicity at completion of treatment:**
- ☐ Yes (enter type(s) and grade(s)): __________________________
- ☐ No

### ADDITIONAL THERAPIES PLANNED

<table>
<thead>
<tr>
<th>Drug name</th>
<th>Comments</th>
<th>Date started (or to start)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>( / / )</td>
</tr>
<tr>
<td></td>
<td></td>
<td>( / / )</td>
</tr>
</tbody>
</table>

**Radiation therapy:**
- ☐ Not planned
- ☐ Planned
- ☐ Administered

<table>
<thead>
<tr>
<th>Region treated:</th>
<th>Radiation dose:</th>
<th>Date initiated:</th>
<th>Date completed:</th>
</tr>
</thead>
<tbody>
<tr>
<td>__________________________</td>
<td>__________________________</td>
<td>( / / )</td>
<td>( / / )</td>
</tr>
</tbody>
</table>

### ONCOLOGY TEAM MEMBER CONTACTS

**Provider:**

- **Name:**
- **Contact Info:**

**Provider:**

- **Name:**
- **Contact Info:**

**Provider:**

- **Name:**
- **Contact Info:**

**Provider:**

- **Name:**
- **Contact Info:**

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Important caution: This is a summary document whose purpose is to review the highlights of the cancer treatment for this patient. This does not replace information available in the medical record, a complete medical history provided by the patient, examination and diagnostic information, or educational materials that describe strategies for coping with cancer and cancer therapies in detail. Both medical science and an individual’s health care needs change, and therefore this document is current only as of the date of preparation. This summary document does not prescribe or recommend any particular medical treatment or care for cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.

(Continued on next page)
APPENDIX M (Continued)
Sample Cancer Treatment Plan and Summary

[Insert Practice Name/Info Here]

The Treatment Plan and Summary is a brief record of major aspects of cancer treatment. This is not a complete patient history or comprehensive record of intended therapies.

<table>
<thead>
<tr>
<th>FOLLOW-UP AND SURVIVORSHIP CARE</th>
<th>Coordinating Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Follow up care</td>
<td>When/How Often?</td>
</tr>
<tr>
<td>Medical oncology visits</td>
<td></td>
</tr>
<tr>
<td>Lab tests</td>
<td></td>
</tr>
<tr>
<td>Imaging</td>
<td></td>
</tr>
</tbody>
</table>

Potential late effects of treatment(s):

Call your doctor if you have any of these signs and symptoms:

<table>
<thead>
<tr>
<th>Needs or concerns:</th>
<th>Referrals provided:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevention and wellness:</td>
<td>□ Dietician</td>
</tr>
<tr>
<td>Genetic risk:</td>
<td>□ Smoking cessation counselor</td>
</tr>
<tr>
<td>Emotional or mental health:</td>
<td>□ Physical therapist or exercise specialist</td>
</tr>
<tr>
<td>Personal relationships:</td>
<td>□ Genetic counselor</td>
</tr>
<tr>
<td>Fertility:</td>
<td>□ Psychiatrist</td>
</tr>
<tr>
<td>Financial advice or assistance:</td>
<td>□ Psychologist</td>
</tr>
<tr>
<td>Other:</td>
<td>□ Social worker</td>
</tr>
<tr>
<td></td>
<td>□ Fertility specialist or endocrinologist</td>
</tr>
<tr>
<td></td>
<td>□ Other:</td>
</tr>
</tbody>
</table>

Comments

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### Colon Cancer Adjuvant Treatment Plan and Summary

The Treatment Plan and Summary provide a brief record of major aspects of colorectal cancer adjuvant chemotherapy. This is not a complete patient history or comprehensive record of intended therapies.

**Patient name:**
**Patient DOB:**
**Practice site:**
**Medical record number:**
**Patient phone:**
**Patient cell:**
**Patient email:**
**Hem-onc provider name:**
**Hem-onc phone:**
**Support contact name:**
**Support contact phone:**

### Background Information

- **Age at diagnosis:**
- **Cancer detection:**
  - Screening
  - Symptoms
  - Incidental
- **Site in colon:**
  - Right
  - Transverse
  - Left
  - Sigmoid
- **Predisposing conditions:**
  - None
  - Inflammatory bowel disease
  - FAP
  - HNPCC
- **Family history:**
  - None
  - 2nd degree relative
  - 1st degree relative
  - Multiple relatives
- **Pre-op colonoscopy to cecum:**
  - Yes
  - No
- **Other lesions:**
  - None
  - Low risk polyps
  - High risk polyps
- **Primary colon operation:**
- **Date of surgery:**
- **Surgery type:**
  - Elective
  - Emergent
- **CEA pre-op:**
- **CEA post-op:**
- **Stage:**
  - IA
  - IB
  - II
  - III
  - IV
  - T1
  - T2
  - T3
  - T4
  - N stage:
    - No
    - N1
    - N2
- **Number of lymph nodes removed:**
- **Number of lymph nodes positive:**
- **Notable surgical findings/complications:**
- **Ostomy:**
  - Yes
  - No

### Major comorbidity conditions:

### Adjuvant Treatment Plan

<table>
<thead>
<tr>
<th>Bio/Chemotherapy drug name</th>
<th>Route</th>
<th>Dose</th>
<th>Schedule</th>
<th>Dose reduction needed</th>
<th>Number of cycles administered</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- **Tolerability:**
- **Hospitalization for toxicity during treatment:**
  - Yes
  - No

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Important caution: This is a summary document whose purpose is to review the options of the colon cancer chemotherapy treatment plan for the patient. This does not replace information available in the medical record, or complete medical history provided by the patient, examination and diagnostic information, or educational materials that describe strategies for coping with colon cancer and adjuvant chemotherapy in detail. Both medical science and an individual's health care needs change, and therefore this document is current only as of the date of preparation. This summary document does not prescribe or recommend any particular medical treatment or care for colon cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.

(Continued on next page)
APPENDIX N (Continued)

Colon Cancer Adjuvant Treatment Plan and Summary

The Treatment Plan and Summary provide a brief record of major aspects of colon cancer adjuvant chemotherapy. This is not a complete patient history or comprehensive record of intended therapies.

<table>
<thead>
<tr>
<th>Reason for stopping chemotherapy:</th>
<th>Disease status at end of treatment (check all that apply):</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Completed therapy</td>
<td>☐ No evidence of disease</td>
</tr>
<tr>
<td>☐ Progression of disease on treatment</td>
<td>☐ Persistently elevated tumor marker</td>
</tr>
<tr>
<td>☐ Other:</td>
<td>☐ Possible recurrence based on imaging</td>
</tr>
<tr>
<td>☐ Comorbid illness</td>
<td>☐ Evidence of persistent/Recurrent disease</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hypersensitivity reaction:</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ None</td>
</tr>
<tr>
<td>☐ Mild</td>
</tr>
<tr>
<td>☐ Moderate</td>
</tr>
<tr>
<td>☐ Severe</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ADJUVANT TREATMENT PLAN</th>
<th>ADJUVANT TREATMENT SUMMARY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Central venous catheter placement needed:</td>
<td>Neuropathy at end of treatment (Grade):</td>
</tr>
<tr>
<td>☐ Yes</td>
<td>☐ No</td>
</tr>
<tr>
<td>ECOG performance status at start of treatment:</td>
<td>ECOG performance status at end of treatment:</td>
</tr>
<tr>
<td>☐ 0</td>
<td>☐ 1</td>
</tr>
<tr>
<td>Nutritional status at start of treatment:</td>
<td>Nutritional status at end of treatment:</td>
</tr>
<tr>
<td>☐ Excellent</td>
<td>☐ Very good</td>
</tr>
<tr>
<td>☐ Excellent</td>
<td>☐ Very good</td>
</tr>
</tbody>
</table>

Special circumstances:

<table>
<thead>
<tr>
<th>ONCOLOGY TEAM MEMBER CONTACTS</th>
<th>SURVIVORSHIP CARE PROVIDER CONTACTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provider:</td>
<td>Provider:</td>
</tr>
<tr>
<td>Name:</td>
<td>Name:</td>
</tr>
<tr>
<td>Contact Info:</td>
<td>Contact Info:</td>
</tr>
<tr>
<td>Provider:</td>
<td>Provider:</td>
</tr>
<tr>
<td>Name:</td>
<td>Name:</td>
</tr>
<tr>
<td>Contact Info:</td>
<td>Contact Info:</td>
</tr>
<tr>
<td>Provider:</td>
<td>Provider:</td>
</tr>
<tr>
<td>Name:</td>
<td>Name:</td>
</tr>
<tr>
<td>Contact Info:</td>
<td>Contact Info:</td>
</tr>
<tr>
<td>Provider:</td>
<td>Provider:</td>
</tr>
<tr>
<td>Name:</td>
<td>Name:</td>
</tr>
<tr>
<td>Contact Info:</td>
<td>Contact Info:</td>
</tr>
<tr>
<td>Pre-treatment comments</td>
<td>Post-treatment comments</td>
</tr>
</tbody>
</table>

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Important caution: this is a summary document whose purpose is to review the major elements of the colon cancer chemotherapy treatment plan for this patient. This does not replace information available in the medical record, a complete medical history provided by the patient, examination and diagnostic information, or educational materials that describe strategies for coping with colon cancer and adjuvant chemotherapy in detail. Only scientific and an individual's health care needs change, and therefore this document is current only as of the date of preparation. This summary document does not prescribe or recommend any particular medical treatment or care for colon cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.

APPENDIX O
Colon Cancer Survivorship Care Plan

Colon Cancer Survivorship Care Plan v3 10/09

<table>
<thead>
<tr>
<th>Patient Name:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name and role of person completing this form:</td>
</tr>
<tr>
<td>Completion date:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FOLLOW-UP CARE RECOMMENDATION</th>
<th>YEAR 1</th>
<th>YEAR 2</th>
<th>YEAR 3</th>
<th>YEARS 4 AND 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor's Visit</td>
<td>Every 3 to 6 months</td>
<td>Every 3 to 6 months</td>
<td>Every 3 to 6 months</td>
<td>Every 6 months</td>
</tr>
<tr>
<td>CEA Test</td>
<td>Every 3 months</td>
<td>Every 3 months</td>
<td>Every 3 months</td>
<td>As determined by your doctor</td>
</tr>
<tr>
<td>CT Scanning</td>
<td>Every year, if recommended by your doctor</td>
<td>Every year, if recommended by your doctor</td>
<td>Every year, if recommended by your doctor</td>
<td>As determined by your doctor</td>
</tr>
<tr>
<td>Colonoscopy</td>
<td>Once</td>
<td></td>
<td>At 3 years</td>
<td></td>
</tr>
</tbody>
</table>

* After 5 years, the need for future tests and visits is decided by the patient and doctor.
† A colonoscopy should be done around the time of surgery. If the examination shows no signs of a recurrent tumor or polyps, a colonoscopy should be done at 3 years, and if normal, every 5 years thereafter.

Scientific evidence for the routine use of the following tests is lacking and they are not recommended for follow-up care:
- A complete blood count (CBC) test or liver function tests
- A fecal occult blood test to look for blood in the stool

<table>
<thead>
<tr>
<th>COLON CANCER FOLLOW-UP SHEET</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE OF SURGERY (DOS):</td>
</tr>
<tr>
<td>ESTIMATED TARGET DATES</td>
</tr>
<tr>
<td>------------------------</td>
</tr>
<tr>
<td>DOS plus</td>
</tr>
<tr>
<td>+ Gy/3m</td>
</tr>
<tr>
<td>+ Gy/6m</td>
</tr>
<tr>
<td>+ Gy/9m</td>
</tr>
<tr>
<td>+ 1y/3m</td>
</tr>
<tr>
<td>+ 1y/6m</td>
</tr>
<tr>
<td>+ 1y/9m</td>
</tr>
<tr>
<td>+ 2y/6m</td>
</tr>
<tr>
<td>+ 2y/9m</td>
</tr>
<tr>
<td>+ 3y/6m</td>
</tr>
<tr>
<td>+ 3y/9m</td>
</tr>
</tbody>
</table>

Comments/Evidence of Recurrence:

1 Carcinoembryonic antigen (CEA) testing is not recommended during the administration of adjuvant chemotherapy.
2 As guidelines suggest 3 to 6 months for counseling visits, optional dates are marked with (opt)
3 Acceptable to wait 3 years for follow-up if the pre- or perioperative colonoscopy examined the entire colon.

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The Survivorship Care Plan recommendations are derived from the 2005 Update of the American Society of Clinical Oncology Practice Guideline. This plan is a practice tool based on ASCO practice guidelines and is not intended to substitute for the independent professional judgment of the treating physician. Practice guidelines do not account for individual variation among patients. This tool does not purport to suggest any particular course of medical treatment. Use of the practice guidelines and this plan is voluntary. The practice guidelines and additional information are available at http://www.asco.org/guidelines/oncology.

### APPENDIX P

**LIVESTRONG™ Care Plan Results for Breast Cancer**

#### Care Plan Results for Breast Cancer
Welcome to your personalized LIVESTRONG Survivorship Care Plan. This tool is designed for survivors of adult cancers and was developed based on the information you entered on the questionnaire. Childhood cancer survivors are encouraged to visit the Children's Oncology Group website for more information specific to them. While every aspect of survivorship is important, including psychosocial, emotional, and financial issues, this plan focuses on the long-term medical risks the survivor may face.

The information in this plan is based on the available research and literature concerning cancer survivors. This area is continually growing and as new information becomes available, it will be added to the program. For this reason, you may want to redo your plan periodically. The goal of the LIVESTRONG Survivorship Care Plan is to provide cancer survivors with information regarding the health risks they face as a result of cancer therapies. The level of risk can vary based on the duration, doses, and combinations of therapy; therefore, this plan should be discussed with your oncology team to better understand your personal risks. These results can be concerning, but remember, not every survivor experiences every side effect, and some do not experience any long-term effects. This plan is to make you aware of possible long-term effects that you and your healthcare team should keep in mind.

The following sections are broken down by the cancer therapies you entered on the questionnaire. Sometimes more than one therapy can cause the same long-term effect, so you may see a particular side effect in more than one section. If there are specific things you can do to reduce the risk for or evaluate for the presence of an effect, these will be summarized at the end of the section.

#### YOUR SUMMARY
You were treated for Breast Cancer
- Sentinel node biopsy
- Lumpectomy
- Cyclophosphamide (Cytoxan®, Neosar®)
- Doxorubicin (Adriamycin®, Rubex®, Doxil®)
- Tamoxifen (Nolvadex®)
- X-ray based radiation/conformal radiotherapy
- Radiation treatment for breast cancer after lumpectomy

#### ALL SURVIVORS

**Coordinating Your Care**
As a survivor, it is important that you keep a journal or notebook of your care. Include your doctor’s contact information, medications taken, therapies received, and radiology testing you have had. (Visit the OncoPilot section for forms you can use to organize this material). While some survivors continue to see an oncologist, many return to a primary care provider or internist for care, many of whom are uncertain how to care for you. Developing the LIVESTRONG Survivorship Care Plan can help you and your primary care provider in understanding what effects to look for and how to handle them. If you are being seen only by a primary care practitioner, it is a good idea to be known to an oncologist or late effects clinic, should you need any guidance or referrals with regards to late effects. The Cancer Survivors Project maintains a list of late effects clinics, which will review the therapies you received, discuss risks with you, and act as a consultant to your primary care team.

(Continued on next page)
Risk of a Second Cancer
As a survivor, your chance of developing a second cancer is about twice that of a person of the same sex and age who has never had cancer. This may be a different type of cancer altogether, or a cancer in the same site as before, that is not related to the first cancer. While this sounds scary, it is important to be aware of this risk and be proactive in your own health care. It is not well understood why survivors have this risk, but having follow-up care, cancer screening, and a healthy lifestyle can decrease your risk. In some cases, a treatment (types of chemotherapy or radiation therapy) increases the risk of another cancer. These are called secondary cancers because they develop as a result of therapy. If you are at risk for a secondary cancer, it will be discussed further in your plan.

Because of this risk, survivors are encouraged to adapt a healthy lifestyle of exercise, avoidance of tobacco use and alcohol only in moderation (less than two drinks a day for men and one for women), maintaining a healthy weight, and eating a health-conscious diet, including lots of fruits and vegetables. The American Institute for Cancer Research has developed nutrition guidelines for cancer survivors to address questions related to diet. Practice safe sun habits by using sunscreen, wearing protective clothing, and not using tanning booths. Survivors should follow recommended guidelines for cancer screening, with earlier screening if they are in a high-risk category (i.e., radiation to an area, genetic syndrome).

The following sections will address risks related to the therapies you received.

Fatigue
Fatigue is the most common side effect of cancer treatment. What many people do not know is that this feeling of overwhelming physical, mental, and emotional exhaustion can last for months to years after therapy ends. Soon after treatment is complete, friends, family and coworkers often expect the survivor to be back to doing the things they did before treatment, with the same vigor. Many survivors report significant fatigue years after completing therapy, which can be extremely frustrating for the survivor and those around them. There have been many studies examining fatigue and ways to combat it during treatment, but there is little to provide guidance for dealing with fatigue after therapy. It is important to remember that fatigue can be caused by many things and, particularly if fatigue is worsening or new, it should be discussed with your healthcare team to rule out treatable causes.

Research has shown that light exercise can aid in relieving fatigue during treatment, so it is possible that this could help post treatment. Talking with other survivors may help in finding ways to deal with fatigue. Most importantly, you should understand it is normal and you will need to give your body time to slowly return to your former energy levels. With a lack of available interventions proven to relieve fatigue, survivors may need to learn to work around it in a sense. A wise survivor once dubbed herself the “master of fatigue” because, she stated, “I had learned how to outsmart it.” By thinking of her energy as a full bowl of candy each morning, and each task a certain number of candies. She only had so many candies each day, so tasks needed to be prioritized and balanced with the amount of candies left in her bowl. By learning to manage tasks, group errands, make lists, prioritize, and delegate, you can, to an extent, outsmart your fatigue.
**Risk of Developing a Blood Cancer**

Certain chemotherapy medications can cause damage to the blood cells in the bone marrow. This damage can cause leukemia or myelodysplasia (MDS) to develop years after therapy has been completed. Both diseases cause an abnormal production of poorly functioning blood cells, making it difficult for the body to fight infection, carry oxygen to the tissues, and prevent bleeding. Because these conditions develop as a result of chemotherapy or radiation exposure, they are often more difficult to treat than typical leukemia or MDS.

Leukemia and MDS caused by chemotherapy or radiation therapy typically occurs between 4–10 years after treatment, but can occur even later. One exception is those caused by etoposide (VP-16) or teniposide (two types of chemotherapy), which generally occur within 1–3 years after therapy. Secondary lymphomas have also been seen in Hodgkin’s disease survivors who received the MOPP (nitrogen mustard [Mustargen®], vincristine [Oncovin®], procarbazine, and prednisone) chemotherapy regimen.

**Risk of Developing Cataracts**

The risk of developing cataracts is linked to busulfan, corticosteroids (dexamethasone, prednisone), tamoxifen, anastrozole, and radiation therapy involving the eye (including total body irradiation). Survivors should report any symptoms of cataracts and have an eye exam performed by an ophthalmologist every few years. Symptoms of cataracts include: blurry vision, light sensitivity, poor night vision, double vision in one eye, seeing halos around objects, needing brighter light to read, or fading or yellowing of colors.

**Summary**
- Have an eye exam by an ophthalmologist every 1–2 years.
- See your doctor immediately if you experience any cataract symptoms.
  - Blurry vision
  - Light sensitivity
  - Poor night vision
  - Double vision in one eye
  - Seeing halos around objects
  - Needing brighter light to read
  - Fading or yellowing of colors

**Risk of Bladder or Urinary Tract Toxicities**

The risk for bladder and urinary tract toxicities is highest for survivors who received cyclophosphamide (doses > 3 g/m²), ifosfamide, and/or radiation to the abdomen. Late effects to the urinary tract can include hemorrhagic cystitis, a condition characterized by bleeding from the bladder lining and bladder scarring leading to a decrease in the bladder capacity. Symptoms of hemorrhagic cystitis include urinary frequency and urgency, blood in the urine, and pain. Bladder scarring can present as difficulty urinating, frequency, or urgency. Survivors at risk should report these symptoms to their healthcare provider right away. Survivors should be counseled that alcohol use and smoking can contribute to bladder dysfunction, so these should be avoided.
Summary
- Avoid alcohol.
- Avoid smoking.
- Report the following symptoms to your healthcare provider.
  - Pain when urinating
  - Urinary hesitancy (difficulty starting the stream)
  - Urinating frequently
    * Urinating more than 5 times per day
    * Getting up in the middle of the night to urinate
  - Blood in your urine

Risk of Developing Bladder Cancer
Cyclophosphamide and streptozocin can contribute to the development of bladder cancer. This risk is increased for those who also received radiation therapy to the abdomen. Symptoms of bladder cancer include blood in the urine, urinary frequency and urgency, urinating at night, and incontinence and should be reported to the healthcare provider. Survivors should be counseled that alcohol use and smoking can contribute to bladder cancer, so these should be avoided.

Summary
- Avoid alcohol.
- Avoid smoking.
- Report the following symptoms to your healthcare provider.
  - Pain when urinating
  - Urinary hesitancy—starting and stopping while urinating
  - Urinating frequently
    * Urinating more than 5 times per day
    * Getting up in the middle of the night to urinate
  - Blood in your urine

Risk for Cardiac (Heart) Problems Related to Anthracycline Chemotherapies
The group of chemotherapy agents called anthracycline antibiotics are known to cause specific cardiac toxicities, including cardiomyopathy (weakening of the heart muscle), arrhythmias (rhythm abnormalities), and left ventricle dysfunction (causing heart failure). The risk of developing one of these problems is tied to the cumulative (lifetime) dose a person has received, but even low doses can lead to abnormalities. Toxicity can develop anywhere from shortly after completing chemotherapy (called chronic) to decades later (called delayed). For example, it is known that cumulative doses of doxorubicin greater than 550 mg/m² can lead to cardiac toxicity, but doses as low as 250 mg/m² can result in subclinical cardiac changes. Subclinical changes can be detected on tests such as ECG, echocardiogram, and/or MUGA scan, but they do not cause symptoms for the survivor. The doses of the various anthracycline agents are not equivalent, so you should discuss the dose you received and your risk with your physician.

Risk is further increased for those survivors who also received radiation to the chest or those who received high-dose cyclophosphamide (dose levels used in bone marrow and stem cell transplant preparation). Survivors should maintain healthy lifestyles as smoking, drug use, obesity, sedentary lifestyle, and poor dietary choices can increase the risk of cardiac disease.
Risk is further increased for those survivors who also received radiation to the chest or those who received high-dose cyclophosphamide (dose levels used in bone marrow and stem cell transplant preparation). Survivors should maintain healthy lifestyles as smoking, drug use, obesity, sedentary lifestyle, and poor dietary choices can increase the risk of cardiac disease.

Cardiac toxicities can cause symptoms such as shortness of breath (with or without exertion), orthopnea (difficulty breathing when lying down), chest pain, palpitations, exercise intolerance, dizziness/light-headedness or edema (swelling of the extremities). In younger survivors (under age 25), cardiac symptoms may present as abdominal symptoms such as nausea and vomiting. Annual history and physical by a healthcare provider should include a cardiac exam and review of possible symptoms. Survivors who received anthracyclines (any dose) should have their left ventricular function evaluated at baseline with an echocardiogram or MUGA (nuclear imaging radiology exam of heart function) scan, as studies have found many people with abnormalities did not exhibit symptoms. Repeat evaluation should be performed periodically (more frequently for higher risk individuals) or if symptoms develop or worsen.

Summary

- Maintain healthy lifestyle.
  - Avoid smoking.
  - Avoid drug use.
  - Maintain a healthy weight.
  - Exercise regularly.
  - Eat a well-balanced diet.
- Have an annual physical exam that includes a cardiac exam.
  - Periodic repeated cardiac studies (echocardiogram or MUGA)
- Report the following symptoms to your healthcare provider.
  - Shortness of breath (with or without exertion)
  - Difficulty breathing when lying down
  - Chest pain/heartburn
  - Palpitations
  - Dizziness/light-headedness
  - Swelling of the arms or legs
- If you received chemotherapy under age 25
  - Report symptoms of nausea and vomiting.

Risk of Developing Osteoporosis

Osteoporosis and osteopenia (the precursor to osteoporosis) are decreases in bone density, which increases the risk of fracture of the affected bones. Long-term use of corticosteroids (dexamethasone or prednisone, > 5 mg per day for more than 2 months), receiving chemotherapy medications (including methotrexate, ifosfamide, Cytoxan®, fluorouracil, and interferon alpha), or radiation to weight-bearing bones (spine, hips, legs) all increase the risk of developing osteoporosis.

Women who develop premature menopause, have their ovaries removed before menopause, or those who take aromatase inhibitors (anastrozole, letrozole, and exemestane) are at increased risk for osteoporosis. Men who receive hormone therapy for prostate cancer or undergo orchietomy are at greater risk. In addition, patients who have undergone gastrectomy (removal of the stomach) are at increased risk to develop osteoporosis.
As for lifestyle risks, smokers, people who consume excessive alcohol, and those who do not participate in weight-bearing exercise have an increased risk of developing osteoporosis. Therefore, it is very important that survivors not drink alcohol or smoke. In addition, survivors should engage in weight-bearing exercise such as walking, weight lifting, riding a stationary bicycle, jogging, dancing, and any exercise where the legs are supporting the body’s weight. These efforts, combined with increasing calcium and vitamin D in your diet and taking calcium and vitamin D supplements, will greatly help to reduce your risk of developing osteoporosis.

Survivors at risk should have adequate intake of calcium (1,200–1,500 mg total per day, taken in divided doses) and vitamin D (400–800 international units per day if under age 50, and 800–1,000 international units per day if over age 50). Calcium supplements are an easy way to get the recommended daily amount and come in 2 forms: calcium carbonate and calcium citrate. The body does have some trouble absorbing large amounts of calcium, so supplements should be split into 2 or more doses per day. Calcium carbonate requires stomach acid to be absorbed by the body; therefore, people that take acid reducers (such as Zantac®, Tagamet®) and/or proton pump inhibitors (such as Prilosec®, Prevacid®, etc.) should use calcium citrate. If you have trouble tolerating your calcium supplement, talk to your doctor or nurse; there may be another formulation you can tolerate more easily. It is important to take vitamin D with the calcium supplements because it helps your body to absorb calcium better. Survivors should talk to their healthcare provider about screening with DEXA scan (a test used to assess bone density) and options for treatment, if necessary.

Summary
- Avoid smoking and excessive alcohol intake.
- Perform weight-bearing exercise 2–3 times per week.
- Calcium intake of 1,200–1,500 mg per day plus vitamin D 400–800 IU or 800–1,000 IU per day (either in dietary intake or supplements).
- Consider screening with DEXA scan.

Risk of Liver Toxicity
Hepatic dysfunction is abnormal functioning of the liver. This can range from having abnormal results on a blood test with no symptoms to cirrhosis or liver failure. The majority of complications tend to occur during or soon after therapy and patients who receive methotrexate, mercaptopurine, thioguanine, BCNU (carmustine), plicamycin, and tamoxifen are at highest risk of developing liver problems. Toxicities may resolve over time, but in some cases, can result in chronic liver problems.

Skin Toxicities
Some chemotherapy agents will cause the skin to darken or lighten in spots or cause the nails to change color or fall off. While this typically happens while on therapy, these effects can become chronic. Good hygiene and skin care, including washing with a mild soap and water, hydrating lotions for dry or scaly skin, and protecting any open skin wounds can all aid in recovery from these toxicities.
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#### Understanding “Chemo-Brain”
Many survivors who have previously received or are currently undergoing chemotherapy report experiencing cognitive changes, often referred to as “chemo-brain.” These changes include difficulty with short-term memory, multi-tasking, new learning, reading comprehension, working with numbers, and a decrease in concentration ability. For many years this was attributed, by physicians and researchers, to depression or anxiety over the diagnosis and treatment of cancer. More recently, researchers have begun to study and document what survivors have been saying all long; cognitive changes after chemotherapy are real. Although we are not yet able to pinpoint whether only certain chemotherapies are responsible, it seems certain that the effects are cumulative. That is, those who receive more chemotherapy tend to experience greater deficits. Studies have found that cognitive ability can improve over time in some survivors, but deficits are still present in many long term survivors, years after treatment.

Some medications are being studied as potential treatments for cognitive changes, but there is not yet enough data to support their use. Some of the agents being studied include: methylphenidate (Ritalin®), modafinil (a medication approved to treat narcolepsy), various antidepressants, herbal therapies, such as ginkgo biloba, ginseng, and certain amino acids. Cognitive rehabilitation programs are structured programs utilizing exercise, tasks that use memory and puzzles to “rehabilitate” one’s mind. These programs are typically used for people with brain injuries, but therapists have tailored programs for cancer survivors. Bookstores and websites offer memory training, which may be helpful to survivors. Puzzles using numbers, like Sudoku, may help “exercise” your brain. Fatigue can enhance cognitive problems, so avoiding fatigue by getting enough sleep, incorporating exercise into your life, and eating a healthy diet may be helpful.

It is important to remember that some very treatable problems can result in cognitive difficulties, such as thyroid dysfunction, depression, and anxiety, so it is important to exclude or treat these diagnoses. Hypothyroidism (low thyroid hormone levels) is a common issue for survivors and can make you feel “fuzzy” or “out of it.” This is easily treatable with supplemental thyroid hormone. Survivors who may be depressed or experiencing anxiety would benefit from consulting with a psychiatrist or psychologist experienced in working with cancer patients or survivors.

#### Side Effects While Taking Tamoxifen
Your OncoLife plan focuses on late effects of therapy, or those that can occur months to years after completing therapy. Current hormone therapy regimens last anywhere from 5 to 10 years, so we felt it was important to include some information about the acute side effects of these agents.

Tamoxifen commonly causes hot flashes and other symptoms of menopause. Avoiding triggers such as warm rooms, spicy, caffeinated, or alcohol-containing foods or beverages can help reduce hot flashes. Drink plenty of fluids, wear breathable clothing, and exercise regularly. For some women, certain antidepressant medications can provide relief of hot flashes.

The more serious, though low risk, complications of tamoxifen include endometrial cancer and blood clots. Women should promptly report any menstrual irregularities, vaginal bleeding, pelvic pressure/pain, or any vaginal discharge, as these may be symptoms of endometrial cancer. An endometrial biopsy should be done to test for cancer if any of these symptoms occur.
Blood clots are rare, but most often occur in the calf or lung. Signs of a blood clot in the leg may include any of the following: leg pain, warmth, swelling of one leg more than the other. Signs of a blood clot in the lung could include: fever, shortness of breath that comes on very quickly, racing heart, chest pain (that tends to be worse when you take a deep breath). Any of these symptoms should be reported to your physician immediately.

Sexuality Concerns for Female Survivors
Women of any age may have sexuality concerns after cancer treatment. Do not hesitate to talk with your oncology team about these common concerns. Chemotherapy agents are associated with vaginal dryness, painful intercourse, and reduced sexual desire and ability to achieve orgasm. Many of these issues are caused by the sudden onset of menopause, which can occur with cancer therapy. This sudden change in hormone levels leads to physical changes such as vaginal atrophy (thinning and inflammation of the vaginal walls), loss of tissue elasticity, and decreased vaginal lubrication. In addition, women may experience hot flashes, mood swings, fatigue, and irritability.

Decreased lubrication leading to painful intercourse is a common concern for survivors. This can often be treated with vaginal lubricants and moisturizers and/or estrogen therapy (taken orally or used in the vagina). Women who have had a hormone-dependent cancer should discuss current research on using these therapies with their healthcare team. Surgery and/or radiation therapy can result in scarring that may cause discomfort during intercourse. Open communication about position changes and alternative methods of expressing affection with your partner can help when resuming sexual activity after treatment.

Concerns about changes in your body, cancer recurrence, the stress and anxiety caused by cancer therapy, or changes in your relationship with your partner can all affect how you feel about your sexuality. It is important to understand that sexual activity cannot cause cancer to recur, nor can you spread cancer to another person through sexual activity. If you find that your feelings are significantly impacting your sexuality, you should talk with your healthcare team about finding a therapist experienced in helping cancer survivors.

Of utmost importance in addressing sexuality issues is communication, both between partners and between survivors and their healthcare teams. Understand that these concerns are common and communication is the first step to finding the right solutions. Visit OncoLink’s section on sexuality for more information.

Surgery Side Effects
Lumpectomy
Surgery for breast cancer can include mastectomy (removal of the entire breast) or lumpectomy (sometimes called breast-conserving surgery, where only the breast mass [lump] and a surrounding area of normal tissue is removed). The surgeries can result in cosmetic deformities. In some cases, these can be corrected with breast reconstruction performed by a plastic surgeon. There is a risk of nerve damage during breast surgeries, which can lead to pain in the chest wall and/or pain and tingling in the arm/hand on the side of the surgery. Injuries like this can be aggravated by scar tissue formation after radiation therapy to the area, which can develop years after therapy. Neuropathic (nerve) pain is often described as burning or electric and can also include numbness, tingling, and decreased strength or sensation. Survivors who develop chronic pain may benefit from a consult with a pain specialist.
Those who undergo a modified radical mastectomy, and sometimes those undergoing lumpectomy, may also have lymph nodes removed during surgery. The removal of lymph nodes increases the risk of developing lymphedema. In addition, patients, who have undergone lymph node dissection, may also develop nerve damage (as described previously), pain in the shoulder, or limitations in movement of the arm and shoulder. These complications may be temporary, but could become permanent. Exercises to promote shoulder mobility may be of help, and can be described and taught by a physical therapist.

Survivors of breast cancer should speak with their healthcare provider regarding the possibility of a genetic or family syndrome. If there does appear to be a family history or possible genetic link, genetic counseling and testing may be warranted for the survivor and his or her family.

Summary
- Be vigilant for signs/symptoms of lymphedema and ensure early and proper management.
- Remember to do monthly self-breast exam. Get a mammogram on remaining breast(s) every year.
- Report pain in the breast or chest wall to your healthcare provider.
- Consider physical therapy for decreased range of motion in the shoulder.

Sentinel Node Biopsy
The removal of lymph nodes from the axilla (underarm), abdomen, or groin area can lead to decreased drainage in the closest limb, causing lymphedema (a swelling of the limb) to result. In the case of head and neck cancers, the swelling can involve the neck and face. Survivors who have also received radiation therapy to the area are at greater risk of developing lymphedema, which can occur years after therapy. While sentinel node biopsy can decrease the risk of developing subsequent lymphedema, the risk is not completely eliminated. Lymphedema can cause pain, disfigurement, functional limitations, and increase the risk of a serious infection in that limb. A certified lymphedema therapist should be consulted at the first sign of swelling to achieve the best outcomes. Survivors should be aware of this potential complication, given information on self-care, and instructed to notify the healthcare team with any signs of swelling or infection.

Signs of lymphedema may include the following changes in the area near surgery (arm, leg, abdomen, genitals): full or heavy feeling, skin changes (reddened, warm, cool, dry, hard, stiff), aching/discomfort, tightness, or less movement/flexibility in nearby joints. You may also experience difficulty fitting into clothes like the sleeve of a jacket or pant leg, or feel your socks are too tight. In addition, you may notice jewelry feels tight even though you have not gained any weight. Lymphedema can occur right after surgery, weeks, months, or even years later. The possibility of developing lymphedema continues throughout a person’s lifetime. Survivors should be vigilant in monitoring for early signs of swelling and practice prevention. If swelling develops, prompt, proper management and therapy allows for the best outcomes.

To help prevent and control lymphedema, survivors should try to avoid infections, burns, cuts, excessive hot/cold, or injury to the limb that is at risk. Avoid insect bites by using insect repellent. Use lotion to prevent dry, chapped skin. Use sunscreen with SPF 15 or higher and try to avoid the sun during the hottest time of day. Avoid pressure or constriction of the limb. Avoid tight-fitting clothes and jewelry.
Those at risk for lymphedema can and should exercise. Start with low intensity exercise and gradually increase intensity while monitoring for changes in your limb including swelling or redness. If any swelling or redness occurs, stop the exercise and consult your physician. The person at risk for lymphedema should consider wearing a compression garment with vigorous or very strenuous exercise.

Whenever possible, have blood drawn, IVs placed, and shots/vaccinations given and blood pressure taken in the unaffected arm. For more information on what you can do to help prevent lymphedema, look at the Lymphedema Self Care Tip Sheet on the OncoLink website. The National Lymphedema Network is also a great resource for information.

Surgery to remove the lymph nodes (or sentinel node[s]) can result in injury to the nerves in that area. Nerve damage can cause pain, numbness, tingling, and decreased sensation or strength in the area or limb. For instance, axillary (underarm) lymph node removal can result in these symptoms on the chest wall, under the arm (armpit), or in the arm and/or hand on the treated side. Injuries like this could be aggravated by scar tissue formation after radiation therapy to the area, which can develop years after therapy. This type of pain is called nerve pain and is treated with different medications than other types of pain. Survivors with this type of pain may benefit from a consult with a pain specialist.

Summary
- Report any signs of swelling in the at-risk limb to your healthcare provider, and see a certified lymphedema therapist promptly if these symptoms develop.
- Practice preventive measures to decrease the risk of developing or worsening lymphedema.

RADIATION SIDE EFFECTS

Long-term effects of radiation therapy vary greatly depending on the areas included in the field of radiation and the radiation techniques that were used, as these continue to develop and improve. One issue that is consistent across all tissues is the possibility of developing a second cancer in or near the radiation field. Secondary cancers develop as a result of the exposure of healthy tissue to radiation. Newer radiation techniques are designed to limit this exposure, but it is not always possible to prevent all exposure and still achieve the desired outcomes.

Heart/Cardiovascular
Potential late effects of radiation fields including the heart include premature coronary artery disease and hypertension (high blood pressure), valve abnormalities, fibrosis or scarring of the cardiac tissue resulting in decreased heart function, pericarditis (inflammation of the heart sack), heart failure, and myocardial infarction (heart attack). The actual risk varies greatly depending on the total dose of radiation, number of fractions (doses), amount of radiation actually delivered to the heart, time since radiation, and whether or not chemotherapy agents with known cardiac toxicity were also given. Survivors at risk should have a yearly history and physical by a healthcare provider to evaluate cardiac function and blood pressure and should be counseled on lifestyle choices including exercise, tobacco avoidance, and a healthy diet. High-risk survivors may benefit from yearly ECG and screening echocardiogram to evaluate heart function.
Survivors should also be especially aware of other factors that increase risk of heart disease and death from heart attack. These include high cholesterol, obesity, high blood pressure, diabetes, smoking, and illegal drug use (cocaine). Screening for all of these risk factors can allow for early intervention.

- Avoidance of tobacco and illegal drug use
- Yearly history and physical exam with monitoring of cholesterol levels, blood pressure, and blood sugar by primary care physician to reduce risk of heart disease/attack
- Yearly ECG and/or echocardiogram for high-risk patients

**Lung**

Radiation fields involving the lung can lead to scarring (fibrosis), inflammation (pneumonitis), and restrictive or obstructive lung disease. Risk for these problems is increased with higher doses of radiation and radiation given in combination with certain chemotherapies (bleomycin, busulfan, BCNU, and CCNU) and for those survivors who also had part of the lung surgically removed (lobectomy). Survivors who have had radiation to the lung are strongly encouraged not to smoke, as this can greatly increase the risk of problems. Annual history and physical by a healthcare provider should include a pulmonary exam and review of possible symptoms (cough, shortness of breath, wheezing). Survivors should receive annual flu vaccines and the pneumococcal vaccine. Physicians may consider chest x-rays or pulmonary function tests for those at highest risk or a change in pulmonary status.

Scarring within the lungs can result from radiation, and uncommonly this scarring may affect blood vessels. Any survivor coughing up blood should be evaluated immediately by a physician, either in the office or the emergency room.

Of note, the Children’s Oncology Group recommends survivors not scuba dive without medical clearance from a diving medicine specialist. The National Comprehensive Cancer Network recommends Hodgkin disease survivors who received chest irradiation consider annual chest x-ray or CT scan to screen for lung cancer, beginning 5 years after treatment. We should note that studies have not yet been done to support this recommendation.

- Annual influenza vaccine
- Pneumococcal vaccine every 5 years
- Tobacco avoidance/smoking cessation
- Chest x-ray for new cough or shortness of breath
- Immediate evaluation of hemoptysis (coughing up blood)

**Bone**

Damage to the bone from radiation can cause small cracks (fractures) in that bone. The ribs are more susceptible to fracture after radiation, although these fractures will almost always heal normally. If radiation is given in the area of a joint, permanent stiffness, pain, and arthritis can develop in that joint.

- Rapid evaluation for fractures after trauma (for example, after a motor vehicle accident)
- Physical/occupational therapy for arthritis
- Nonsteroidal inflammatory medicines for arthritis

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**Skin**
Radiation can lead to permanent changes in the skin. This can include changes in the color or texture of the skin, scars, and changes in the color or texture of hair or permanent loss of the hair in the treated area. The soft tissue and muscles under the skin can develop scarring and/or shrinkage, which can lead to a loss of flexibility and movement or chronic swelling. Some patients develop chronic or recurring ulcers of the skin in the area treated. Blood vessels of this skin may become dilated and more noticeable, although this is not harmful. If the skin feels tight or sore, regular use of vitamin E applied to the skin can be helpful.

After radiation the skin is more sensitive to sunlight, and survivors should be especially cautious to use sunscreens when outdoors.
- Diligent use of sunscreen
- Evaluation by a wound care specialist or surgeon for nonhealing ulcers

**Lymph Nodes**
The removal of lymph nodes from the axillary (underarm), abdominal, or groin areas can lead to decreased drainage in the closest limb causing lymphedema (a swelling of the limb) to result. Survivors who have also received radiation therapy to the area are at greater risk of developing lymphedema which can occur years after therapy. While sentinel node biopsy can decrease the risk of developing subsequent lymphedema, it does not completely eliminate the risk. Lymphedema can cause pain, disfigurement, and functional limitations, and may increase the risk of a serious infection in that limb. A certified lymphedema therapist should be consulted at the first sign of swelling to achieve the best outcomes. Survivors should be aware of this potential complication, given information on self-care, and instructed to notify the healthcare team with any signs of swelling or infection.

Surgery to remove the lymph nodes (or sentinel node) can result in injury to the nerves in that area. Nerve damage can cause pain, numbness, tingling, decreased sensation or strength in the area or limb. For instance, axillary (underarm) lymph node removal can result in these symptoms on the chest wall under the arm (armpit) or in the arm and/or hand on the treated side. Injuries like this could be aggravated by scar tissue formation after radiation therapy to the area. This type of pain is called nerve pain and is treated with different medications than other types of pain. Survivors with this type of pain may benefit from a consult with a pain specialist.

**Radiation for Breast Cancer (After Lumpectomy)**
Any patient who has had breast cancer is at risk for developing a second breast cancer in either the treated or the opposite breast. It is recommended that women undergo annual mammograms after treatment for breast cancer, as well as yearly breast exams by a breast cancer specialist (medical oncologist, radiation oncologist, or breast surgeon).

Some women who receive radiation to the breast may later want to breastfeed. It is possible for the irradiated breast to produce small amounts of milk, but it is not recommended to use this breast for feeding because of the risk of mastitis (inflammation/infection of the breast tissue), which could be difficult to treat. If only one breast was treated with radiation, the untreated breast should produce milk and can be used safely for breastfeeding.
LIVESTRONG™ Care Plan Results for Breast Cancer

Other long-term effects of breast irradiation include changes in the size or shape of the breast and damage to the nerves, leading to pain or loss of strength or feeling in the arm on the side that was irradiated. Damage to the drainage (lymphatic) system in the area can lead to chronic swelling, called lymphedema. Risk of lymphedema is highest for women who also had surgical lymph node dissections and, to a lesser extent, sentinel node biopsy. A survivor with lymphedema who develops pain or redness in the arm, especially with fever, should be evaluated as these signs may indicate infection.

Survivors of breast cancers, particularly left-sided breast cancers, may be at increased risk of cardiac complications. Please see the description of heart/cardiovascular late effects for more information.

- Yearly mammograms and examination by breast cancer specialist
- Consideration of physical/occupational therapy for arm pain, weakness, or swelling
- Rapid evaluation for new arm swelling, redness, or pain, especially with fever

FOLLOW-UP CARE

Breast Cancer
After receiving treatment for breast cancer, it is important for survivors to adhere to their physician’s plan for follow-up care. Guidelines developed by the National Comprehensive Cancer Network state that survivors who have had breast-conserving therapy (lumpectomy) should have their first mammogram approximately 6 months after completing radiation therapy, then annually. Survivors who underwent single mastectomy should have a mammogram annually. In addition, breast MRI may be considered for survivors with the BRCA1 or 2 genes. Those who had double mastectomy do not need mammograms, but should examine the chest wall for swelling or rash and report any changes to their oncologist. However, some oncologists recommend that mammograms be performed of the reconstructed breast or breasts.

Survivors should be seen by their oncologist every 4–6 months for the first 5 years and then annually. Women who are taking tamoxifen should be seen annually by a gynecologist and be sure to report any vaginal bleeding to their physician right away.

Many survivors find it difficult to not have periodic CT scans or bone scans to look for spread of the cancer. Research has shown that the type of treatment, response to treatment, and overall survival are all the same, regardless of when the treatment is initiated. In other words, the outcomes are similar for those who are treated for metastases found on routine screening (with no symptoms present) and women who are not treated until those metastases cause symptoms. Therefore, we no longer screen patients without symptoms for metastases, but rather wait until symptoms develop.

- Mammogram annually for those who had single mastectomy (first one six months after therapy for survivors who had lumpectomy and radiation therapy).
- Perform monthly self breast exams and/or examination of the chest wall and scar line. Report any changes, lumps, swelling, or skin rashes to your physician.
- Seen by oncologist every 4–6 months for 5 years, then annually.
- Women taking tamoxifen should see a gynecologist annually and notify their physician of any vaginal bleeding.

Note. Copyrighted to the Trustees of the University of Pennsylvania and partially funded by an educational grant from the Lance Armstrong Foundation, available at www.livestrongcareplan.org. Reprinted with permission.
Survivorship Care Plan for Breast Cancer
Prepared by: NearSpace, Inc. on 9/4/2008

### General Information

<table>
<thead>
<tr>
<th>Patient Name</th>
<th>Jane Doe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient ID</td>
<td>#121365</td>
</tr>
<tr>
<td>Phone</td>
<td>707-XXX-XXXX</td>
</tr>
<tr>
<td>Date of birth</td>
<td>9/10/1963</td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td>45</td>
</tr>
<tr>
<td>Support contact</td>
<td>John Doe, 707-XXX-XXXX</td>
</tr>
</tbody>
</table>

### Care team

- **Medical oncologist**: Dr. Patricia Ganz, 707-XXX-XXXX
- **General/breast surgeon**: Dr. McDermon, 707-XXX-XXXX
- **Radiation therapist**: Dr. Vascedio, 707-XXX-XXXX
- **Plastic surgeon**: Dr. Roman, 707-XXX-XXXX
- **Primary care physician**: Dr. Vorgis, 707-XXX-XXXX
- **OB-GYN**: Dr. Drexel, 707-XXX-XXXX
- **Nurse/nurse practitioner**: Faith Berght, 707-XXX-XXXX
- **Mental health/social worker**: Mary Kratz, 707-XXX-XXXX
- **Other**

### Background Information

<table>
<thead>
<tr>
<th>Family history</th>
<th>Multiple relatives</th>
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<tbody>
<tr>
<td>Genetic testing</td>
<td>Ordered, Results:</td>
</tr>
<tr>
<td>Major comorbid conditions</td>
<td>Migraine headaches</td>
</tr>
<tr>
<td>Echocardiogram or MUGA result</td>
<td>EF = 65%</td>
</tr>
<tr>
<td>Additional comments</td>
<td>No notable surgical findings.</td>
</tr>
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</table>

(Continued on next page)
## Survivorship Care Plan for Breast Cancer

### Background Information (Cont.)

#### Left breast
- **Definitive breast surgery**: Mastectomy, on 5/6/2008
- **Lymph nodes**: 5 removed, 2 positive
- **Tumor type & stage**: Infiltrating ductal, T1, N1
- **Pathologic stage**: Stage II
- **ER status**: Negative
- **PR status**: Negative
- **HER2 status**: Negative

#### Right breast
- **Definitive breast surgery**: Mastectomy, on 5/6/2008
- **Lymph nodes**: 8 removed, 3 positive
- **Tumor type & stage**: Mixed, T1, N1
- **Pathologic stage**: Stage III
- **ER status**: Negative
- **PR status**: Negative
- **HER2 status**: Negative

### Treatment Plan & Summary

<table>
<thead>
<tr>
<th></th>
<th>Pre-treatment</th>
<th>Post-treatment</th>
</tr>
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<tbody>
<tr>
<td><strong>Patient’s height</strong></td>
<td>157.5 cm</td>
<td></td>
</tr>
<tr>
<td><strong>Patient’s weight</strong></td>
<td>50.8 kg</td>
<td>54.4 kg</td>
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<tr>
<td><strong>Patient’s BSA</strong></td>
<td>1.49 m²</td>
<td>1.54 m²</td>
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<tr>
<td><strong>Patient’s BMI</strong></td>
<td>20.5</td>
<td>22.0</td>
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<tr>
<td><strong>Date last menstrual period</strong></td>
<td>6/2/2008</td>
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<tr>
<td><strong>Comments</strong></td>
<td></td>
<td>Dose reduction due to sepsis.</td>
</tr>
</tbody>
</table>

(Continued on next page)
## APPENDIX Q (Continued)
### Survivorship Care Plan for Breast Cancer

**SAMPLE**  
Jane Doe  
DOB: 9/10/1963

#### Treatment Plan & Summary (Cont.)

| Regimen        | TAC Docetaxel (Taxotere) 75 mg/m² iv d1  
|                | Doxorubicin (Adriamycin) 50 mg/m² iv d1  
|                | Cyclophosphamide (Cytoxan) 500 mg/m² iv d1  
|                | Q3w x 6 cycles  
|                | Filgrastim (Neupogen) support  
| Chemotherapy agents | # cycles | % dose reduction  
| Docetaxel       | 6         | 25% in cycle 6  
| Doxorubicin     | 6         |  
| Cyclophosphamide | 6         | 25% in cycle 6  
| Filgrastim support |          |  
| Anthracycline administered | Doxorubicin, 430 mg (279 mg/m²)  
| Treatment on clinical trial      | No       |  
| Chemotherapy treatment period    | 6/14/2008 – 10/20/2008  
| Possible side effects of regimen | Anemia, fatigue, hair loss, infertility, low blood count, menopause symptoms, nausea/vomiting, neuropathy, sores in mouth  
| Reconstruction                  | Planned: Yes  
| Radiation therapy               | Planned: Yes, completed: 12/20/2008, dose:  
| Growth factor given             | Yes       |  
| Grade 3 or higher toxicities    | Anemia, dehydration, mucositis, neutropenia, sepsis, thrombocytopenia  
| Hospitalization for toxicities  | Yes       |  
| Neurotoxicity impairing activities | No       |  
| Early termination of treatment | NA–treatment completed  
| Biologic therapy                | Planned: No, Prescribed: No  

(Continued on next page)
## APPENDIX Q (Continued)

**Survivorship Care Plan for Breast Cancer**

**SAMPLE**  
**Jane Doe**  
**DOB: 9/10/1963**

<table>
<thead>
<tr>
<th>Test</th>
<th>Frequency</th>
<th>Provider to contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical history/physical exam: Yrs 1–3</td>
<td>Every 3 months</td>
<td>Dr. Vorgis</td>
</tr>
<tr>
<td>Medical history/physical exam: Yrs 4, 5</td>
<td>Every 6 months</td>
<td></td>
</tr>
<tr>
<td>Post-treatment mammography</td>
<td>Every year</td>
<td></td>
</tr>
<tr>
<td>MRI</td>
<td>Every 3 years</td>
<td></td>
</tr>
<tr>
<td>Bone densitometry</td>
<td>Every 3 years</td>
<td></td>
</tr>
<tr>
<td>Pelvic examination</td>
<td>Every year</td>
<td></td>
</tr>
<tr>
<td>Genetic counseling referral</td>
<td>Recommended</td>
<td>Dr. Smithey</td>
</tr>
<tr>
<td>Breast self-examination</td>
<td>Every month</td>
<td></td>
</tr>
</tbody>
</table>

**Preventive care recommendations**  
Bone health, cholesterol monitoring/management, diet, exercise, mental health, weight management

### ASCO Surveillance Guidelines

**Medical history and physical (H&P) examination**  
Visit your doctor every three to six months for the first three years after the first treatment, every six to 12 months for years four and five, and every year thereafter.

**Post-treatment mammography**  
Schedule a mammogram one year after your first mammogram that led to diagnosis, but no earlier than six months after radiation therapy. Obtain a mammogram every six to 12 months thereafter.

**Breast self-examination**  
Perform a breast self-examination every month. This procedure is not a substitute for a mammogram.

**Pelvic examination**  
Continue to visit a gynecologist regularly. If you use tamoxifen, you have a greater risk for developing endometrial cancer (cancer of the lining of the uterus). Women taking tamoxifen should report any vaginal bleeding to their doctor.

(Continued on next page)
APPENDIX Q (Continued)
Survivorship Care Plan for Breast Cancer

SAMPLE
Jane Doe
DOB: 9/10/1963

ASCO Surveillance Guidelines (Cont.)

Coordination of care
About a year after diagnosis, you may continue to visit your oncologist or transfer your care to a primary care doctor. Women receiving hormone therapy should talk with their oncologist about how often to schedule follow-up visits for reevaluation of their treatment.

Genetic counseling referral
Tell your doctor if there is a history of cancer in your family. The following risk factors may indicate that breast cancer could run in the family:
- Ashkenazi Jewish heritage
- Personal or family history of ovarian cancer
- Any first-degree relative (mother, sister, daughter) diagnosed with breast cancer before age 50
- Two or more first-degree or second-degree relatives (grandparent, aunt, uncle) diagnosed with breast cancer
- Personal or family history of breast cancer in both breasts
- History of breast cancer in a male relative

Not Recommended
The following tests are not recommended for routine breast cancer follow-up: breast MRI, FDG-PET scans, complete blood cell counts, automated chemistry studies, chest x-rays, bone scans, liver ultrasound, and tumor markers (CA 15-3, CA 27.29, CEA). Talk with your doctor about reliable testing options.


Symptoms to Watch For

| Patient should report these signs and symptoms if persistent: | • Abdominal pain | • New lumps |
| | • Arm swelling | • Palpitations |
| | • Bone pain | • Persistent headaches |
| | • Chest pain | • Shortness of breath or difficulty breathing |
| | • Fractures | • Swelling in legs |
| | • Hot flashes or other menopausal symptoms | |

APPENDIX Q (Continued)
Survivorship Care Plan for Breast Cancer

SAMPLE
Jane Doe
DOB: 9/10/1963

Potential Late Effects of Cancer Treatment

You may experience the following effects after cancer treatment.

- **Surgery:**
  - Numbness, weakness, pain, loss of range of motion (ROM), or arm swelling (lymphedema).

- **Chemo/Biotherapy:**
  - Fatigue, ovarian failure with associated menopausal symptoms, neuropathy, cognitive dysfunction, weight gain, psychological distress, and sexual dysfunction; increased risk of leukemia (after anthracycline based therapy), osteoporosis from premature ovarian failure, increased risk of cardiac dysfunction secondary to anthracycline and/or trastuzumab.

- **Radiation:**
  - Breast pain, fibrosis, telangiectasia, atrophy, poor cosmetic outcome.

- **Hormone therapies:**
  - Tamoxifen—hot flashes, increased risk of blood clots, uterine cancer, and stroke.
  - Aromatase inhibitors—increased risk of osteoporosis and fracture.

*Patricia A. Ganz and Erin E. Hahn, J Clin Oncol 26:759-767.*

Resources for Physicians

**Late Effects of Cancer Treatment and Survivorship: Strategies for Primary Care and Oncology Care Providers**
- A free online Continuing Medical Education (CME) Program available through September 2009, providing 3.0 AMA PRA Category 1 Credits. This educational program has been designed to promote understanding regarding late effects of cancer treatment and survivorship and their role in the long-term surveillance in order to reduce adverse health outcomes of cancer Survivors.
  [cemedicus.com/cancersurvivorship](http://cemedicus.com/cancersurvivorship), click “Launch Activity” link to begin the activity.

**Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs—October 2007**
- The report by the Institute of Medicine studies the delivery of psychosocial services to cancer patients and their families and identifies ways to improve it.
  [IOM.edu](http://IOM.edu)

(Continued on next page)
## Resources for Physicians (Cont.)

### Cancer Survivorship Care Planning—November 2005
- A report by the Institute of Medicine, based on From Cancer Patient to Cancer Survivor: Lost in Transition, 2006, details the elements of a survivorship care plan as well as frequent questions survivors may ask.

[IOM.edu](http://IOM.edu)

### From Cancer Patient to Cancer Survivor: Lost in Transition Report Recommendations—November 2005
- The recommendations in this report, taken from the Institute of Medicine's report, From Cancer Patient to Cancer Survivor: Lost in Transition, are directed to cancer patients and their advocates, health care providers and their leadership, health insurers and plans, employers, research sponsors, and the public and their elected representatives.

[IOM.edu](http://IOM.edu)

### American Society of Clinical Oncology® Chemotherapy Treatment and Summary Templates
- Developed by volunteer oncologists, these treatment plan and summary templates for breast and colon cancer can be downloaded in a modifiable format allowing oncologists to customize and adapt them to suit their own practices.

[ASCO.org](http://ASCO.org)

### Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers
- These guidelines provide recommendations for screening and management of late effects that may potentially arise as a result of therapeutic exposures used during treatment for pediatric malignancies. They were developed as a resource for clinicians who provide ongoing healthcare to survivors of pediatric malignancies. The screening recommendations in these guidelines are appropriate for asymptomatic survivors of childhood, adolescent, or young adult cancer presenting for routine exposure-based medical follow-up.

[survivorshipguidelines.org](http://survivorshipguidelines.org)

## Resources for Patients

### American Cancer Society (ACS) Guidelines on Nutrition and Physical Activity for Cancer Prevention
- Updated every five years, this document is a short version of the ACS Nutrition and Physical Activity Guidelines. It includes how to maintain a healthy weight and how to stay active.

[Cancer.org](http://Cancer.org)

(Continued on next page)
APPENDIX Q (Continued)
Survivorship Care Plan for Breast Cancer

SAMPLE
Jane Doe
DOB: 9/10/1963

Resources for Patients (Cont.)

CancerCare
- CancerCare is a national nonprofit group that gives free support services to those affected by cancer: people with cancer, caregivers, children, loved ones and those who have lost loved ones. These programs include counseling, education, financial and practical help. They are given at no cost by trained social workers. Founded in 1944, CancerCare helps more than 91,000 people each year. And each year, as many as 1.6 million people visit the website to learn more and find resources. Call 1-800-813-HOPE (4673), send an e-mail to info@cancercare.org, or visit the website at cancercare.org.

Cancer.Net™
- Cancer.Net™ is the award-winning patient information website of the American Society of Clinical Oncology® (ASCO). ASCO® is the world’s leading professional organization representing physicians of all oncology subspecialties who care for people with cancer. This website provides timely, oncologist-approved information to help patients and families make informed health-care decisions. All content is subject to a formal peer review process by more than 150 medical, surgical, radiation, and pediatric oncologists, oncology nurses, social workers, and patient advocates. In addition, ASCO® editorial staff reviews the content for easy readability. Cancer.Net™ is reviewed on an annual basis or as needed.

Employee Assistance Program (EAP)
- This service is offered, for the most part, through large employer groups. EAPs help employees and their families deal with issues such as:
  - Short- and long-term disability
  - Personal and emotional concerns
  - Legal and financial advice.
- EAPs can give access without barriers to an open network of community resources and licensed mental health counselors. Employee contact with the EAP is kept private. To learn more, ask your employer about your company's EAP.

Facing Forward: Life After Cancer Treatment
- Written by the National Cancer Institute, this booklet shares the feelings and feedback that many people have after cancer treatment. It also offers tips to help people get through this time.

cancer.gov

From Cancer Patient to Cancer Survivor: Lost in Transition—video
- This short film by the Institute of Medicine features the stories of cancer survivors and supports the need for a Survivorship Care Plan.

IOM.edu or YouTube.com

(Continued on next page)
Survivorship Care Plan for Breast Cancer

SAMPLE
Jane Doe
DOB: 9/10/1963

Resources for Patients (Cont.)

Heal: Living Well After Cancer
- Cancer survivors can use the information in this pamphlet for the rest of their lives from the day treatment ends. Topics include:
  - Cancer’s after-effects
  - Financial security
  - Best nutrition and fitness
  - Working after cancer
  - Faith and belief after cancer
  - Insurance strategies.
  healtoday.com

The LIVESTRONG™ Survivorship Center of Excellence
- LIVESTRONG™ Survivorship Center of Excellence is funded by the Lance Armstrong Foundation (LAF).
  - These centers:
      * Help people living with cancer deal with the emotional, practical and physical issues they face.
      * Serve as a one-stop source of information, care and service for cancer survivors, family members and service providers.
  - Centers include:
      * Abramson Cancer Center, University of Pennsylvania, Philadelphia, PA, 215-615-3371
      * Dana-Farber Cancer Institute, Boston, MA, 617-632-5100
      * Fred Hutchinson Cancer Research Center, Seattle, WA, 206-667-2814
      * Memorial Sloan-Kettering Cancer Center, New York, NY, 212-639-2851
      * Ohio State University Comprehensive Cancer Center – James Cancer Hospital and Solove Research Institute, Columbus, Ohio, 614-293-6401
      * UCLA’s Jonsson Comprehensive Cancer Center, Los Angeles, CA, 310-206-1404
      * University of Colorado Cancer Center, Denver, CO, 303-239-3397
      * University of North Carolina Lineberger Comprehensive Cancer Center, Chapel Hill, NC, 919-966-7230

National Center for Complementary and Alternative Medicine (NCCAM)
- NCCAM is the federal government’s lead agency for scientific research on complementary and alternative medicine (CAM). The mission of NCCAM is to:
  1. Explore healing practices in the context of science.
  2. Train medical researchers.
  3. Spread information to the public and professionals.
Call 1-888-644-6226, send an e-mail to info@nccam.nih.gov or visit the website at http://nccam.nih.gov

(Continued on next page)
APPENDIX Q (Continued)

Survivorship Care Plan for Breast Cancer

SAMPLE
Jane Doe
DOB: 9/10/1963

Resources for Patients (Cont.)

National Coalition for Cancer Survivorship (NCCS)
- NCCS is the oldest survivor-led cancer advocacy organization in the country. Members advocate for quality cancer care for all Americans and empowering cancer survivors. Patient education also is a priority for NCCS, which offers the Cancer Survival Toolbox®. This award-winning audio set is provided to Survivors, caregivers and clinicians at no cost. NCCS believes access to credible and accurate patient data is vital to asking for and getting quality cancer care.

Call 1-888-650-9127 or visit the website at canceradvocacy.org.

Northern California Cancer Center (NCCC)
- The NCCC is a nonprofit group that works with researchers, patients, educators, community based groups and academic centers. The NCCC is committed to preventing cancer and improving the quality of life for those living with cancer. The NCCC studies:
  - The causes of cancer
  - Cancer survivorship
  - Cancer screening.
- The NCCC manages:
  - A statewide breast and cervical cancer referral service for low-income women.
  - A statewide NCI-Cancer Information Service Partnership Program that focuses on improving outcomes that have to do with cancer. (This is done mainly in places where people may not be getting the medical care they need).
  - A community education program for patients and families, the general public and healthcare providers.

Call 1-510-608-5000 or visit the website at nccc.org.

The Wellness Community
- This is a global nonprofit group that gives support, education and hope to people with cancer and their loved ones. They can learn vital skills that let them regain control, reduce isolation, and restore hope by taking part in professional-led support groups, workshops, nutrition and exercise programs, as well as stress reduction classes. All programs are free.

Call 1-888-793-WELL send an e-mail to help@thewellnesscommunity.org or visit the website at thewellnesscommunity.org.
**APPENDIX Q (Continued)**

Survivorship Care Plan for Breast Cancer

<table>
<thead>
<tr>
<th>SAMPLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jane Doe</td>
</tr>
<tr>
<td>DOB: 9/10/1963</td>
</tr>
</tbody>
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**Endnotes**

Note 1: Important caution. This is a summary document whose purpose is to review the highlights of the cancer chemotherapy treatment plan for this patient. This does not replace information available in the medical record, a complete medical history provided by the patient, examination and diagnostic information, or educational materials that describe strategies for coping with cancer and adjuvant chemotherapy in detail. Both medical science and an individual’s healthcare needs change, and therefore this document is current only as of the date of preparation. This summary document does not prescribe or recommend any particular medical treatment or care for breast cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.

*Note. The Survivorship Care Plan included is a product of Journey Forward, a collaboration among the National Coalition for Cancer Survivorship, the UCLA Cancer Survivorship Center, WellPoint, Inc., and Genentech. Reprinted with permission.*
### Selected U.S. Adult Invasive Cancers, Survival Rates and Distribution by Stage, and Advanced-Stage Survival Rates

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<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1999–2005</td>
<td></td>
<td>Total Localized % Regional % Distant # Regional # Distant</td>
</tr>
<tr>
<td>Brain and other central nervous system</td>
<td>25.1</td>
<td>35.9</td>
<td>27,103 73 16 2 4,336 542</td>
</tr>
<tr>
<td>Female breast</td>
<td>74.9</td>
<td>90.1</td>
<td>272,566 60 33 5 89,947 13,628</td>
</tr>
<tr>
<td>Female cervical</td>
<td>68.6</td>
<td>71.8</td>
<td>19,972 50 35 11 6,990 2,197</td>
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<tr>
<td>Female endometrial</td>
<td>83.6</td>
<td>84.4</td>
<td>51,071 69 19 8 9,703 4,086</td>
</tr>
<tr>
<td>Colon and rectum</td>
<td>52.5</td>
<td>66.8</td>
<td>188,224 39 37 19 69,643 35,763</td>
</tr>
<tr>
<td>Esophagus</td>
<td>5.1</td>
<td>18.8</td>
<td>16,822 23 30 32 5,047 5,383</td>
</tr>
<tr>
<td>Lymphoma—Hodgkin</td>
<td>73.4</td>
<td>86.4</td>
<td>12,374 19 40 35 4,950 4,331</td>
</tr>
<tr>
<td>Lymphoma—non-Hodgkin</td>
<td>49.9</td>
<td>68.7</td>
<td>75,219 30 15 47 11,283 35,353</td>
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<tr>
<td>Renal and renal pelvis</td>
<td>54.1</td>
<td>69.1</td>
<td>47,144 58 18 19 8,486 8,957</td>
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<td>Head and neck: Larynx</td>
<td>66</td>
<td>63.2</td>
<td>13,972 59 19 17 2,655 2,375</td>
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<tr>
<td>Head and neck: Oral cavity and pharynx</td>
<td>54</td>
<td>62.5</td>
<td>39,621 34 46 14 18,226 5,547</td>
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<td>Leukemia</td>
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<td>37.8 54</td>
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<tr>
<td>Lymphocytic leukemia</td>
<td>50.4</td>
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<tr>
<td>Acute myeloid leukemia</td>
<td>8.4</td>
<td>23.4</td>
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<tr>
<td>Chronic myeloid leukemia</td>
<td>25.1</td>
<td>53.3</td>
<td></td>
</tr>
<tr>
<td>Liver and intrahepatic bile duct</td>
<td>3.5</td>
<td>13.7</td>
<td>25,053 37 26 19 6,514 4,760</td>
</tr>
<tr>
<td>Lung: Small cell lung and bronchus</td>
<td>4.4</td>
<td>6.3</td>
<td>31,163 5 21 69 6,544 21,502</td>
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(Continued on next page)
### APPENDIX R (Continued)

**Selected U.S. Adult Invasive Cancers, Survival Rates and Distribution by Stage, and Advanced-Stage Survival Rates**

<table>
<thead>
<tr>
<th>Invasive Cancer</th>
<th>Overall Relative Survival Rates</th>
<th>1999–2005</th>
<th>Distribution (Unstaged Excluded)</th>
<th># Regional</th>
<th># Distant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Relative Survival Rates</td>
<td>1978–1980 1999–2005</td>
<td>Total</td>
<td>% Regional % Distant # Regional # Distant</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Lung: Non-small cell lung and bronchus</strong></td>
<td>15 18</td>
<td>196,756</td>
<td>16 22 53 43,286 104,281</td>
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<td></td>
</tr>
<tr>
<td><strong>Mesothelioma</strong></td>
<td>6.3 7.7</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cutaneous melanoma</strong></td>
<td>83.3 93</td>
<td>71,842</td>
<td>84 8 4 5,747 2,874</td>
<td></td>
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</tr>
<tr>
<td><strong>Myeloma</strong></td>
<td>27 37.1</td>
<td>21,769</td>
<td>5 0 95 0 20,681</td>
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<td></td>
</tr>
<tr>
<td><strong>Female: Ovary</strong></td>
<td>38.9 45.6</td>
<td>29,168</td>
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<tr>
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<td>7 26 53 10,979 22,381</td>
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<tr>
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<td>23 32 33 9,815 10,121</td>
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<tr>
<td><strong>Testis</strong></td>
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<tr>
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<td>68 24 6 8,989 2,247</td>
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<tr>
<td><strong>Bladder</strong></td>
<td>76 81.7</td>
<td>72,583</td>
<td>50 36 8 26,130 5,807</td>
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</table>

Note that substantial numbers of persons are identified to have regional and distant disease. Clinicians managing survivorship care will encounter substantial symptoms related to cancer and cancer treatments in these patients. The survivorship clinic must also be skillful and adept to assess and manage distress, communications, and support for patients with chronic metastatic disease and those patients who encounter progression or recurrence of cancer. Presently, a “survivorship clinic” overtly or covertly may exclude patients with metastatic disease or those in active treatment from eligibility in survivorship clinic care. The epidemiologic data suggest that a substantial number of patients live with recurrent and/or metastatic cancer.

# APPENDIX S

Selected U.S. Adult Invasive Cancers, Overall Survival Rates, and Advanced-Stage Survival and Mortality Rates

<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>Brain and other central nervous system</td>
<td>25.1</td>
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<td>Female breast</td>
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<td>Female cervical</td>
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<td>71.8</td>
<td>57.7</td>
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<tr>
<td>Female endometrial</td>
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<tr>
<td>Colon and rectum</td>
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<td>69.5</td>
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<td>Esophagus</td>
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<td>Lymphoma—non-Hodgkin</td>
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<td>Renal and renal pelvis</td>
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<td>Head and neck: Larynx</td>
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<td>54.3</td>
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<td>Leukemia</td>
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<tr>
<td>Lymphocytic leukemia</td>
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<tr>
<td>Acute myeloid leukemia</td>
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<tr>
<td>Chronic myeloid leukemia</td>
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<tr>
<td>Liver and intrahepatic bile duct</td>
<td>3.5</td>
<td>13.7</td>
<td>8.5</td>
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</table>

(Continued on next page)
### Selected U.S. Adult Invasive Cancers, Overall Survival Rates, and Advanced-Stage Survival and Mortality Rates

<table>
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</thead>
<tbody>
<tr>
<td>-------------------------------------</td>
<td>--------------------------------</td>
<td>--------------------------------</td>
<td>--------------------------------</td>
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<tr>
<td>Lung: Small cell lung and bronchus</td>
<td>4.4 6.3</td>
<td>13.3</td>
<td>86.7</td>
</tr>
<tr>
<td>Lung: Non-small cell lung and bronchus</td>
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<tr>
<td>Mesothelioma</td>
<td>6.3 7.7</td>
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<tr>
<td>Cutaneous melanoma</td>
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<td>61.9</td>
<td>38.1</td>
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<tr>
<td>Myeloma</td>
<td>27 37.1</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Female: Ovary</td>
<td>38.9 45.6</td>
<td>72.8</td>
<td>27.2</td>
</tr>
<tr>
<td>Pancreas</td>
<td>2.5 5.6</td>
<td>8.7</td>
<td>91.3</td>
</tr>
<tr>
<td>Prostate</td>
<td>72 99.9</td>
<td>100.0</td>
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<td>Stomach</td>
<td>16.8 26.5</td>
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<tr>
<td>Testis</td>
<td>89.1 96.2</td>
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</tr>
<tr>
<td>Thyroid</td>
<td>93.2 97.3</td>
<td>97.0</td>
<td>3.0</td>
</tr>
<tr>
<td>Bladder</td>
<td>76 81.7</td>
<td>36.2</td>
<td>63.8</td>
</tr>
</tbody>
</table>

Note that substantial numbers of persons are identified to have regional and distant disease. On one hand, persons with 5-year regional and distant metastatic survival will be living with chronic illness in their cancer survivorship. On the other hand, note that 5-year mortality remains high for many cancers with regional and metastatic disease; in these populations of patients the survivorship clinic must be skillful and adept to transition patients and families to comprehensive interdisciplinary end-of-life care, particularly when palliative oncologic treatment options are exhausted.

## APPENDIX T

### Skills for Attaining Quality Cancer Care

<table>
<thead>
<tr>
<th>Communicating</th>
<th>Finding Information</th>
<th>Making Decisions</th>
<th>Solving Problems</th>
<th>Negotiating</th>
<th>Standing Up for Your Rights</th>
</tr>
</thead>
</table>

#### Self-Advocacy
- Arming yourself with tools and skills to feel comfortable asserting yourself and communicating clearly about your needs
- Taking responsibility and assuming some control of your life circumstances with cancer
  - **Communicating:** Discussing different treatment options with your doctor
  - **Finding Information:** Researching your cancer
  - **Making Decisions:** Getting a second opinion
  - **Solving Problems:** Asking for flexible time or time off from work
  - **Negotiating:** Adjusting your treatment schedule
  - **Standing Up for Your Rights:** Resubmitting an insurance claim

#### Community Advocacy
- Using what you’ve learned through your cancer experience (as a survivor or caregiver) and using it to help others
- Becoming a resource to help others speak up as they face a cancer diagnosis and its challenges
  - **Communicating:** Speaking at events in your community
  - **Finding Information:** Researching local support groups to start or to participate in
  - **Making Decisions:** Determining an unmet need in your community that you can fill
  - **Solving Problems:** Pulling together appropriate resources for others that you would have found helpful but didn’t know of
  - **Negotiating:** Sitting on a Review Board at your local hospital
  - **Standing Up for One’s Rights:** Mentoring someone who has just been diagnosed

#### Public Interest Advocacy
- Changing the cancer care system by working with policymakers at the local, state, and federal level
- Using your experience and the experience of others to improve the quality of cancer care
  - **Communicating:** Writing to the Editors of your newspaper to let them know how you feel about a cancer issue
  - **Making Decisions:** Determining legislation you do or don’t support
  - **Solving Problems:** Participating in events like marches and rallies
  - **Negotiating:** Attending Town Meetings and bringing up important issues
  - **Standing Up for One’s Rights:** Testifying before Congress

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**Note.** Created by Melissa Glim, MPH, and Anne Willis, MA.
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The letter f after a page number indicates that relevant content appears in a figure; the letter t, in a table.

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