

Psychosocial Concerns and Interventions for Cancer Survivors

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ABSTRACT

In light of the increasing population living with a history of cancer in the United States, it is important to attend to quality of life and health in this group, and to develop effective interventions to address psychosocial and physical concerns across the course of the cancer trajectory. The goals of this article are to document the need for attention to psychosocial domains; offer a brief overview of the current status of the empirical literature on effects of psychosocial interventions with cancer survivors, relying on systematic reviews and meta-analyses conducted in the last decade; highlight recent examples of randomized, controlled psychosocial intervention trials directed toward cancer survivors after the completion of primary medical treatments (ie, the re-entry phase and beyond); and identify directions for application and research.

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INTRODUCTION

During the last three decades, the number of people living with a cancer diagnosis in the United States has tripled, increasing from 3 million (1.5% of the population) in 1971 to 10.1 million (3.5% of the population) in 2002.^{1,2} Although the earliest phase of diagnosis and treatment of life-threatening disease certainly is recognized as psychologically taxing for affected individuals and their loved ones, those diagnosed with cancer often confront lingering physical, psychological, and interpersonal (hereafter referred to as psychosocial) challenges that extend into longer term survivorship. The goals of this article are to document the need for attention to psychosocial domains across the cancer trajectory; provide a brief overview of the current status of the empirical literature on effects of psychosocial interventions with cancer survivors, relying on systematic reviews and meta-analyses conducted in the last decade; highlight recent examples of randomized, controlled psychosocial intervention trials directed toward cancer survivors after the completion of primary medical treatment (ie, the re-entry phase³) and in later survivorship; and identify directions for application and research.

NEED FOR ATTENTION TO PSYCHOSOCIAL DOMAINS ACROSS CANCER SURVIVORSHIP

A review of the literature on psychological adjustment in individuals diagnosed with cancer yields several broad conclusions, with the caveat that the preponderance of psychosocial research has been

conducted with samples of breast cancer patients. First, a diagnosis of cancer has the potential to result in marked psychological distress and life disruption. This observation comes from studies in which patients are assessed before and after a definitive cancer diagnosis or in relation to comparison groups or norms (eg, Carver et al,⁴ Perczek et al,⁵ Stanton and Snider,⁶ Michael et al,⁷ and Zabora et al⁸). For example, in the Nurses' Health Study cohort of 48,892 women, 759 were diagnosed with breast cancer during the 4-year study period.⁷ After control for multiple covariates in the analyses, women diagnosed with cancer experienced an increase in pain and declines in the realms of physical and social function, vitality, and ability to perform emotional and physical roles, compared with women who did not receive a cancer diagnosis. Declines in quality of life were particularly pronounced in women age 40 years or younger.⁹ Fewer problems were apparent as time since diagnosis increased, but group differences remained significant for four of seven quality of life domains up to 4 years after diagnosis.

In a review of studies with prostate cancer patients, Eton and Lepore¹⁰ concluded that the cancer and its treatment affect both disease-specific quality of life (ie, urinary, sexual, and bowel function) and general life quality (ie, vitality, physical and social role performance). To place cancer in the context of other serious diseases, Polsky et al¹¹ examined five biennial waves of the Health and Retirement Study in more than 8,000 adults age 51 to 61 years without significant depressive symptoms at study onset. Within 2 years of initial diagnosis, individuals with cancer had the highest risk of significant depressive

symptoms (hazard ratio = 3.55 *v* no incident disease) relative to other diagnosed diseases (eg, chronic lung disease, heart disease, arthritis, diabetes). The hazard ratio for depressive symptoms decreased during the next 6 years for cancer patients.

Second, rates of clinically significant psychological disorder in cancer patients frequently are found to exceed those of the general population. The conclusion of most reviews is that the prevalence of clinically significant depressive symptoms in cancer patients exceeds general population norms (eg, Massie et al¹² and van't Spijker¹³), although estimates of prevalence vary widely across studies. Although anxiety as a symptom is commonly reported by cancer patients, elevated prevalence of clinically significant anxiety disorder is less consistently documented.¹³ For example, although 41% of 115 women reported that they had responded to their breast cancer diagnosis with intense fear, helplessness, or horror, a hallmark criterion of post-traumatic stress disorder, only 4% met criteria for a diagnosis for cancer-related post-traumatic stress disorder in one study.¹⁴

Third, for most individuals, distress remits during the first 24 months after diagnosis, although specific problems can persist. As an example, Burgess et al¹⁵ conducted structured diagnostic interviews for depressive and anxiety disorders with 202 early-stage breast cancer patients who were younger than 60 years old, beginning at 5 months after diagnosis and then every 18 months up to 5 years. The annual prevalence of 48% for depression, anxiety, or both disorders during the year of diagnosis was twice that of the general population of women (note that this was a relatively young sample and that younger age typically is related to higher distress in breast cancer patients). The prevalence of depression/anxiety disorders decreased and became equivalent to that of the general population after the first year, except for women who experienced a cancer recurrence. Stommel et al¹⁶ observed 860 patients older than age 65 for 1 year after an initial diagnosis of breast, colon, lung, or prostate cancer, and found that depressive symptoms declined rapidly during the year, although patients' sense of well-being did not recover during that period. Troubling physical symptoms and declines in physical function also can endure.^{17,18} For example, in a population-based study, Sweeney et al¹⁹ found that women diagnosed with cancer for fewer than 2 years reported the most functional limitations, but even long-term cancer survivors reported more functional limitations than did individuals never diagnosed with cancer. Such disease-specific concerns as fear of cancer recurrence, concerns regarding body image and sexuality, and financial burden also can persist.^{20,21}

As a group, long-term (eg, 5 or more years after diagnosis), disease-free cancer survivors often report quality of life that matches or exceeds population norms, although receipt of chemotherapy and other systemic treatments (eg, tamoxifen) can compromise quality of life.^{17,22} In addition, effects on quality of life are uneven across persons. Helgeson et al²³ observed 287 women with breast cancer and identified trajectories of functioning from 4 months after diagnosis through 55 months. With regard to psychological functioning (Mental Component Summary on the Short Form 36-Item Physical and Mental Health Summary Scales²⁴), 43% of the sample evidenced high and stable mental health over time, 18% began somewhat lower and improved slightly, 26% evidenced low psychological functioning shortly after diagnosis but showed rapid improvement, and 12% had an immediate and substantial decline in psychological functioning, with only slight improvement by 43 months. With regard to functioning related to physical health (Physical Component Summary on the

Short Form 36-Item Physical and Mental Health Summary Scales), 55% had sound functioning at study entry, which improved slightly over time, 23% began at an intermediate level of functioning and evidenced improvement over time, 20% began at that level but did not improve, and 2% began with low physical function, which deteriorated further. Participants' demographic attributes and psychosocial resources in part distinguished the trajectories. Clearly, adjustment trajectories are heterogeneous.

Fourth, many individuals extract positive meaning and benefit from their experience with cancer, reporting that it prompts enhanced interpersonal relationships, deepened appreciation for life, increased personal strength, greater spirituality, valued change in life priorities and goals, and greater attention to health-promoting behaviors.²⁵ Moreover, Carver and Antoni²⁶ found that finding benefit in the year after surgery for breast cancer predicted lower distress and depressive symptoms 4 to 7 years later.

The finding that most people with cancer adjust well over time does not suggest that attention to psychosocial and physical concerns is not essential. Indeed, research documents important unmet needs that persist after completion of primary medical treatments.²⁷ In a survey of 191 cancer patients, 54% reported receiving insufficient cancer-related information, and 50% searched for information on the Internet.²⁸ Luker et al²⁹ found that 105 breast cancer patients before treatment reported gaining useful information from medical professionals. At 21-month follow-up, however, women gained information primarily from the popular media and often reported discomfort in requesting information from medical providers. The majority (66%) reported needs that had not been met at follow-up. Needs for aid seem most common in the domains of managing physical sequelae of cancer and its treatment, and promoting psychological adjustment.^{30,31} A recent report from a committee established by the Institute of Medicine documented specific prevalent medical and psychological concerns after treatment for distinct cancers.¹ Lack of effective attention to such concerns can exact a toll not only on survivors' health and well-being,³² but also on the extent of required medical care. For example, Himelhoch et al³³ found that Medicare beneficiaries diagnosed with cancer of the prostate, breast, lung, or colon were at least twice as likely to use emergency department services and medical inpatient hospital services if they had clinically significant depressive symptoms than if they did not.

Taken together, studies suggest that persistent psychological and physical decrements occur for a subset of cancer survivors. Another body of research^{34,35} has identified risk and protective factors for these outcomes. Such factors as receipt of chemotherapy, social isolation or conflict, expectancies for low control and negative outcomes, and concerted attempts to avoid thoughts and feelings surrounding cancer predict poor adjustment and functional limitations over time, whereas protective factors include having emotionally supportive relationships and using active coping strategies such as problem solving, positive reappraisal, and emotional expression. What measures can be taken to reduce psychological morbidities in cancer patients and promote adaptive cancer survivorship?

PSYCHOSOCIAL INTERVENTIONS FOR ADAPTIVE CANCER SURVIVORSHIP

Although a systematic review of the more than 200 randomized, controlled trials of psychosocial interventions for people diagnosed

with cancer is not feasible here, some general observations can be offered. First, it should be noted that psychosocial interventions span a range of approaches, and many interventions involve multiple components, such as education regarding cancer and its treatment, provision of emotional support, training in coping skills, challenging unhelpful thoughts, and relaxation training. Second, systematic reviews and meta-analyses of psychosocial interventions published to 2003³⁶⁻⁴⁶ reveal that the majority of psychosocial intervention research has focused on the early diagnostic and treatment phase. This focus is understandable in light of patients' considerable distress and the associated life disruption apparent at that time. There is evidence that relatively minimal interventions, which can be adopted readily in clinical practice, can be effective. For example, McQuellon et al⁴⁷ found that a brief orientation program for cancer patients at their initial oncology clinic visit, which involved a clinic tour, information about clinic operations, and an opportunity to ask questions of an oncology counselor, significantly reduced anxiety, depressive symptoms, and overall distress, and increased knowledge of clinic operations and satisfaction with care, relative to a usual-care control. Jacobsen et al⁴⁸ evaluated stress management training self-administered by patients (58% breast cancer, 21% lung cancer, 21% other cancers) beginning chemotherapy. The intervention involved a 10-minute meeting with a psychologist, who provided a videotape and booklet on coping with chemotherapy and a relaxation audiotape. In follow-up assessments conducted during chemotherapy, participants in self-administered stress management reported significantly better physical function and vitality, fewer emotional role limitations, and better general mental health than did usual-care participants.

Although most trials conducted during the treatment phase do not incorporate long-term follow-up, there is some evidence that such interventions can set the stage for more positive psychological functioning during later survivorship. For example, Helgeson et al⁴⁹ tested the effects of 8-week educational (ie, presentations by professionals on topics such as chemotherapy adverse effects, nutrition) or facilitator-led peer discussion or combined education-discussion groups administered during chemotherapy versus a usual-care control on quality of life in women with early-stage breast cancer. Effects of the educational group were significant on several quality-of-life parameters immediately after the intervention and 6 months later, largely mediated through enhanced self-esteem and body image, and reduced cancer-related intrusive thoughts. At a 3-year follow-up,⁵⁰ the superiority of the educational intervention versus usual care was maintained on the quality-of-life indicators of vitality, bodily pain, and physical functioning.

A third observation is that reviews are mixed in their conclusions regarding effectiveness of psychosocial interventions. Early meta-analyses^{38,41} revealed significant positive effects of psychosocial interventions on such outcomes as emotional adjustment, disease and treatment-related symptoms, and functional adjustment. Most meta-analyses yield heterogeneous effect sizes across trials, indicating that some interventions carry robust positive effects, whereas others produce null findings. They also suggest factors that might distinguish effective interventions from less effective approaches, such that larger effects have been reported for trials in which participants were selected for significant distress,⁴⁵ more experienced therapists administered the interventions,⁴⁵ and intervention durations were at least 12 weeks.⁴³ Some reviews have demonstrated that effects of psychosocial interventions are dependent on the specific outcome variable exam-

ined. For example, meta-analyses have suggested stronger intervention effects on anxiety than on depressive symptoms,⁴⁵ a beneficial effect on pain in adults with cancer,³⁹ and no significant effect on survival.⁴⁶

In a recent systematic review, Jacobsen et al⁴⁰ examined effects of 60 studies of psychosocial interventions and 12 pharmacologic interventions on anxiety or depressive symptoms in randomized, controlled trials published from 1980 to 2003 (partial year). The substantial majority of interventions were directed toward newly diagnosed patients or those receiving medical treatment. The median interval between intervention administration and final follow-up was 6 weeks in psychosocial trials and 4 weeks in pharmacologic studies. As found in meta-analyses, intervention effects were not consistent across trials. Among the most impressive findings is that interventions directed toward instruction in relaxation skills for newly diagnosed patients produced significant improvement in seven of seven trials on anxiety and six of six trials on depressive symptoms.

EXAMPLES OF RECENT TRIALS OF PSYCHOSOCIAL INTERVENTIONS BEYOND THE TREATMENT PHASE

Few psychosocial interventions have been directed toward cancer survivors beyond the early diagnostic and treatment phase. Recently, researchers have studied effects of approaches to enhance well-being during the period shortly after the completion of medical treatment (ie, the re-entry phase). Although effects are not entirely consistent across outcome variables, these randomized, controlled trials suggest that interventions offered to early-stage breast and prostate cancer patients at re-entry can be effective. Specifically for women diagnosed with breast cancer, educational and nutritional group-delivered interventions reduced depressive symptoms and improved physical functioning at the 13-month follow-up⁵¹; a peer-modeling videotape accelerated the recovery of vitality, particularly in women who felt unprepared for the re-entry phase⁵²; and writing about deepest cancer-related thoughts and feelings reduced physical symptoms and medical appointments for cancer-related morbidities,⁵³ relative to control conditions. For men with prostate cancer, group stress management (eg, relaxation training, challenging dysfunctional thoughts, use of social support) improved global quality of life,⁵⁴ and group education with discussion resulted in less bother from sexual problems and more steady employment, and for those without a college education, better physical function and more positive health behaviors through 6- and/or 12-month follow-up.⁵⁵

Few psychosocial interventions have been directed toward long-term survivors. A recent exception is a trial to address uncertainty about cancer recurrence, a major concern of individuals after treatment completion, as well as management of long-term adverse effects, in women treated for breast cancer 5 to 9 years previously.⁵⁶ Relative to usual care, the intervention improved knowledge regarding living with long-term adverse effects and with fears of recurrence, and it enhanced several coping skills directed toward fear of recurrence at a 10-month follow-up in African American and white women. Evidence-based interventions targeting specific concerns of long-term survivors are needed.

Another recent development is empirical attention to a broader range of relevant end points and intervention approaches. Psychosocial interventions for people diagnosed with cancer increasingly incorporate biologic (eg, endocrine and immune⁵⁷⁻⁵⁹) and behavioral (eg,

medical treatment compliance, physical activity^{57,60,61}) outcomes. Targeted interventions for specific cancer-related symptoms (eg, pain, fatigue^{39,62,63}) continue to be studied. Furthermore, interventions directed toward the affected couple and family also are gaining attention.^{64,65} In light of documented interest in complementary approaches,^{66,67} research is beginning to accumulate on such interventions for cancer survivors as mindfulness meditation,⁶⁸ yoga,⁶⁹ and massage.⁷⁰

RECOMMENDATIONS FOR APPLICATION AND RESEARCH

What can the oncologist glean from the body of literature on psychosocial issues and interventions across survivorship to enhance clinical practice? Voiced by many national bodies, including the National Cancer Policy Board,¹ the President's Cancer Panel,⁷¹ and the National Comprehensive Cancer Network,⁷² the first observation is that routine assessment of patients' psychological and physical well-being is warranted. This recommendation is relevant not only during diagnosis and treatment, but also across the course of the cancer trajectory, in light of cancer survivors' shifting concerns and needs across time and the evidence that external sources of support erode over time, particularly for those who are most distressed.^{73,74}

Most cancer patients want their physicians to ask about emotional well-being. For example, a study of 95 gynecologic cancer patients approximately 2 years after treatment completion⁷⁵ demonstrated that 57% of the sample reported that they had needed help in dealing with cancer-related emotions, but only 35% had received such help; 73% stated that physicians should ask whether cancer patients want help in dealing with emotions. In a study of 273 cancer patients receiving palliative chemotherapy and 10 of their oncologists, Detmar et al⁷⁶ found that 94% of patients expressed a desire to discuss emotional functioning with their doctors, but 39% of that group stated that they would do so only if the physician initiated the discussion. Four of 10 physicians reported that primarily it was their task to discuss the patient's emotional functioning, and six indicated that it was a shared task with other health care professionals. None reported that they generally initiated a discussion of emotional concerns; rather, they indicated that the patient typically began such a discussion or reported equal initiation with the patient. Certainly, patients may feel reluctant to initiate discussions of sensitive concerns, and physicians can play a key role in routinely querying for concerns and providing resources for addressing them.

With regard to assessing the psychosocial concerns of cancer survivors, brief in-person or computerized screening of psychological and physical symptoms seems feasible and may contribute to favorable outcomes.⁷⁷⁻⁷⁹ Detmar et al⁸⁰ found in a randomized trial that when oncologists and patients were provided with a summary of patients' standardized quality-of-life assessments before a consultation, quality-of-life issues were discussed significantly more frequently and patients received more counseling from oncologists on how to manage problems (although they did not receive more referrals to other professionals or prescription of medications). McLachlan et al⁷⁹ found that provision of screening information on patients' cancer-related needs, quality of life, and depressive symptoms to the physician and coordinating nurse before patients' consultation appointments did not produce significant overall improvement on those variables at 2 or 6 months relative to an assessment-only control. However, the

intervention significantly reduced depressive symptoms at 6 months for those who initially reported moderate or severe depressive symptoms. Additional evidence that routine screening and follow-up ultimately results in improved outcomes is necessary.⁸¹

After medical treatment completion, patients often report that they are more likely to learn about psychological support or specific cancer information/support services on their own than from medical personnel,⁸² suggesting that proactive provision of psychosocial resources to patients through comprehensive survivorship care¹ and appropriate referrals is warranted. Many academic centers provide free or low-cost psychosocial care for people with cancer and their loved ones, and some group oncology practices involve psychologists and other mental health professionals as members of the treatment team. Even when on-site psychological resources are not readily available, patients can be referred to print materials (eg, the National Cancer Institute's [NCI's] Facing Forward series for post-treatment survivorship⁸³); telephone services (eg, the NCI's Cancer Information Service, 1-800-4-CANCER), in which trained cancer information specialists can help the caller translate and make sense of material that can seem overwhelming, as well as provide emotional support; and Web sites for cancer survivors (eg, NCI, <http://cis.nci.nih.gov/> and www.cancer.gov; the American Society of Clinical Oncology People Living with Cancer, www.plwc.org; the American Cancer Society, www.cancer.org). Additional resources are provided in the Institute of Medicine report.¹ The promotion of evidence-based approaches to psychosocial care is important, both through referral of patients to well-designed intervention trials and through incorporation of these approaches into practice. Pathways for effective dissemination of evidence-based interventions require much more attention.⁸⁴⁻⁸⁶

Many gaps remain in the knowledge base on psychosocial interventions for cancer survivors. Greater empirical consideration of theoretically based mechanisms for effects of interventions will promote the development of maximally effective interventions.^{51,54} For example, evidence suggests that interventions explicitly designed to enhance capacities to monitor and alter cancer-relevant thoughts, emotions, and behaviors (eg, practice of new coping skills, relaxation training, role playing, goal setting, problem solving) produce larger effect sizes than do interventions lacking those components.⁸⁷ This observation is consistent with findings that psychoeducational interventions are more effective than peer discussion.^{43,49} In addition, continued research to identify for whom and under what conditions psychosocial interventions are most effective (ie, moderators of effects) is important. Accumulating research suggests that particular psychosocial interventions may be more effective for individuals who have fewer psychosocial resources, such as low interpersonal support,^{64,88} less optimism,⁸⁹ or lower level of education,⁵⁵ whereas individuals with sound resources often are able to recover well in their natural environment with no or minimal formal intervention.⁹⁰ Research with diverse groups also is needed. Few psychosocial interventions have been tested with African American cancer survivors, for example.^{56,91} The largest group of cancer survivors in the United States has been diagnosed with breast cancer,¹ and the preponderance of psychosocial intervention research has been directed toward that group; potentially distinct approaches for individuals with other cancers require consideration. Certainly, as the number of people living with a history of cancer continues to increase, identification of optimal methods for promoting the health and well-being of long-term survivors and individuals who encounter recurrent disease is essential.

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The author indicated no potential conflicts of interest.