
Life After Diagnosis and Treatment of Cancer in Adulthood

Contributions From Psychosocial Oncology Research

Annette L. Stanton
Julia H. Rowland
Patricia A. Ganz

University of California, Los Angeles
National Cancer Institute, Bethesda
University of California, Los Angeles

The number of individuals living with a history of cancer is estimated at 13.7 million in the United States and is expected to rise with the aging of the population. With expanding attention to the psychosocial and physical consequences of surviving illness, psychological science and evidence-based practice are making important contributions to addressing the pressing needs of cancer survivors. Research is demonstrating that adults diagnosed with cancer evidence generally positive psychosocial adjustment over time; however, a subset is at risk for compromised psychological and physical health stemming from long-term or late effects of cancer and its treatment. In this article, we characterize survivorship after medical treatment completion during the periods of reentry, early survivorship, and long-term survivorship. We describe the major psychosocial and physical sequelae facing adults during those periods, highlight promising posttreatment psychosocial and behavioral interventions, and offer recommendations for future research and evidence-based practice.

Keywords: cancer, survivorship, psychosocial, quality of life, intervention

Nearly three decades have passed since the founding of the National Coalition for Cancer Survivorship. This advocacy organization catalyzed the establishment of the National Cancer Institute's (NCI) Office of Cancer Survivorship in 1996, and raised awareness of the growing population of cancer survivors and their unique medical and psychosocial needs. A decade later, the landmark Institute of Medicine (2006; IOM) report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, identified important gaps in the evidence base regarding the experience and care of individuals who have completed their primary cancer treatments (e.g., surgery, radiotherapy, chemotherapy). The substantial majority of research on psychosocial aspects of cancer, however, remains focused on the phases of cancer diagnosis and treatment, with less attention to the immediate posttreatment period and beyond.

Fortunately, this picture is changing. Accumulating research is elucidating the experience of cancer survivors as they move into the posttreatment phase and longer-term survivorship, and is testing interventions to address cancer-related morbidities and promote health and well-being. Our

goals in this article are to highlight the importance of psychosocial research and clinical care directed toward cancer survivors beyond completion of curative cancer treatments, characterize specific periods during the survivorship phase, describe central issues facing survivors, highlight promising psychosocial and behavioral interventions for survivors, and offer recommendations for research and evidence-based practice. We focus on research with adult cancer survivors and refer the reader to other sources on children and adolescents (Kazak & Noll, 2015; Zebrack & Isaacson, 2012) and caregivers (e.g., Northouse, Williams, Given, & McCorkle, 2012). Owing to page limitations, we address the experience of survivorship for adults treated with curative intent rather than those who receive solely palliative treatment and those nearing the end of life.

Importance of Empirical and Clinical Attention to Posttreatment Survivors

The Growing Population of Cancer Survivors

Approximately 14.5 million individuals in the United States and more than 28 million worldwide are living with a cancer diagnosis (American Cancer Society, 2012; de Moor et al., 2013; Edwards et al., 2014; IOM, 2013; DeSantis et al., 2014; Stewart & Wild, 2014). Women with breast cancer and men with prostate cancer comprise the two largest survivor groups, owing to the relatively high incidence and favorable prognosis of those cancers. In the United States, more than 50% of cancer diagnoses and deaths occur in adults 65 years of age or older—the age group that also constitutes the majority of cancer survivors. Consequently, cancer often is experienced in

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Authors' note. Annette L. Stanton, Department of Psychology, University of California, Los Angeles; Julia H. Rowland, National Cancer Institute, Bethesda; Patricia A. Ganz, Fielding School of Public Health and David Geffen School of Medicine, University of California, Los Angeles.

Correspondence concerning this article should be addressed to Annette L. Stanton, Department of Psychology, 1285 Franz Hall, Box 951563, University of California, Los Angeles, Los Angeles, CA 90095-1563. E-mail: astanton@ucla.edu



Annette L. Stanton

the setting of other comorbid conditions (Edwards et al., 2014; IOM, 2013).

As displayed in Figure 1, a 37% rise in the U.S. population living for 5 or more years with a cancer diagnosis is expected over the next decade (i.e., 2012 to 2022). Prolonged survival is attributable, in part, to improvements in early detection and combined modality treatments (de Moor et al., 2013). An IOM (2013) panel recently concluded that, along with other factors, the increase in the survivor population has produced a crisis in care delivery. Because many modern cancer treatments result in side effects that must be managed after treatment completion, growing evidence indicates that care should extend into long-term survivorship. These include persistent effects, such as fatigue, which develop during treatment and can continue for months or years (i.e., long-term effects; Feuerstein & Ganz, 2011). Cancer survivors also are at risk for previously unrecognized toxicities that emerge after treatment completion (i.e., late effects). Most worrisome among these are second cancers; other late effects can include thyroid dysfunction and problems with bone or cardiac health (see Ganz, Earle, & Goodwin, 2012, and Mariotto, Rowland, Ries, Scoppa, & Feuer, 2007). Researchers and clinicians in health psychology and other disciplines are contributing to our understanding of the psychosocial sequelae that affect the large and growing population of cancer survivors—information that will be essential to providing evidence-based mental health services (IOM, 2013).

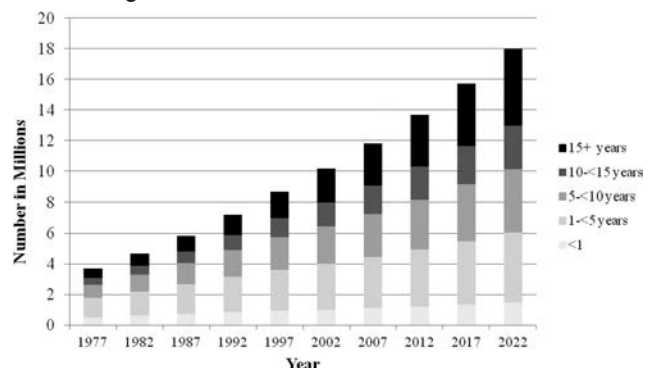
The Need for Attention to Psychosocial Sequelae in Cancer Survivors

The diagnosis and treatment of cancer provokes psychosocial disruption, such that symptoms of depression and

anxiety are elevated in samples of cancer patients undergoing diagnosis and treatment compared with normative populations (see Jacobsen & Andrykowski, 2015). Large prospective studies provide a portrait of adjustment across the years after cancer diagnosis (C. H. Kroenke et al., 2004; Michael, Kawachi, Berkman, Holmes, & Colditz, 2000; Polsky et al., 2005; Reeve et al., 2009). In such research, study entry occurs prior to disease diagnosis, and participants subsequently diagnosed with cancer are compared over time with those with no incident disease. An example is the Nurses' Health Study cohort of 48,892 women, of whom 759 women were diagnosed with breast cancer over a 4-year period (Michael et al., 2000).

This small body of research allows four preliminary conclusions. First, *on average*, adults diagnosed with cancer evidence compromise in physical and psychological health, primarily indicated through standard quality-of-life measures, relative to those not diagnosed. Second, psychosocial and physical health indices improve over time within the diagnosed group (Michael et al., 2000; Polsky et al., 2005). Third, significant between-group differences in impairment can persist through 2 to more than 5 years after diagnosis (Michael et al., 2000; Reeve et al., 2009). Fourth, particular subsets of survivors, such as adults who are younger, socially isolated, or who have specific cancers, are at risk for more pronounced or enduring decrements in psychological health (C. H. Kroenke et al., 2004; Michael et al., 2000; Reeve et al., 2009). Given the anticipated rapid expansion of the survivor population, it is important to characterize and address specific psychosocial and physical sequelae, as well as their risk and protective factors, experienced by cancer survivors beyond treatment completion.

Figure 1
Estimated and Projected Number of Cancer Survivors in the United States from 1977 to 2022 by Years Since Diagnosis



Note. Reprinted from de Moor et al. (2013). Copyright 2013 by the American Association for Cancer Research.

Julia H. Rowland



What Happens When Cancer Treatments Are Complete?

Conceptualizing Periods of Cancer Survivorship

In addition to prevention, diagnosis, and treatment phases, the NCI designates survivorship as a distinct phase of the cancer control continuum. Evidence that particular psychosocial and behavioral experiences are more pronounced in

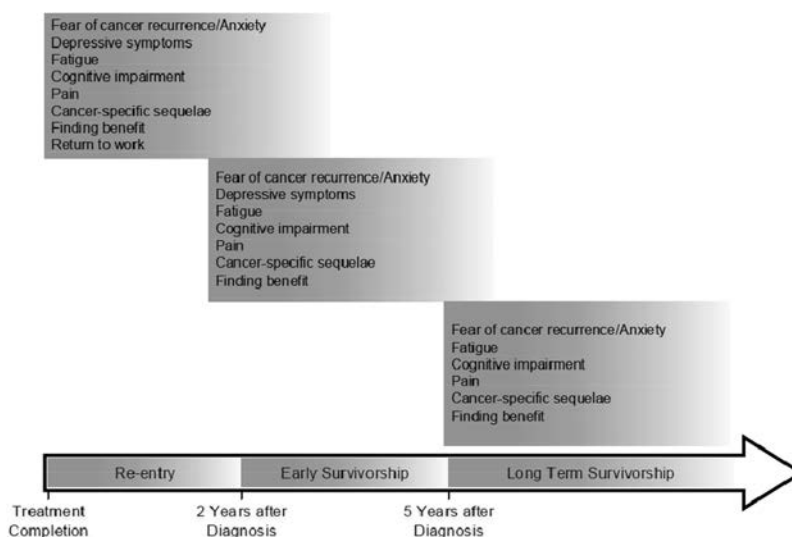
some periods of survivorship than others leads us to propose three periods within the survivorship phase: reentry, early survivorship, and long-term survivorship. Figure 2 displays these periods and several experiences relevant to each. Although distinct periods of survivorship have some precedent in the literature (e.g., Gotay & Muraoka, 1998; Mullan, 1985), our conceptualization includes no sharp boundaries between periods, but rather fluidity in transition from one period to the next. Meant as a heuristic for considering variation along what can be a long course of survivorship, Figure 2 includes experiences commonly documented in a proportion of cancer survivors during each period. Important caveats are that some sequelae are experienced by a minority of survivors, and additional longitudinal research is needed to specify their trajectories.

The Reentry Period

The reentry period (Mullan, 1985), wherein one makes the psychosocial transition from “cancer patient” to “person with a history of cancer,” typically spans the point from completion of major cancer treatments, which can vary from a few weeks to more than 1 year, through the next several months. Health care professionals often do little to prepare patients for the reentry period, which can contribute to cancer survivors and intimate others holding unrealistically lofty expectations for rapid recovery (IOM, 2006; Janz et al., 2008; Marcus et al., 2002) and being surprised by their feelings as treatment ends. As physician Elizabeth McKinley (2000) wrote, “I thought I would feel happy about finally reaching the end of treatment, but instead, I was sobbing . . . Instead of joyous, I felt lonely, abandoned, and terrified. This was the rocky beginning of cancer survivorship for me” (p. 479).

Figure 2

Hypothesized Periods of Cancer Survivorship and Associated Sequelae: An Evolving Heuristic Model



Patricia A. Ganz



As described in clinical accounts and research reports, the months after treatment typically involve loss of the safety net of active treatment and the accompanying supportive milieu offered by frequent visits to health care providers, resumption or alteration of former roles within and outside the home, a decline in social support, and experience of lingering or emerging physical and psychological effects of diagnosis and treatment (e.g., IOM, 2006; Stanton, 2012; Talcott et al., 2003). During reentry, survivors also may strive to make sense of the disease and its ultimate impact. Research on psychological trajectories suggests that some survivors experience an increase in psychological distress following the completion of medical treatment (15% of 171 breast cancer survivors in Henselmans et al., 2010).

The boundaries of the reentry period are variable; we suggest that reentry can span more than 1 year after medical treatment completion, depending on the length and intensity of treatment as well as other contextual factors. The reentry period might be truncated when only brief, local treatment is used (i.e., no chemotherapy or biotherapies following surgery or radiation). Reentry can be prolonged and more challenging when treatment is onerous or the cancer experience prompts a profound shift in core beliefs, activities, or relationships. When cancer is diagnosed in young adulthood, for example, survivors often face unique demands at reentry. Cancer can represent an abrupt transition into the responsible world of adulthood, while also necessitating at least temporary dependence on parents and others for support. The classic tasks of this developmental period—creating intimacy, establishing a niche in society, starting families, and building careers (Erickson, 1968)—can be uniquely jeopardized by life-threatening illness. Issues related to childbearing

and fertility preservation can compound the complexity of treatment decisions (Lee et al., 2006) and present challenges after treatment. Although fertility preservation is often discussed along with treatment decisions (Forman, Anders, & Behera, 2010), some survivors become aware of these issues only as they begin to consider childbearing.

The Early Survivorship Period

As shown in Figure 2, the early survivorship period extends from several months after diagnosis to approximately five years after diagnosis. Treatment-related acute physical morbidities have subsided for the majority of survivors by this time, and most survivors have resolved the cancer experience psychologically. Certainly, psychosocial and physical sequelae can persist or periodically arise for some survivors, however. For example, cancer surveillance appointments can prompt marked fear of cancer recurrence. As coined by Andersen and colleagues (Andersen, Anderson, & deProse, 1989), cancer survivors often experience “islands” of psychosocial disruption after they have recovered from primary treatments.

The Long-Term Survivorship Period

Long-term survivorship characterizes the experience beyond 5 years after diagnosis (e.g., Gotay & Muraoka, 1998), by which time many survivors can expect to attain normative values on standard measures of health-related quality of life (Bloom, Petersen, & Kang, 2007; Foster, Wright, Hill, Hopkinson, & Roffe, 2009; Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2005). Just as the 5-year postdiagnosis marker in oncology does not guarantee that cancer will not recur, however, a 5-year marker for long-term survivorship does not imply that psychological or physical recovery is complete. Even many years after cancer diagnosis, long-term treatment toxicities can carry physical and psychological effects (Burkett & Cleeland, 2007; Foster et al., 2009; Mols et al., 2005; Syrjala, Martin, & Lee, 2012; Weaver et al., 2012).

A population-based longitudinal study in 1,288 prostate cancer patients beginning 6 to 12 months after diagnosis through 5 years provides an example of how specific sequelae of cancer treatments can persist in a subset of survivors (Penson et al., 2005). The majority of men reported no significant problems or declining urinary and sexual problems from 6 months to 5 years after diagnosis. However, incontinence was present in 10% of men at 2 years, and in 14% at 5 years, as were erectile problems in 22% and 28% of men at those assessment points (see also Gore, Kwan, Lee, Reiter, & Litwin, 2009, for a prospective study).

Research on nationally representative samples also suggests that poorer health status and activity limitations (Yabroff et al., 2007), as well as higher medical expenditures and indirect morbidity costs (e.g., lost productivity; Guy et al., 2013), characterize cancer survivors years after diagnosis, relative to those with no cancer diagnosis. Long-term psychological effects may also persist for a minority

(e.g., Weaver et al., 2012). Although there is little evidence for a psychological parallel for late physical effects of cancer treatment, medical conditions such as late-emerging cardiac problems or second cancers can carry psychosocial impact.

Prominent Psychosocial Experiences Across Periods of Cancer Survivorship

In this section, we describe prominent cancer-related psychosocial and behavioral sequelae and experiences during posttreatment survivorship. We briefly summarize what is known about their prevalence and course across the proposed posttreatment periods, as well as longitudinal predictors of each. It should be noted that the largest body of research addressed in this section is conducted with survivors of breast cancer, and that most researchers do not conduct analyses based on landmarks in medical treatment (i.e., treatment completion), but rather examine the variable of months or years since cancer diagnosis; therefore, our descriptions pertaining to the specific periods of survivorship are approximate.

Anxiety and Fear of Cancer Recurrence

Worry that cancer may return after treatment is among the most commonly experienced psychological sequelae (Koch, Jansen, Brenner, & Arndt, 2013; Mehnert, Berg, Henrich, & Herschbach, 2009; note that a clinical cutoff has not been widely adopted). Healthcare professionals see it as challenging to manage (Thewes et al., 2014). Higher fear of recurrence is related to survivors' higher use of healthcare services (Lebel, Tomei, Feldstain, Beattie, & McCallum, 2013), as well as poorer quality of life in survivors and their caregivers (Kim, Carver, Spillers, Love-Ghaffari, & Kaw, 2012).

In a review, Koch et al. (2013) found that most long-term survivors experience modest to moderate levels of fear of recurrence. It can be exacerbated or reactivated by a number of triggers (Ghazali et al., 2013), such as follow-up medical visits, symptoms that mimic illness (e.g., pain that may be attributed to disease spread), death of a public figure from cancer, or a family member's illness (Gill et al., 2004). Heightened fear of recurrence is reported by adult survivors of younger age, with lower educational level, with fewer significant others, and with Hispanic or White/Caucasian race/ethnicity (Crist & Grunfeld, 2013; Mehnert, Koch, Sundermann, & Dinkel, 2013; Phillips et al., 2013). Lower optimism and social support, family stressors, and depressive symptoms, pain, and other physical symptoms also are linked to higher fear (Crist & Grunfeld, 2013; Mehnert et al., 2013; Phillips et al., 2013).

Cancer-related posttraumatic stress disorder (PTSD), assessed via validated interview or questionnaire, is typically found to occur in less than 10% of cancer survivors after treatment completion, and has been found to decrease over time (e.g., Kangas, Henry, & Bryant, 2002). Those at most risk tend to be younger, have more serious disease and aggressive therapy (such as stem cell transplant), and

be more likely to have experienced PTSD previously (e.g., French-Rosas, Moye, & Naik, 2011; O'Connor, Christensen, Jensen, Møller, & Zachariae, 2011). Symptoms of subthreshold PTSD, however, such as intrusive thoughts, reexperiencing of cancer-related events, and avoidance of reminders of cancer are fairly common among survivors in the 2 years after diagnosis. For example, in a nationwide inception cohort of Danish women receiving surgery for breast cancer, 20.1% and 14.3% reported severe posttraumatic stress symptoms at 3 and 15 months after surgery, respectively (O'Connor et al., 2011; see also Posluszny, Edwards, Dew, & Baum, 2011). In a longitudinal sample of non-Hodgkin lymphoma survivors, over one third experienced continued or worsening PTSD symptoms 7 years after diagnosis (Smith et al., 2011). Lower income and self-reported negative impact of cancer were independent predictors of PTSD symptoms. It is unknown whether cancer-related PTSD is related to physical morbidity and adverse health behaviors (e.g., alcohol use, nonadherence to treatment), as observed in other populations (Buckley, Mozley, Bedard, Dewulf, & Grief, 2004).

Depressive Symptoms

A meta-analysis of 66 studies of interview-diagnosed major depression in cancer survivors in nonpalliative care settings revealed a 16.3% prevalence of major depression (95% confidence interval [13.4, 19.5]; Mitchell et al., 2011). Prevalence ranged widely from 1% to 77.5% in single studies. The risk of depression over time could not be examined reliably in that meta-analysis; when the pool of studies was expanded to include questionnaire assessments of depression in cancer survivors versus healthy controls, findings demonstrated that the relative risk (RR) for depression is significantly higher within the 2 years after diagnosis (RR = 2.19) compared with 2 to 10 years (RR = 1.26) and more than 10 years (RR = 1.05) after diagnosis (Mitchell, Ferguson, Gill, Paul, & Symonds, 2013). At a mean of 7 years after diagnosis, cancer survivors evidenced an 11.6% rate of depression—a nonsignificant difference from the 10.2% rate in healthy controls. A similar meta-analysis also demonstrated that prevalence of depression is highest during treatment relative to the first year after diagnosis and beyond (Krebbert et al., 2014). Most studies suggest that the risk for depression relative to normative comparison groups is no longer significant during long-term survivorship (e.g., Harrison et al., 2011; Polsky et al., 2005; Rossen, Pedersen, Zachariae, & von der Maase, 2009), although risk for hospitalization for depression may remain elevated through 10 years after diagnosis (Dalton, Laursen, Ross, Mortensen, & Johansen, 2009).

Depression is painful in itself, can delay return to work (Steiner et al., 2008), and is associated with lower adherence to medical regimens (DiMatteo, Lepper, & Croghan, 2000) in cancer survivors. Depression also may confer risk for mortality in cancer (e.g., Cuijpers et al., 2014; Mols, Husson, Roukema, & van de Poll-Franse, 2013; Vodermaier et al., 2014), a relationship for which plausible biological mediators exist (Antoni et al., 2006). Evidence suggests that the risk of suicide is also elevated in

cancer survivors in the years after diagnosis compared with the general population (e.g., Fang et al., 2012; Misono, Weiss, Fann, Redman, & Yueh, 2008). Such severe consequences render it essential to identify risk and protective factors, as well as to test interventions for depression in cancer survivors.

Although addressed in relatively few longitudinal studies, several risk factors for high or increasing depressive symptoms in the reentry and early survivorship periods have empirical support. Adults with more advanced cancer, and those who receive chemotherapy and have more physical symptoms, are more at risk for depressive symptoms (e.g., Avis et al., 2013; Dunn et al., 2013). Intrapersonal risk factors include relatively young adult age and higher engagement in coping through avoidance of cancer-related thoughts and feelings (e.g., Avis et al., 2013; Dunn et al., 2013). Interpersonal risk factors for elevated depressive symptoms into survivorship include loneliness (also a predictor of pain and fatigue, as well as the symptom cluster; Jaremka et al., 2013), familial and marital conflict (Oh, Ell, & Subica, 2014), and low social support (Avis et al., 2013; Dunn et al., 2013).

Fatigue

As defined by the National Comprehensive Cancer Network (2014), cancer-related fatigue is “a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning” (p. FT-1). A review found a prevalence of fatigue ranging from 4% to over 90%, depending on the population studied (Lawrence, Kulpnick, Miller, Devine, & Lau, 2004). In the majority of studies, 30% to 60% of patients report moderate to severe fatigue during treatment, which gradually abates during the reentry and early survivorship periods (Bower, 2014).

Although fatigue is most prevalent during active treatment, of concern for survivors is the persistence of marked posttreatment fatigue, when exposure to medical therapies can no longer explain the experience. Cella, Davis, Breitbart, and Curt (2001) proposed diagnostic criteria for this entity, and research on conceptualization and measurement continues (see Barsevick et al., 2013; Donovan, McGinty, & Jacobsen, 2013). Research suggests that approximately 25% to 33% experience persistent fatigue through 10 years after cancer diagnosis (Bower, 2014). For example, in a cohort of 1,957 breast cancer survivors between 1 and 5 years after diagnosis, 35% had fatigue in the higher than normal range (Bower et al., 2000). Furthermore, in subsequent evaluation 5 years later, fatigue persisted in 21% of the sample, and overall, 34% reported fatigue 5 to 10 years after diagnosis (Bower et al., 2006). In a sample of 652 non-Hodgkin lymphoma (NHL) survivors, more than 10 years after diagnosis, the average SF-36 Vitality score was more than half a standard deviation below the age-matched mean (Crespi, Smith, Petersen, Zimmerman, & Ganz, 2010). A follow-up study of the same NHL survivor cohort 5 years later demonstrated a further, significant decline in vitality (Smith et al., 2013).

Research is shedding light on the etiology of persistent cancer-related fatigue (see Bower, 2014; Jacobsen & Andrykowski, 2015). Fatigue assessed prior to the onset of cancer treatments predicts fatigue after treatment completion, suggesting that some vulnerability for persistent cancer-related fatigue exists prior to the cancer diagnosis. A developing body of research suggests that fatigue is associated with inflammatory processes, as well as dysregulation of the hypothalamic-pituitary-adrenal axis and autonomic nervous system. Risk factors for persistent fatigue also include a history of psychological disorder and elevated depressive symptoms and anxiety in the acute diagnostic and treatment phase, elevated body mass (and perhaps physical inactivity), the tendency to “catastrophize” (i.e., engage in negative thoughts and self-statements about fatigue), loneliness, and early life adversity (Bower, 2014).

Cognitive Impairment

Increasingly, cancer survivors are complaining of cognitive changes, including problems in memory, attention, concentration, and executive function, which may begin during cancer treatments but become more apparent in the reentry period when survivors return to employment and other activities (e.g., childcare). Data from the National Health and Nutrition Examination Survey identified 40% higher endorsement of an item regarding memory problems among adults with a history of cancer relative to those with no cancer history, with demographic and health status variables controlled statistically (Jean-Pierre et al., 2012).

A review of 21 longitudinal studies including neuropsychological assessments administered prior to and after medical treatment suggests an incidence of cognitive problems in the reentry and early survivorship periods of 15% to 25%, with a range as high as 61% (Ahles, Root, & Ryan, 2012). Neuropsychological test performance decrements are usually small (Hodgson, Hutchinson, Wilson, & Nettelbeck, 2013; Jim et al., 2012), but can be substantial among individuals treated with whole brain irradiation. Nonhuman animal studies and brain imaging research showing structural and metabolic changes are consistent with cognitive changes that accompany chemotherapy (Ahles et al., 2012; Pomykala, de Ruiter, Deprez, McDonald, & Silverman, 2013; Reuter-Lorenz & Cimpich, 2013).

One of the challenges in this research area is that among survivors studied, many have high IQ and educational attainment, such that their neuropsychological test performance is above average and demonstrates only modest change over time (Jim et al., 2012). Often, studies do not show a decline in performance with treatment, but rather a failure to improve with practice (Ahles et al., 2010). It should be noted that the majority of research in this area spans only the reentry and early survivorship periods and has been conducted in younger women with breast cancer, although research with other groups also documents cognitive problems (e.g., Wefel et al., 2014). The few studies of long-term survivors suggest evidence of cognitive problems relative to matched adults with no cancer history (Ahles et al., 2012).

The etiology of cancer-related cognitive impairment is multifactorial. Systemic proinflammatory cytokines that cross the blood–brain barrier, as well as direct treatment toxicities, are implicated (Ahles & Saykin, 2007). Although cognitive problems were initially attributed to chemotherapy, impairment can occur with other cancer treatments, including endocrine therapy and biotherapies, and some studies document cognitive performance that is lower than expected in 20% to 30% of patients, even prior to chemotherapy (Ahles et al., 2012). Thus, a more accurate term to describe the cognitive changes that survivors experience is *cancer and cancer-treatment-associated cognitive change* (Hurria, Somlo, & Ahles, 2007). Risk factors for cognitive problems after cancer treatment include older age and having lower cognitive reserve (i.e., lower education or IQ), which contributes to the hypothesis that cancer treatments accelerate the aging process (Ahles et al., 2012).

Pain

In an analysis of data from the 2002 National Health Interview Survey, Mao et al. (2007) found that 34% of cancer survivors reported pain, a substantially higher rate than that of the general population comparison group without a cancer history (18%). Survivors reported pain more frequently than insomnia and depressed/anxious mood. Pain was more often reported by cancer survivors who were younger than 50 years, who were women, or who had more comorbid diseases or a history of multiple cancers. Pain reports did not vary by time elapsed since cancer diagnosis (<2 years vs. >2 years after diagnosis).

Patient groups with the highest prevalence of persistent pain include those who have received thoracotomy (up to 80%), amputation of a limb (50 to 80%), radical neck dissection (52%), or breast cancer surgery (63%; see Davies, 2013, for review). The local effects of surgery, combined with radiation therapy, may exacerbate the pain and lead to long-term tissue fibrosis and nerve entrapment, which may cause late-occurring pain in some cancer survivors. In addition, lymphedema, which results from surgical and radiation therapy involving lymph nodes, may occur years after a cancer diagnosis (Paskett, Dean, Oliveri, & Harrop, 2012). It is a common source of pain for breast cancer survivors and those who have had pelvic surgery (e.g., 21.4% overall incidence of arm lymphedema after breast cancer surgery in prospective cohort studies, with increasing incidence up to 2 years; DiSipio, Rye, Newman, & Hayes, 2013).

Chronic pain can also result from chemotherapy and endocrine therapies. Several chemotherapy drugs (e.g., taxanes, vinca alkaloids, platinum compounds, thalidomide) are responsible for neuropathic pain (numbness, tingling) as a dose-limiting toxicity (Farquhar-Smith, 2011). For some drugs, the pain resolves once treatment ends, but some survivors can have pain for years (Henry, Giles, & Stearns, 2008). Musculoskeletal pain and arthralgias are commonly associated with aromatase inhibitors, which may be given for 5 or more years to women with breast cancer. The etiology of this pain is uncertain but is likely related to low estrogen. Chronic steroid use is responsible

for accelerated osteoporosis and fracture, along with avascular necrosis in some survivors. These conditions can cause late-emerging pain syndromes.

The cause of cancer-related pain can be attributed, for the most part, to surgery, radiation, chemotherapy, and endocrine therapies—singly or in combination. There is an acute phase that occurs with initial therapy, and then a decrease over time, with exceptions being related to late effects (fracture, fibrosis syndromes). Predictors of cancer pain also include self-efficacy for managing pain, distress and catastrophizing, and caregivers' response to the pain (Porter & Keefe, 2011).

Sexual and Urinary/Bowel Problems

Sexual and urinary/bowel problems are common cancer-related side effects, in particular among survivors of gastrointestinal, urologic, and gynecologic malignancies (e.g., Den Ouden et al., 2012; Taylor et al., 2012). Depending on the population examined, the timing of assessments, and the measures used, the prevalence of sexual complaints range from 30% to 100% of breast cancer survivors, for example (Desimone et al., 2014; Sadovsky et al., 2010). Unlike other areas of function that tend to improve with time away from treatment, sexual problems tend to get worse over time, not better (Rowland et al., 2009). Disruptions in key functional pathways can contribute to sexual problems. For example, adverse sexual effects in breast cancer may be secondary to body image disruption and the effects of premature menopause, as well as the direct consequence of systemic treatments, such as hot flashes or pain (Kwan & Chlebowski, 2009).

Frequency of bladder and bowel problems varies widely, depending largely on the type of cancer and treatment. For example, of men who had prostatectomy or radiation therapy for prostate cancer, 9% and 18%, respectively, reported incontinence at 15 years after treatment, whereas 22% and 36% reported bowel urgency (Resnick et al., 2013). Up to 60% of women treated for rectal cancer experienced ongoing fecal and urinary incontinence concerns in the early months to years after treatment (Panjari et al., 2012).

Finding Benefit in the Experience of Cancer

Most survivors of various cancers report finding benefit in the experience (also studied as “posttraumatic growth,” Tedeschi & Calhoun, 1996). Approximately 50% to more than 80% of posttreatment survivors report positive changes (Stanton, Bower, & Low, 2006). On questionnaires assessing retrospective reports of growth in several life domains (e.g., Posttraumatic Growth Inventory; Tedeschi & Calhoun, 1996), cancer survivors, on average, report a small to moderate degree of positive change (see Jim & Jacobsen, 2008; Sawyer, Ayers, & Field, 2010; Stanton et al., 2006, for reviews). Key domains of self-reported benefit include strengthened interpersonal relationships, commitment to life priorities, life appreciation, personal regard, spirituality, and attention to health behaviors. Longitudinal research suggests that finding benefit increases from the diagnostic and treatment phase through the reentry and

early survivorship periods (e.g., Danhauer et al., 2013; Manne et al., 2004). Long-term survivors also report deriving benefit (e.g., Jansen, Hoffmeister, Chang-Claude, Brenner, & Arndt, 2011; Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2009), although there is some indication that finding benefit decreases in the long term (Bower et al., 2005).

Most studies of cancer survivors involve retrospective reports of positive change as a result of the stressful experience, which raises questions regarding their accuracy (Tennen & Affleck, 2009). In addition, distinct motivations might underlie reports of benefit (e.g., Zoellner & Maercker, 2006), including both a motive to avoid cancer-related threats through wishful thinking and a motive to approach the stressor actively through pursuing positive changes. Such measurement issues might account, in part, for the many mixed findings regarding predictors and consequences of benefit finding. Longitudinal research suggests, however, that greater impact of cancer, in the form of higher perceived threat and life disruption, promotes benefit finding, as does active engagement in the experience of cancer, as indicated by more problem-focused coping and intentional positive reappraisal of the experience, for example (e.g., Danhauer et al., 2013; Llewellyn et al., 2013; Sears, Stanton, & Danoff-Burg, 2003). Contextual factors, including social support, also predict benefit finding in survivors (e.g., Schroevers, Helgeson, Sanderman, & Ranchor, 2010).

Does finding benefit predict positive adjustment (see Algoe & Stanton, 2009; Helgeson, Reynolds, & Tomich, 2006; Sawyer et al., 2010)? Although null findings exist, longitudinal and experimental research demonstrates that benefit finding can predict improved psychological adjustment, which can persist into reentry and long-term survivorship (e.g., Bower et al., 2005; Carver & Antoni, 2004; Rinaldis, Pakenham, & Lynch, 2010; Stanton et al., 2002).

Return to Work

Today's frequent use of more limited (tissue-sparing) surgeries and targeted radiation and drug therapies, coupled with better symptom management than in prior decades, means that most adults can continue to work after cancer. In an interview study of 1,433 cancer survivors 1 to 5 years after diagnosis, 39% of women and 41% of men stopped work during cancer treatments, and the projected rate of return to work at 4 years was 84%, with the large majority returning during the reentry period in the first year after diagnosis (Short, Vasey, & Tunceli, 2005). Although most survivors return to employment, changes in work are not unusual. In the Short et al. study, 21% of women and 16% of men who were employed at diagnosis reported cancer-related limitations in the ability to work. In one cancer-registry-based study, 57% of survivors had reduced their work over the 2 years following diagnosis by more than 4 hr per week, and 56% reported some change in role (Steiner et al., 2008). Cancer-related sequelae, such as depression, cognitive impairment, fatigue, and mobility problems, can interfere with work (Duijts et al., 2014). Predictors of lower likelihood of returning to work and limitations at work include having more invasive treatments, older age,

lower socioeconomic status, and a physically demanding job (Earle et al., 2010; van Muijen et al., 2013).

Because the majority of Americans derive medical benefits from the workplace, unemployment and underemployment diminishes vital coverage for health care. Psychosocial benefits of continued working can be mixed. On the one hand, employment can provide survivors with a source of self-esteem, meaning, social support, and distraction from illness. On the other hand, work demands may become a source of stress. Population-based studies reveal that lost work productivity is a burden for cancer survivors throughout the trajectory (e.g., Torp, Nielsen, Fosså, Gudbergsson, & Dahl, 2013; Yabroff, Lawrence, Clauser, Davis, & Brown, 2004).

Summary

Psychological and physical adjustment after medical treatment often is positive and can include finding benefit in the cancer experience. However, adults with cancer and their loved ones often are ill-prepared for the exigencies of the reentry period, particularly when complicated by symptoms of depression and anxiety, fatigue, cognitive problems, pain, or other posttreatment challenges. It is important to note that some cancer-related sequelae tend to co-occur, prompting research on symptom clusters such as depression, fatigue, and pain (Jaremka et al., 2013; Reyes-Gibby, Aday, Anderson, Mendoza, & Cleeland, 2006). Although some evidence suggests that the experience of sleep disturbance and fatigue may precede the onset of depressive symptoms and pain in the reentry and early survivorship periods (Irwin, Olmstead, Ganz, & Haque, 2013; Trudel-Fitzgerald, Savard, & Ivers, 2013), other research has not established temporal precedence (Krebbler et al., 2014).

In most cases, research suggests that problems improve or resolve during the reentry and early survivorship periods, although a minority of survivors appears at risk for long-term untoward effects. Although contributors vary as a function of the specific outcome examined, general predictors include more aggressive medical treatment, personal factors such as younger adult age, high use of avoidance-oriented coping and low use of approach-oriented coping, and aspects of the interpersonal context, such as loneliness and low social support.

Psychosocial and Behavioral Interventions After Cancer Treatments

Survivorship Care Planning and the Place of Psychology

The IOM (2006) *Lost in Transition* report called for the development of a survivorship care plan for patients completing curative-intent treatment. The proposed plan was intended to be comprehensive, including attention to the physical and psychosocial needs of the patient, as well as information about the time course of recovery and potential late effects of treatment. Ideally, the care planning process includes written documentation of treatments received; plans for follow-up care and cancer surveillance; and assessment of, and plans for, addressing the survivor's phys-

ical and psychosocial needs. The plan is to be completed by the treating oncologist and team, and is presented as part of an educational and forward-looking consultation.

A subsequent IOM (2008) report on the psychosocial needs of cancer survivors provides detail on the wealth of psychosocial resources, the lack of attention to those needs, and the failure to provide referrals for and to use effective resources. The report emphasized the need for effective patient-provider communication as a prelude to psychosocial needs identification. Training oncology professionals in communication skills holds promise for bolstering the effectiveness of the patient-provider relationship (e.g., Kissane et al., 2012).

Who on the cancer care team should conduct psychosocial assessments and referrals? Some treating oncologists may have these competencies, but this will more likely be taken up by psychologists, nurses, or social workers on the oncology team. Use of brief self-report instruments (Andersen et al., 2014; Basch et al., 2012; K. Kroenke, Spitzer, Williams, & Löwe, 2010; Mitchell, 2010) can provide efficient assessment and offer a valuable research database. Although timing of assessment during active therapy is well delineated, it is less clear how often assessment after treatment is useful. At minimum, assessment is needed as survivors make the reentry transition. Because long-term and late effects are possible, assessment should likely be repeated at regularly scheduled oncology appointments through at least the year after treatment.

Evidence-Based Psychosocial Intervention at Treatment Completion and Beyond

Although much less numerous than trials performed during cancer treatments, randomized controlled trials (RCTs) of psychosocial and behavioral interventions conducted during reentry and survivorship periods demonstrate efficacy. Interventions include cognitive-behavioral therapy and stress management techniques such as relaxation and mindfulness (e.g., Espie et al., 2008; Mann et al., 2012; Penedo et al., 2006; Piet, Würtzen, & Zachariae, 2012), psychoeducational approaches (e.g., Dolbeault et al., 2009; Marcus et al., 2010; Meneses et al., 2007; Scheier et al., 2005; Stanton et al., 2005), and other methods such as written or verbal emotional expression and processing regarding the cancer experience (Carmack, Basen-Engquist, Yuan, et al., 2011; Stanton et al., 2002). Some interventions specifically address the challenges of the reentry period, whereas others are designed to promote psychological adjustment during survivorship more broadly or to reduce specific cancer-related sequelae.

The small body of RCTs focused on the reentry transition and conducted shortly after treatment completion most often includes psychoeducation regarding what to expect during reentry, and cognitive and behavioral strategies for actively addressing those challenges. In general, findings demonstrate accelerated improvement in the intervention group, compared with the control condition, on such outcomes as depressive symptoms and negative mood (Dolbeault et al., 2009; Marcus et al., 2010), fatigue (Dolbeault et al., 2009; Stanton et al., 2005), sexual dysfunction (Marcus et al., 2010), quality of life (Meneses et al., 2007),

and cancer-related benefit finding (Marcus et al., 2010). All conducted with breast cancer survivors, most interventions evidenced positive effects 1 to 6 months later (Dolbeault et al., 2009; Meneses et al., 2007; Stanton et al., 2005), and some positive effects persisted through 18 months (Marcus et al., 2010). Few controlled trials of interventions to promote return to work during reentry are available (Hoving, Broekhuizen, & Frings-Dresen, 2009), although multidisciplinary approaches (e.g., physical exercise, education, counseling) show promise (de Boer et al., 2011).

Another small group of RCTs addresses psychological adjustment during survivorship more broadly. Relative to control conditions, group cognitive-behavioral stress management increased quality of life and cancer-related benefit finding in men after prostate cancer treatment (Penedo et al., 2006), and a psychoeducation or nutrition education intervention improved depressive symptoms and quality of life related to physical functioning in young breast cancer survivors (Scheier et al., 2005). RCTs that involve promotion of processing and expression of cancer-related feelings and thoughts also suggest benefits for psychological and physical health in colorectal and breast cancer survivors (Carmack, Basen-Engquist, Yuan, et al., 2011; Stanton et al., 2002), and mindfulness-based therapy reduces anxiety and depressive symptoms in cancer survivors relative to wait-list or standard-care control groups (see Piet et al., 2012, for a review).

Several interventions target particular symptoms experienced across posttreatment survivorship periods, such as fatigue, insomnia, and pain. This focus on targeted outcomes is warranted in light of the evidence that specific problems can persist in the context of otherwise positive psychological adjustment. A strength of such interventions is that eligibility is often limited to cancer survivors who meet a threshold for relatively poor function on the targeted outcome, unlike the large majority of psychosocial RCTs conducted during medical treatment, which are often open to all-comers. Effect sizes for interventions are substantially larger when cancer survivors are selected on the basis of a threshold on the outcome variable than when participants are included regardless of their baseline standing (Faller et al., 2013).

Fatigue is a frequently targeted outcome in posttreatment RCTs. Reviewing psychological RCTs conducted after medical treatment, Bower (2014) concluded that the provision of psychoeducation and cognitive-behavioral strategies can reduce fatigue, as can other approaches, such as mindfulness-based cognitive therapy and yoga. A meta-analysis of RCTs conducted after cancer treatment also revealed aerobic exercise to be effective in the reduction of cancer-related fatigue, with a moderate effect size (e.g., Puetz & Herring, 2012). Other specific conditions for which cognitive-behavioral, psychoeducational, and other interventions demonstrate efficacy include uncertainty or fear of recurrence and posttraumatic stress symptoms (Butow et al., 2013; DuHamel et al., 2010; Germino et al., 2013; Gill et al., 2006), depression (Hopko et al., 2011, 2013), cognitive problems (Ercoli et al., 2013; Ferguson et al., 2012), pain (Johannsen, Farver, Beck, & Zachariae, 2014), sexual problems (Dizon, Suzin, & McIlvenna, 2014; Steinke, 2013), and menopausal symptoms (Ganz et al., 2000; Mann et al., 2012).

Evidence-Based Health Promotion During Long-Term Survivorship

Ongoing follow-up care during cancer survivorship offers opportunities to enhance prevention and health promotion efforts. Cancer survivors report that the medical team is unlikely to discuss physical activity, smoking, or diet (e.g., Demark-Wahnefried, Pinto, & Gritz, 2006). RCTs suggest that health promotion in these domains after cancer treatment can be effective. With regard to physical activity, for example, a review of 40 RCTs (Speck, Courneya, Mâsse, Duval, & Schmitz, 2010), 86% of which targeted women with breast cancer, established the efficacy of physical activity interventions initiated after cancer treatment across several outcomes, including bodily strength, aerobic fitness, overall quality of life, fatigue, and other cancer-specific problems (an additional 26 trials were conducted during cancer treatment). Although most were supervised programs, more accessible programs—including home-based activity or print materials combined with pedometer provision—can also generate positive effects (e.g., Stevinson et al., 2009; Vallance, Courneya, Plotnikoff, Yasui, & Mackey, 2007). Though currently limited to observational studies in which reciprocal relationships are likely, data suggest that remaining physically active after cancer may not only improve health and quality of life but also prolong survival (Meyerhardt et al., 2009). Recent guidelines from the American College of Sports Medicine (Schmitz et al., 2010) are helpful in encouraging general physicians and oncology team members to advise their patients on regular exercise and diet-related issues (see Carmack, Basen-Engquist, & Gritz, 2011, Ligibel, 2012, and Pekmezi & Demark-Wahnefried, 2011, for reviews on diet and smoking).

Managing Cancer as a Chronic Disease

The initial diagnostic and therapeutic phases of the cancer trajectory have garnered so much attention that the lingering psychological and physical sequelae of acute treatment, ongoing treatments after the acute phase (e.g., endocrine therapies in breast cancer), and chronic therapies to control the disease (e.g., imatinib in patients with chronic myelogenous leukemia) have received comparatively little consideration. As the complexity of initial treatments has increased (e.g., multimodal treatments), their length has extended from a few weeks to years, which, in turn, increases the frequency of contact with the health care system and the costs of care.

The health care system is fragmented and often disorganized, with the patient often being the primary coordinator of care among various specialists and treatment facilities (IOM, 2006, 2013). This situation has prompted increased calls for patient self-management, similar to other chronic conditions, but with the added burdens of treatment toxicities and the potentially life-threatening nature of the cancer diagnosis (Gruman et al., 2010; McCorkle et al., 2011). Survivors must have their physical and psychosocial needs addressed if they are to navigate the complex trajectory of cancer treatments (Jacobsen & Wagner, 2012), and, over time, must be empowered to advocate for themselves with respect to treatment and quality of care.

Directions for Psychological Science and Evidence-Based Practice in Cancer Survivorship

As highlighted in recent oncology journals (Ganz et al., 2012; Jacobsen, Holland, & Steensma, 2012; Robison & Demark-Wahnefried, 2011), and in this issue of the *American Psychologist*, cancer survivorship research is accruing rapidly. Progress is evident in specification of posttreatment cancer-related psychosocial and physical sequelae, identification of their risk and protective factors, and development of evidence-based interventions. Much of this body of research represents sound psychological science, enriched by contributions from researchers in oncology, epidemiology, nursing, public health, and other fields. So, too, is evidence-based practice advancing through interprofessional collaboration (IOM, 2013). We offer observations regarding work needed to move the field forward.

Continued investigation of long-term and late effects of cancer and its treatment is essential, as is research to specify risk and protective factors for each of them. Sophisticated quantitative approaches are available to characterize the trajectories of cancer-related psychosocial and physical sequelae, as well as their contributors, over reentry and early and long-term survivorship. It is vital to identify biopsychosocial etiologies of specific problems (and symptom clusters) such as fatigue, depression, and pain. To fully appreciate cancer's effects both over time and as care evolves, creation of large, well-documented cohorts of survivors who are followed with respect to their psychosocial status, health behaviors, and health-related outcomes, assessed with validated measures (contrasted with adults with no cancer history), would be invaluable. Although we have such a research resource for childhood cancer survivors (Childhood Cancer Survivor Cohort; Robison et al., 2002), an equivalent database for adult survivors is lacking. Research with existing large population cohorts (e.g., Hispanic Community Health Study/Study of Latinos) would also allow prospective examination of adults from prior to cancer diagnosis through periods of survivorship. Such research would address the deficits in knowledge regarding the proportion and characteristics of those who develop new cancers and recurrent or progressive disease, information not routinely captured in current tumor registry systems, as well regarding risk for serious and lasting psychosocial sequelae.

Much of the knowledge base regarding the psychosocial concomitants of cancer derives from studies of White, middle-class, early-stage breast cancer survivors treated at large cancer centers. Gathering data that will permit comparison of the health and function of adults with and without a history of cancer will be critical if we are to understand the unique contribution that having cancer has on individual outcomes. This will mean leveraging extant resources wherever possible (Elena et al., 2013). Research is needed on contributors to physical and psychosocial outcomes for the largest group of survivors, those aged 65 and older, who currently constitute almost 60% of the survivor population and who are likely to have additional comorbid conditions (IOM, 2013). Expanded attention to the heterogeneity of the survivor population is

warranted, including low-income and racially diverse groups. Research is also needed on survivors with understudied cancers, such as colorectal cancer and advanced cancers for which long-term survival is increasingly likely. The resulting knowledge base will help guide the refinement of early interventions designed to minimize damage and disability. Comparative effectiveness research to identify interventions that reduce both cancer-related morbidities and costs of medical care (e.g., ER visits, interim physician appointments, treatment nonadherence) would help justify weaving them into the fabric of standard care.

Although efficacious interventions for psychosocial and behavioral consequences beyond cancer diagnosis and treatment are accruing, continued intervention development, extension to diverse groups, and dissemination research are needed. Designing interventions for dissemination remains a significant challenge (Glasgow et al., 2012; Leviton, Khan, Rog, Dawkins, & Cotton, 2010). Such factors as such factors as cost, availability, feasibility, and acceptability require attention. For example, LIVESTRONG and researchers are using a broad-based community organization, the YMCA, to deliver fitness programs for adults completing cancer treatments.¹ Because YMCAs in communities across the country are low cost and heavily used, the reach of such programs holds potential for meeting the needs of survivors. Using communication technologies (mobile telephones, web portals) will also promote broader access to care and allow flexibility in accommodating rapidly changing information needs. Furthermore, inclusion in future research of biomedical, psychosocial, and behavioral assessment indicators will be needed if we are to advance understanding of mechanisms for the effects of interventions.

Researchers and health care professionals have come a long way in understanding and advancing psychosocial and behavioral outcomes for today's cancer survivors. Although much work remains, equipped with the science at hand, we are positioned to reduce much avoidable pain and suffering. As scientists and clinicians, psychologists are well situated to contribute to the next generation of research and evidence-based practice to promote the health and well-being of the millions who are living beyond a cancer diagnosis.

¹ For an example of one of these programs, see <http://www.livestrong.org/What-We-Do/Our-Actions/Programs-Partnerships/LIVESTRONG-at-the-YMCA>

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