

Chapter 10

Building a Team to Improve Cancer Survivorship: Integrative Care's Increasing Role



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Introduction to the Four Major Domains for Survivors

Numerous breakthroughs in cancer treatment, and greater understanding of the biology of the numerous diseases that fall under the diagnosis of “cancer,” have led to improved rates of survival, from what was once considered a terminal diagnosis. While progress in the treatment of some cancers (i.e., breast, prostate, colon) is greater than in others (i.e., pancreatic, lung) the statistics of survival after a cancer diagnosis are improving. According to the National Cancer Institute, the number of people living beyond a cancer diagnosis in the United States reached 14.5 million in 2016. That number is expected to reach 19 million by 2024 [1, 2]. The term “survivorship” describes the patient’s experience of moving beyond the diagnosis of cancer and treatment toward health maintenance and wellness.

The definitions of a “cancer survivor” vary, but most sources rely on the definition provided by the National Coalition of Cancer Survivors, which describes a person as a survivor from the diagnosis going forward. While most cancer programs consider cancer survivors as those treated with curative intent or those who have transitioned to maintenance therapy, not all patient advocacy groups define cancer survivorship in that way. Additionally, not all people who have had a cancer diagnosis identify with or like the term “survivor.”

The Institute of Medicine published an important text, *From Cancer Patient to Cancer Survivor: Lost in Transition* (2006) [3], and it highlighted the breadth of survivor needs, including support across psychological, physical, social, and spiritual domains. Many survivors report feeling lost following the completion of active treatment. They no longer have the structure of regular treatment visits and the support that comes from frequent interaction with their care team, but they live in fear

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of a recurrence. Meeting the needs in any one of these domains for each patient can be difficult. Trying to meet them across a growing population of survivors requires a new model of care delivery that extends into the survivorship period.

The Institute of Medicine outlined a quality-of-life model that addressed the four domains of most concern to cancer survivors.

Physical

Many cancer survivors report lingering side effects long after the completion of active treatment. Among the most common are fatigue, and issues related to strength. For others, pain or peripheral neuropathies, lymphedema, and other lingering side effects may persist. Problems with sleep and concerns about overall physical health may remain. Returning to normal functional activities may prove difficult. For patients of childbearing age, fertility issues may be highlighted. Sexual functioning is often altered as a result of treatment as well.

Psychological

It is not uncommon for cancer survivors to experience distress at diagnosis and throughout the course of treatment. This distress may extend into the survivorship period, and may involve fear of recurrence, feelings of lack of control, and may at times be experienced as anxiety or depression. For others, employment may have been interrupted by diagnosis and treatment, and the financial burdens incurred as a result of treatment may be extreme.

In a systematic review of studies on financial hardship in cancer survivors, 47–49% of cancer survivors report financial distress. Financial distress due to out-of-pocket costs related to cancer treatment is associated with increased risk of death by 79% [4]. Additionally a 2016 study by CancerCare revealed that patients alter care to reduce costs: 29% skipped doctors' appointments, 38% postponed or did not fill medication prescriptions, 34% skipped medication doses, and 31% cut oral medications in half [5, 6].

Social

Cancer impacts both the individual with the disease and those who care about him/her. Families also experience high levels of distress throughout the cancer experience, and may be eager for the cancer survivor to get back "to normal." The survivor, on the other hand, may no longer feel able or willing to resume all of the old roles and activities, having been changed by the cancer experience. This dynamic

can challenge even the healthiest of relationships. The cancer survivor may have both body image concerns and changes in sexual functioning. Roles and relationships may be challenged, and may lead to isolation for the cancer survivor.

Spiritual

It is not uncommon for cancer survivors to search for a sense of meaning in the experience. Some may find their faith strengthened, and others find their faith shaken as a result. Many survivors report a new sense of purpose and/or priorities and hope. Others may find their sense of self shaken. It is possible to discover one's inner strength and resilience after the cancer experience, but may require assistance in doing so.

Given the breadth and depth of survivor needs, it is not surprising that most cancer providers are not able to provide comprehensive support.

A 2013 survey found that 60–75% of survivors reported unmet needs [7]. Another recent study found that more than 50% of survivors reported receiving no psychosocial support from either support groups or professional counseling [8].

This lack of support is concerning on multiple levels. One concern is that unaddressed psychosocial needs can have implications for survivor's health. A 2013 population-based study found that depressed cancer survivors were twice as likely to die prematurely compared to non-distressed survivors [9].

Cancer survivors are at especially high risk for anxiety, depression, and other forms of psychosocial distress because of the multiple stressors, vulnerabilities, and challenges they face. According to the NCCN Guidelines for Distress Management risk factors for psychosocial distress include cognitive impairment, severe comorbid illnesses, uncontrolled symptoms, communication barriers, or a history of psychiatric disorder, depression, or substance abuse. Social issues such as living alone, having young children, being of younger age or female, and prior physical or sexual abuse are also risk factors for psychosocial distress [10].

Surveillance

Another area of concern is that of surveillance. Cancer surveillance involves using physical exams, imaging, blood tests, and other strategies to monitor patients for recurrence and development of secondary cancers. Cancer providers find surveillance challenging for a number of reasons: they may lack evidence-based guidelines, patients do not always prioritize follow-up care, and it is not always clear which clinicians should deliver which services. As a result, US providers vary significantly in their clinical practice. The American Society of Clinical Oncology (ASCO) surveyed its 3400 members who identified breast cancer as a major part of their work. Using four idealized patient vignettes, the survey found significant

variations in surveillance patterns, despite evidence from well-designed, randomized clinical trials. “There was marked variation in surveillance intensity” [11].

Recognizing this relatively new “stage” along the treatment continuum, ASCO issued suggested guidelines for follow-up and surveillance specific to disease sites and types. They also developed a Survivorship Care Plan (SCP) template intended to assist with this need. The SCP includes a summary of the patient’s diagnosis, all treatments received, a list of providers, and where treatment was received. This first part of the document is intended to be the “looking back” part of the care plan. Additionally, the document includes follow-up and surveillance guidelines, including healthy living recommendations (e.g.: smoking cessation, weight management, psychosocial support). This represents the “looking ahead” part of the document. The document is to be given to the patient following completion of treatment, and forwarded to the patient’s primary care provider as well.

In 2015, the Commission on Cancer program of the College of Surgeon, which accredits most cancer centers nationally, issued three new “patient-centered” standards as a part of the accreditation standards [12]. The three standards, patient navigation, distress screening, and survivorship, are being rolled out and cancer centers are being evaluated to determine their compliance in addressing these needs. While cancer centers vary widely in scope, size, and number of patients treated, the survivorship standard is the one proving most difficult to implement. The standard mandates that any patient treated with curative intent receive a completed Survivorship Care Plan (SCP) at the end of active treatment that includes treatment summary, surveillance guidelines, and recommendation for health lifestyle behaviors. The Commission on Cancer’s original survivorship standard required that by 2015, 10% of eligible patients receive the SCP, and the percentage increased annually so that by 2019 100% of patients would receive the care plan. This standard has recently been revised to require cancer programs accredited by the CoC meet a threshold of 50% of patients treated with curative intent to receive a Survivorship Care Plan. This will be implemented beginning January 1, 2018.

There are a number of barriers that cancer centers have experienced in meeting this standard as previously written. For large, often academic medical centers with multiple providers and clinical settings, it is difficult to identify all of those treated with curative intent. While working with the institution’s cancer registry is very helpful, there exists great variation in how providers document and practice, extending the challenge in identifying who is eligible.

A major barrier is that in many centers using electronic health records, the system does not auto-populate the care plan, thus requiring someone to “mine” the data in the medical record to complete the summaries. Additionally, many cancer centers use multiple electronic health records that do not communicate with one another. Thus, creating a SCP requires mining data from multiple systems. For example, surgery reports may exist in one system, whereas chemotherapy and radiation medicine exist in other systems. Completion of the SCP is time consuming, with many providers reporting the time it takes to complete the document as anywhere from

30 min to 2 h, and this is not reimbursable. Reimbursement is available for survivorship visits if provided by an MD, nurse practitioner, or physician assistant. There is little reimbursement for social workers or dietitians. The final barrier that has been raised is the lack of evidence that receiving the SCP makes a difference in patient behavior or follow-up. This has made it a particularly hard “sell” to providers and cancer programs already stretched to meet patient needs. This unfunded mandate, with little evidence to support patient compliance, coupled with the time it takes to complete the document, and limited reimbursement, has been met with frustration and resistance in some cancer centers. As noted, the Commission on Cancer has reevaluated and rewritten this standard [12].

The spirit of the mandate, however, goes well beyond the document itself. Ideally, survivorship care improves patient outcomes and patient satisfaction, and may reduce costs of care by supporting the overall physical and psychological well-being of survivors. Providers should monitor patients for cancer recurrence and educate patients about late and long-term effects. Psychosocial needs should be addressed by referrals to support services, social workers, or other counselors to meet their emotional needs. Referral to rehabilitation and nutritional support is important throughout the cancer continuum, beginning at diagnosis, and well into the survivorship period. Diet, smoking cessation, and exercise are also important aspects of recovery and health maintenance. Assessing a patient's readiness to make lifestyle changes can be helpful through the use of motivational interviewing techniques. Motivational interviewing is being increasingly used in healthcare settings to determine the best strategies to assist patients in making lifestyle changes [13]. There is evidence that today's young adults may be the first generation in modern history to be less healthy than their parents. Respiratory diseases and cancers, diabetes and obesity, heart and liver disease, and some psychological problems such as depression are all strongly linked to health behavior and lifestyles. Many of the maladies that cause people to consult healthcare professionals are largely preventable or remedial through health behavior change.

Motivational interviewing is a counseling approach developed by William Miller and Stephen Rollnick, originally evolved from the experience of working with “problem drinkers.” Miller and Rollnick described a more detailed description of the motivational procedures. Motivational interviewing is a goal-oriented, client-centered counseling style for eliciting behavior change by helping clients explore and resolve their ambivalence toward change. It is a focus- and goal-directed approach in which the therapist or physician attempts to influence clients/patients to consider making change. For patients considering healthier lifestyle changes, exploring and acknowledging ambivalence is central to the conversation. Change can be very difficult, and acknowledging this, vs. judging it is central to the purpose of motivational interviewing. The intention is to elicit client awareness of the issues and consequences of the continued behavior, and to help them see more about the future. It is essential that the practitioner be nonjudgmental, nonconfrontational, and nondirective, but rather curious and supportive [14].

Integrative Care

Many cancer survivors reevaluate their lives and lifestyles following the diagnosis and treatment of cancer. In an effort to keep cancer at bay, and to exert some control over one's health, an increasing number of cancer patients are choosing to use integrative approaches to aid in their recovery. Previously referred to as "alternative" or "complementary" therapies, an estimated 50% of Americans are increasingly utilizing integrative approaches to maintain health. An estimated 90% of cancer patients and survivors are said to use such approaches [15]. These approaches fall under several categories: healing touch, mind-body approaches, creative arts, nutrition, and fitness. Many integrative approaches are highly effective in managing the symptoms and side effects of cancer. Additionally, it gives cancer patients a sense of efficacy and control by taking an active approach to their health.

Integrative medicine addresses a patient's body, mind, and spirit, and encourages patients to be partners in their treatment [16]. Integrative medicine includes support groups, therapeutic massage, acupuncture, meditation, yoga, art, and music therapy, among others. It is important to note that some integrative therapies have not been studied. Others have been shown to be effective for symptom relief (e.g., to alleviate nausea, vomiting, and fatigue). To date, there is not consistently proven scientific evidence that integrative medicine will slow cancer progression.

As noted, the use of integrative medicine has grown partly in response to efforts by patients to take a more active role in their health care and use therapies that focus on overall health and healing. By integrating integrative medicine into conventional allopathic treatment, healthcare providers are better able to address the physical, emotional, spiritual, and quality of life needs of patients (Table 10.1).

In 1998, the National Institutes of Health (NIH) expanded its efforts to evaluate integrative medicine (then referred to as complementary medicine-CAM) by founding the National Center for Complementary and Alternative Medicine (NCCAM). NIH has invested in research to study how integrative therapies work, where they are effective, and which patients might benefit from specific therapies (e.g., people living with cancer, HIV/AIDs, heart disease, diabetes, or chronic illnesses). The National Cancer Institute Office of Cancer Complementary and Alternative Therapy is charged with holding integrative medicine therapies to the same rigorous scientific investigation used to evaluate standard cancer treatments.

Table 10.1 Basic principles of integrative medicine [17]

• Reaffirms importance of the relationship between health providers and patients
• Encourages patient-centered care, empowering patients as partners in their treatment
• Focuses on the whole person—the body, mind, and spirit
• Uses evidence-based therapies (conventional and integrative medicine) to support and achieve optimal health and healing

A growing number of hospitals, cancer centers, and individual healthcare providers are offering integrative medicine options and increasingly they are important for survivorship care. When used in addition to other standard cancer treatments, certain integrative therapies can play an important role in enhancing the quality of a person's overall care and peace of mind. Some techniques are "passive," requiring limited participation (e.g., massage, Reiki) while others are "active" (yoga, tai chi, support groups).

Integrative therapies can help manage symptoms, reduce treatment side effects (e.g., fatigue, depression, nausea), and enhance feelings of well-being and quality of life. The following describes some of the integrative medicine offerings available in many cancer centers.

Alternative Medical Systems

Alternative medical systems include Chinese medicine, Ayurveda, homeopathic, and naturopathic medicine. Chinese medicine emphasizes the balance of *qi* ("chee") or vital energy. Within this system, illness is described as a disturbance of vital energy. Ayurveda is a system of healing which evolved from the teachings of ancient India. It stresses the use of body, mind, and spirit in disease prevention and treatment and strives to achieve harmony within the individuals. Integrative approaches include acupuncture, herbal medicine, restorative physical exercise, and controlled breathing.

Mind-Body Interventions

Mind-body interventions use strategies to enhance the mind's impact on the body's function and physical symptoms. Interventions are used to help patients relax, reduce stress, and relieve symptoms associated with cancer treatments. Examples include meditation, support groups, hypnosis, yoga, tai chi, expressive arts (music, art, writing), and prayer.

Examples of touch therapies are massage and Reiki. Massage offers the benefit of maintaining energy, relieving stress and tension, and decreasing anxiety [18]. Reiki promotes healing through gentle hands-on touch for restoring harmony and relaxation.

Examples of mind-body therapies include yoga, meditation, and mindfulness-based stress reduction (MBSR). MBSR has experienced growing popularity in healthcare settings for both patients and healthcare providers alike. Mindfulness refers to open, nonjudgmental, moment-to-moment awareness of what is present. Randomized controlled trials demonstrate beneficial changes in psychosocial quality of life, anxiety, depression, fatigue, sleep disturbances, pain, sexual dysfunction, physiological arousal (e.g., blood pressure), immune function, and cortisol levels [19, 20].

Acupuncture is a safe, painless, and effective form of traditional Chinese medicine. Acupuncture is used to reopen the normal flow of energy, thereby relieving symptoms associated with the specific points of needle placement. Acupuncture can be very helpful as adjunctive care for treatment in cancer. Many of the side effects from cancer therapies can be minimized if not avoided by utilizing alternative measures to support the body during the continuum from diagnosis through survivorship. Research supports using acupuncture to treat chemotherapy-induced nausea and vomiting, poor appetite, constipation or diarrhea, insomnia and fatigue, hot flashes, xerostomia, anxiety and depression, peripheral neuropathy, and pain [21, 22].

The creative arts can offer a useful outlet for cancer survivors that may allow them to work through some of the changes and emotions that accompany the cancer journey. While many people take advantage of the benefits of counseling and/or support groups, others find that writing, creating art work, or music can offer a different opportunity for expression [23]. The expressive arts allow individuals to use art as a means of self-expression to reconcile emotional conflicts and to foster self-awareness and personal growth. Thus, through the creative process, individuals under physical, emotional, and/or spiritual stress can work through and integrate their situations to facilitate healing. The creative process is naturally healing; therefore the benefits and possibilities with people under stress can be profound.

Nutrition and fitness are also areas in which cancer survivors can influence their healing. Numerous studies have shown the benefits of physical activity on the reduction of fatigue and improved strength and physical functioning [24, 25], and others find that modifying diet becomes important [26].

Support Groups

Cancer support groups became popular, particularly in the 1980s as the “silence” around a cancer diagnosis began to change. Prior to that time, many people were reluctant to talk about cancer, in part because of the fear associated with the diagnosis, compounded by the lack of understanding of the disease itself, and limited treatment options.

Support groups began as a way to offer mutual support with others going through a similar experience. It helped to reduce the isolation and loneliness of the cancer journey.

In 2000, Dr. David Spiegel and Dr. Catherine Classen published a seminal work about the value of support groups, *Group Therapy for Cancer Patients: A Research-based Handbook of Psychosocial Care* [27]. In one study Spiegel matched demographically women with metastatic breast cancer. He randomly assigned one group of women to support groups, and another to traditional psychosocial support offered through the cancer center. The underlying assumption was that women in the support group arm would report higher levels of support than women assigned

to traditional support, which proved to be true. What was not expected was the finding that the women assigned to the support group arm lived an additional 18 months longer than the women not in the support group [27]. Support groups gained great popularity during that time. Further research has suggested that the longer survival time is not directly linked to being in a cancer support group per se, but rather that having high levels of good psychosocial support in one's life aids in recovery and quality of life.

Since that time, support groups have evolved and changed. Support groups may be disease specific, general cancer support, and/or support groups for families and caregivers. Most groups are facilitated by trained oncology professionals including oncology social workers, psychologists, and/or oncology nurses. Most are open ended, and often include psycho-education as a part of the support. Family groups may offer the opportunity for couples, children, and other family members to give and receive support.

Based on the principle of *mutual aid*, support groups offer reassurance and support by coming together with others who share similar experiences. Support groups can greatly reduce a sense of isolation that can come with the cancer experience.

Other sources of support can include weekend retreats, classes on specific topics, and peer volunteer outreach. More recently, online support groups have become increasingly popular. When offered through credible sites (e.g., CancerCare, Cancer Support Community, and others), online groups are accessible to those who have difficulty traveling, are impaired by side effects or other symptoms, and are available at times when traditional support groups may not be.

Some oncology practices are offering education and support groups specific to survivors, and offering topics of interest after treatment. These groups are often facilitated by a nurse, social worker, physician, or nurse practitioner, and may include topics related to recovery or side effects. Such topics may include dealing with neuropathies, fatigue, insomnia, sexual challenges, relationship issues, and financial concerns.

Many cancer survivors discover that they need assistance in navigating life post-cancer diagnosis and treatment. Groups and retreats can offer the opportunity to examine how life and priorities have, and have not, changed, as a result of a cancer diagnosis. Being able to examine fears, discoveries, and opportunities in safe settings with others who understand these dynamics can be very helpful to cancer survivors.

Retreats are another option for people who are recovering from cancer. Offered at a number of sites across the United States, they provide an opportunity for people recovering from cancer to step apart from their daily lives and to consider how the cancer experience has impacted them. Often the retreats include a combination of group support and examination of the cancer experience, as well as wellness activities such as yoga, massage, cooking classes, and other activities. The intention is to help cancer survivors further integrate the experience and identify new or renewed life priorities.

Caregiver Support

Family members of cancer survivors and other caregivers may find value in meeting with others providing support and care to the person with cancer. Particularly if the treatment and recovery process is long, such as with bone marrow transplant, or if the disease itself creates disability or cognitive change for the person with cancer (e.g., brain tumors), additional support is indicated. Caregivers may tend to minimize their own need for care, deferring to the needs of the person with cancer. However, caregivers often experience high levels of depression and anxiety, exhaustion, and social isolation. In these situations, services can be tailored with this special population in mind, and may include education, support, and referral to community resources for additional support.

A Word About Professional Caregivers (Healthcare Providers)

Working as a healthcare professional in oncology is highly rewarding and the advances in treatment options and increased rates of survival are deeply gratifying. However, working in oncology can also be emotionally and physically exhausting, as well as at times very difficult. Despite the numerous steps forward in the field, people still can and do die of cancer. Over a career it is not uncommon for an oncology professional to have experienced numerous losses. It is imperative for oncology professionals to find ways to renew and restore one's self, and to be cognizant of signs of burnout, compassion fatigue, and moral distress. Fortunately, many cancer centers have created opportunities for their teams to receive support both formally and informally. Some teams have created memorial rituals to acknowledge the loss of patients. Other programs offer mindfulness-based stress reduction programs for the healthcare professional and/or opportunities for support groups for the professionals.

Conclusions

As the number of cancer survivors continues to increase, the demand and need for ongoing programs of support will continue to grow. Cancer centers are challenged to develop such programs. Some services are billable and reimbursable, while others may be supported through philanthropy.

Given the profound impact that cancer has on the lives of patients, comprehensive survivorship programs should include attention to the whole person and a range of services to support ongoing recovery. These should include integrative medicine approaches as well as psychosocial support. This will help the person with cancer and their loved ones to feel more fully supported while also enhancing patient

satisfaction, and may give individual cancer programs a competitive edge. Ongoing research regarding the efficacy of integrative therapies is also indicated as well as ongoing evaluation of the best approaches to survivorship.

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