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# Resilience trajectories of cancer survivors: a meaning-making perspective

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*While in treatment, I had been surrounded by the world's best army: My supportive family and friends and a brilliant medical team who had worked tirelessly to keep me alive. . . Now that I had survived the "cut, poison, burn" of this disease, I no longer had the cavalry running after me. Suddenly I found myself standing dazed and alone in the rubble, wondering what had happened and where everyone had gone. Suleika Jaouad, Cancer Survivor, New York Times, March 16, 2015*

## Transition from active treatment to longer-term survivorship

The number of cancer survivors in the United States is large and increasing; there are currently over 16.9 million survivors, and it is estimated that there will be 21.7 million by 2029 (NCI, 2019). Cancer diagnosis and treatment constitute a constellation of stressors for patients and their loved ones. Active/primary treatment can last several years and brings with it challenges that persist and evolve well beyond the point at which treatment concludes (Costanza, Ryff, & Singer, 2009;

Elliott et al., 2011; Santin, Mills, Treanor, & Donnelly, 2012). Indeed, the results of several large-scale surveys have documented high levels of clinically significant symptoms of depression and anxiety following treatment (Champagne et al., 2016; Deimling, Kahana, Bowman, & Schaefer, 2002), with most survivors reporting being significantly concerned about recurrence (Baker, Denniston, Smith, & West, 2005; Bellizzi et al., 2008). Further, a large, nationally representative study indicated that cancer survivors, relative to matched noncancer controls, reported significantly lower levels of physical and mental health as well as greater role limitations and social functioning (Santin et al., 2012). Another large nationally representative sample drawn from the MIDUS Study assessed prediagnosis to postdiagnosis changes in survivors and found that most cancer survivors experienced reductions in mental health following diagnosis, although many demonstrated resilience in social well-being relative to matched controls (Costanza et al., 2009). Further, many cancer survivors experience a significant decrease in existential confidence relating to identity, uncertainty, and worry concerning their future (Hullman, Robb, & Rand, 2016).

In addition to these studies of people in survivorship, there is some evidence that the *transition* from active treatment to survivorship remains a highly stressful and potentially critical juncture in determining their long-term postactive treatment well-being. At treatment end, patients' frequent interactions with their medical team, and the accompanying sense of protection, abruptly ceases. At this point, cancer patients also often experience decreased social and emotional support, face fears of cancer recurrence, and experience lingering or emerging physical and psychological effects of diagnosis and treatment (Stanton, Rowland, & Ganz, 2015). At this time, survivors may also make efforts to make sense of their cancer experience and its ultimate impact on their lives (Stanton, 2012).

This reentry period (Mullan, 1985), wherein one marks 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 a year, through the next several months to their first follow-up or beyond. Health care professionals are often ill-equipped to prepare patients for this reentry period, which can contribute to cancer survivors and their family and friends holding unrealistic expectations for survivors' rapid recovery and "return to normal" (IOM, 2006); survivors are often 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).

As described in clinical accounts and research reports, the months after treatment typically involve loss of the emotional safety net that patients often experience during 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 experiences of lingering or emerging physical and psychological effects of diagnosis and treatment (e.g., IOM, 2006; Stanton, 2012; Talcott et al., 2003).

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 a 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 targeted therapies following surgery or radiation). Reentry may 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 (Erikson, 1968)—can be uniquely jeopardized by life-threatening illness such as cancer. Issues related to childbearing and fertility preservation can compound the complexity of treatment decisions (Lee, Cohen, Edgar, Laizner, & Gagnon, 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. Additionally, the financial toxicity of cancer care can leave a young person without savings, bankrupt, or dependent on employment to maintain existing health insurance.

The reentry phase following cancer treatment has been observed to follow a fairly predictable course in many studies of cancer patients currently undergoing treatment(s) (Henselmans et al., 2010; Hou et al., 2010; Lazovich, Robien, Cutler, Virnig, & Sweeney, 2009; Michael, Kawachi, Berkman, Holmes, & Colditz, 2000) and qualitative researchers have added to our understanding of this phenomenon (Ahles & Saykin, 2007; Armes et al., 2009; Polsky et al., 2005; Talcott et al., 2003). After completion of active cancer treatment, patients are moved to follow-up care and surveillance to monitor the status of remission,

lessening those interactions that patients experienced with their oncologists during active treatment. When this occurs, cancer survivors have reported a significant decrease in their sense of being protected (Henselmans et al., 2010) as well as the amount of emotional support available to them (Bower, 2008; Talcott et al., 2003). In conjunction with the loss in consistent support immediately after active treatment concludes, fears of recurrence (Bellizzi et al., 2008; Bower et al., 2011; Ganz et al., 2004; Luker, Beaver, Lemster, & Owens, 1996) and issues with physical functioning remain (Arora et al., 2002; Bower et al., 2011), but usually subside with time. In a sample of 223 recent breast cancer survivors, many reported worries related to recurrence, pain, death, harm from chemotherapy, and medical bills (Ganz et al., 2004).

Several characteristics of survivors such as demographic, cancer-related, and psychosocial factors have been noted to longitudinally predict reductions in health-related quality of life (HRQoL) and overall health in cancer patients transitioning into the reentry phase. For instance, survivors of younger age have been found to exhibit poorer HRQoL scores and higher unmet needs compared with adults (Beckjord et al., 2008; Bloom, Petersen, & Kang, 2007; Burgess et al., 2005; Costanza et al., 2009; Helgeson, Snyder, & Seltman, 2004; Jansen et al., 2011; Kroenke et al., 2004). Interestingly, completion of cancer treatment (s) such as chemotherapy and endocrine therapies (Armes et al., 2009; Thornton, Carson, Shapiro, Farrar, & Andersen, 2008) or the diagnosis of comorbid conditions (Beckjord et al., 2008; Bower, 2008; Lynch, Steginga, Hawkes, Pakenham, & Dunn, 2008) appear to increase problems during reentry and into survivorship. Highly dependent on developmental stage and explicit treatment(s) undergone, short-term threats to successful reentry and survivorship for pediatric, adolescent and young adult cancer survivors range from sexual and reproductive issues (e.g., fertility, premature menopause), depressive/anxiety symptomology, and experiencing issues in their careers and relationships (Zebrack, 2011). While research into racial and ethnic differences remains in its early stages, the evidence that has accumulated to date suggests that HRQoL is decreased among ethnic minority groups diagnosed with cancer in comparison to their Caucasian counterparts (Hao et al., 2011; Janz et al., 2009; Yanez, Thompson, & Stanton, 2011), and current research is ongoing to better understand why these disparities exist (Hao et al., 2011).

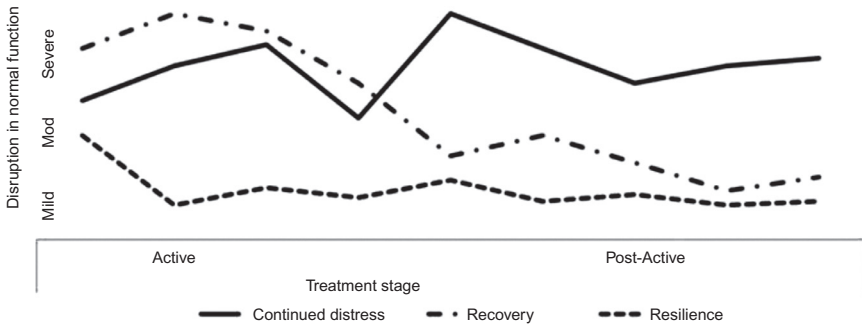
### Individuals vary in their recovery following cancer

Myriad studies of health and well-being in survivorship have demonstrated that while decrements in well-being are often observed *on*

average, there is tremendous variation across survivors on many different indices of well-being (e.g., Costanza et al., 2009). As we noted, many individuals report significant difficulties returning to normal daily life following cancer treatment, with elevated rates of anxiety, depression, and PTSD symptoms, such as intrusive and avoidance symptoms (Bellizzi & Blank, 2011). Importantly, however, thriving and perceptions of posttraumatic growth are also commonly reported coexisting outcomes (Bellizzi et al., 2012). Although researchers have called into question the extent to which reports of positive outcomes reflect well-being as standardly measured (e.g., Frazier et al., 2009), it is clear that individuals vary widely in their psychosocial adjustment, which has important implications for quality of life among cancer survivors. One promising way to understand individuals' courses of recovery is through trajectories over time.

In the broader trauma and coping literature, an analytic approach to modeling posttrauma adjustment has identified four basic posttrauma trajectories: resilience, recovery (sometimes called "emerging resilience"; Bonanno & Diminich, 2013), chronic distress, and impairment (Bonanno, 2004). From this trajectories perspective, resilience is defined as continued well-being across the challenge or stressor ("minimal impact resilience"). By considering individuals' trajectories of adjustment, we can go beyond average tendencies to model individual variations in resilience and recovery. Several studies of cancer survivorship have examined adjustment postcancer, reporting the same four trajectories as proposed in Bonanno's (2004) original model of trauma (e.g., Helgeson et al., 2004). However, studies of trajectories in cancer have not focused on end of primary treatment as an important point of stress; the majority of work in this area has primarily captured data on the experience of individuals as they adjust to a cancer *diagnosis*, rather than as they adjust to the changes inherent in completing treatment (reentry). With just one exception, extant studies of cancer adjustment trajectories have measured uniform times from diagnosis for convenience (e.g., 3, 6, 9 months; Manne et al., 2008) rather than assessing adjustment relative to the milestone of ending treatment and beginning "survivorship." The one study that did identify and assess survivors at this critical point then examined only one later point, concluding the entire study within a year of diagnosis (Henselmans et al., 2010), rather than focusing on posttreatment trajectories. We propose that within cancer survivorship, there are three types of trajectories that occur across the transition to survivorship: continued distress, recovery, and resilience (see Fig. 8.1).

It is worth noting that nearly all existing studies of cancer adjustment trajectories focus on quality of life or psychological distress, which comprise a rather narrow subset of domains of well-being and capture only



**FIGURE 8.1** Hypothetical trajectories of adjustment from active treatment through survivorship. Source: Based on Bonanno, G. A. (2004). *Loss, trauma, and human resilience: Have we underestimated the human capacity to thrive after extremely aversive events?* *American Psychologist*, 59, 20–28.

one piece of the posttreatment experience. It may be that survivors are resilient in some domains and struggle to recover in others, although there is little data on this point at this time (Bellizzi et al., 2012). Further, we know little about why individual survivors exhibit such different patterns of adjustment. Only one existing study of trajectories of adjustment, that of women with gynecological cancer, identified any distinct coping processes as predictors of well-being (Manne et al., 2008). The introduction of coping into the study of resilience is key, as it provides information about both psychological well-being and environmental and intrapersonal resources for adjustment and is an actionable focus of interventions.

While many factors that impede or facilitate recovery and resilience following cancer treatment have been identified, these factors have rarely been examined from and integrated within a strong theoretical base. Further, because of the relevance of appraisals and coping to well-being over time, it remains important to identify individual- and environmental-level factors that guide these processes, which are outlined below. Using a trajectories approach allows the identification of distinct sets of predictors of these processes for each individual rather than simply predicting group trajectories. In doing so, a deeper understanding of survivors' processes of drawing on their resources and coping with the stressors they confront as a part of daily life is necessary to characterize recovery and resilience, as well as informing interventions to promote resilience.

## Pretransition factors

A number of predictive factors about the conditions of cancer predict individual well-being during the transition to survivorship once in

remission. Type of cancer, amount of time since diagnosis, age, and comorbidities all contribute to individual distress or adjustment during the stressful period following cancer treatment. For example, one study found that pancreatic cancer survivors are more likely to have depression alone, while uterine cancer survivors are least likely (Brintzenhofe-Szoc, Levin, Li, Kissane, & Zabora, 2009). Breast cancer survivors are most likely to have anxiety alone, while brain cancer survivors are least likely (Brintzenhofe-Szoc et al., 2009). A combination of both depression and anxiety symptoms are most likely among stomach cancer survivors and least likely among ovarian cancer survivors (Brintzenhofe-Szoc et al., 2009). Previous studies have found that lung, breast, pancreatic, and oropharyngeal cancer survivors are at increased risk of depression compared to survivors of other cancer types (Carney, Jones, Woolson, Noyes, & Doebbeling, 2003; Massie, 2004). It is posited that there may be increased risk of depression among certain types of cancer due to increased concentrations of interleukin-6 (Musselman, Miller, Porter, Manatunga, & Nemeroff, 2001). These differences in psychopathology could also be due to a range of different psychosocial factors, such as support services available to certain types of cancer, the prognosis of certain cancer types, or treatments available for each treatment type.

Studies have found that higher levels of symptoms are associated with younger age and less time since diagnosis. Anxiety and depression symptoms generally decrease as time since diagnosis increases and as survivors get older (Arden-Close, Gidron, & Moss-Morris, 2008; Maass, Roorda, Berendsen, Verhaak, & de Bock, 2015; Park et al., 2018), and there is also evidence of decreased fears of cancer recurrence with increased age and time since diagnosis among breast cancer survivors (Taylor et al., 2012). Interestingly, in a sample of Latina cancer patients who had not yet started chemotherapy, longer time since diagnosis was associated with higher depression and anxiety (Lee et al., 2018). It may be that these symptoms increase as the beginning of treatment gets closer, but then decrease throughout or after treatment. Or it could be that the time spent waiting for treatment to start is correlated with high anxiety, as the fear of the “unknown” is very high during this period (i.e., patients are not sure what side effects they will experience during chemotherapy and the anticipation of these side effects can be worse than those actually experienced).

## Appraised meaning of the cancer

Appraisals refer to the individuals’ understanding of the stressor and their ability to respond to it; as such, appraisals are the central drivers of coping and adjustment (Lazarus & Folkman, 1984; Lent, 2007). Given



their central role, it is surprising that so little research has been conducted on survivors' appraisals and changes in appraisals over time (Hoffman, Lent, & Raque-Bogdan, 2013); the available work suggests that survivors' appraisals are strong predictors of their adjustment (Park, Edmondson, Fenster, & Blank, 2008a). How individuals appraise the meaning or threat related to the cancer may impact how they respond to it on a behavioral and psychological level.

Lazarus and Folkman (1984) posited that differences in appraisals of stressor as threatening, harmful, or challenging predict differential response and outcome. A meta-analysis demonstrated differences in coping responses based on threat appraisals in the context of cancer (Franks & Roesch, 2006). Higher appraisals of harm or threat of cancer predict increased distress over time (Bigatti, Steiner, & Miller, 2012; Mazanec, Daly, Douglas, & Musil, 2011), with evidence that appraisals of cancer harm may result in increased anxiety (Bjorck, Hopp, & Jones, 1999) while increased appraisals of cancer threat may result in increased anxiety, depression, general distress, and cancer-related distress (Bjorck et al., 1999; Hamama-Raz, Solomon, Schachter, & Azizi, 2007; Lynch et al., 2008).

Appraisals of cancer as a threat, harm, or challenge may determine how much control individuals feel they have over the cancer and the survivorship process. Those who perceive a cancer as a challenge to be met may experience increased perceptions of control (Gabrys, Tabri, Anisman, & Matheson, 2018). Increased internal locus of control of the process of dealing with cancer can result in decreased distress (Norton et al., 2005), and may buffer stress responses after chemotherapy (Henselmans, Sanderman, Baas, Smink, & Ranchor, 2009). A lack of a sense of control may prompt feelings of uncertainty about the future, although survivors sometimes report coping with these feelings of uncertainty and lack of control by focusing on engagement with their lives, such as continuing to go to work, reaching out to social supports, and caring for their families (Warren, 2010). These strategies can be utilized as a means of connecting with meaningful aspects of one's life and allowing survivors to behave proactively in their lives rather than ruminating on their uncertainty about their cancer diagnosis. Engaging in strategies that may give one a sense of meaning can be adaptive, as a sense of meaning in life is inversely associated with distress among cancer patients and survivors (Winger, Adams, & Mosher, 2016).

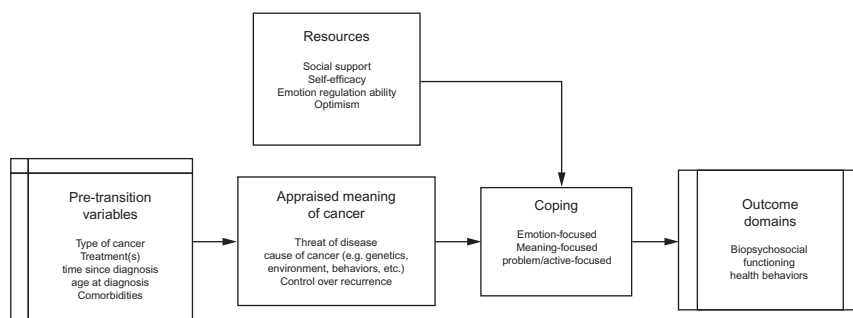
## Psychosocial resources

Environmental and intrapersonal resources coupled with individuals' efforts to adjust to reentry and survivorship also influence trajectories of

adjustment. Studies of survivors of a variety of types of cancer have highlighted consistent relations between social support, self-efficacy, and optimism with increased HRQoL and healthier adjustment to survivorship (e.g., Blank & Bellizzi, 2006; Fong, Scarapicchia, McDonough, Wrosch, & Sabiston, 2016; Park, Cho, Blank, & Wortmann, 2013). More specifically, research has shown that survivors who received higher levels of emotional support immediately after a cancer diagnosis noted more positive experiences relating to their cancer during survivorship (Schroevers, Helgeson, Sanderman, & Ranchor, 2009). Similarly, optimism, combined with stable social support, has been found to moderate negative impacts of cancer diagnosis and survivorship (Friedman et al., 2005), attenuate cancer symptom distress, promote higher HRQoL (Manning-Walsh, 2006), and facilitate higher levels of social support (Sammarco, 2009). Although emotion regulation has seldom been studied in cancer survivors, it has been theorized to promote resilience in survivorship (Wills & Bantum, 2012) and in the broader literature in coping with highly stressful events, emotion regulation has been shown to promote well-being in many important life domains (Heatherston, 2011). Further, emotion regulation skills are highly amenable to improvement and may be a useful target in interventions for cancer survivors (Cameron, Booth, Schlatter, Ziginskis, & Harman, 2007). For example, survivors may benefit from interventions that promote reappraisal skills or mindfulness to promote higher levels of positive emotions and tamp down distress (Boyle, Stanton, Ganz, Crespi, & Bower, 2017).

## Coping

The updated model portrayed in Fig. 8.2 also highlights the critical roles of coping, in conjunction with appraisal (outlined above), in



**FIGURE 8.2** Updated biopsychosocial model of determinants of survivors' trajectories of recovery following completion of primary treatment. Source: From Lent, R. W. (2007). *Restoring emotional well-being: A theoretical model*. In M. Feuerstein (Ed.), *Handbook of cancer survivorship* (pp. 231–247). New York: Springer.

predicting adjustment or resilience during reentry and survivorship. Coping refers to the responses individuals make to the demands of the stressful situation and are often divided into strategies that focus on taking direct action to solve the problem (problem/active-focused coping), strategies that focus on managing distressing emotions because of such problem (emotion-focused coping), and strategies that focus on understanding the situation in a different way (meaning-focused coping) (Park, 2010). Regulating emotional distress through problem-focused avenues (e.g., problem solving, cognitive reappraisal) has been shown to lessen depressive symptoms in breast cancer survivors, and only those who had less positive emotional expression had more depressive symptoms (Marroquin, Czamanski-Cohen, Weihs, & Stanton, 2016). Meaning-focused coping has consistently been found to lead to positive outcomes in cancer survivors as well (Kvillemo & Bränström, 2014). Overall, survivors' coping efforts have been demonstrated to predict well-being in many domains across many studies.

## Outcome domains

The four domains that collectively comprise survivors' well-being (Costanza et al., 2009; Stanton et al., 2005) are outlined in Fig. 8.2. Although other domains exist, these four domains—physical, psychological, and social functioning, and health behaviors—appear to be the most commonly affected by cancer and those most commonly studied (Stanton et al., 2015). Together, these domains provide a comprehensive view of survivors' well-being. Physical functioning includes self-reported general physical functioning and cancer-specific physical functioning such as fatigue. Sleep disturbances are also common among this population, and are associated with mood disturbances, decreased HRQoL, fatigue, immune functioning, and mortality (Palesh et al., 2014; Savard & Morin, 2001). The psychological domain includes general mental functioning as well as cancer-specific distress (PTSD-like symptoms of intrusion and avoidance as well as fear of recurrence). Positive psychological constructs, such as perceptions of thriving or posttraumatic growth, are also included here. The social domain includes satisfaction within social roles over time throughout survivorship. The lifestyle domain includes the usual behaviors, such as diet, physical activity and sedentary behavior, and substance use.

## Using a comprehensive biopsychosocial perspective to understand survivors' trajectories

Cancer-related adjustment may be best understood through a biopsychosocial approach, such as the Biopsychosocial Restorative Model of

Well-Being (Lent, 2007), an illness-specific adaptation of Lazarus and Folkman's (1984) transactional model of stress and coping applied to cancer survivorship (see Fig. 8.2). This model includes cancer- and treatment-related factors, personal and social resources, and appraisal and coping processes that occur throughout the adaptation process and that may influence the path of survivors' trajectories. Importantly, the model emphasizes each survivor's unique circumstances and appraised meaning of their illness as well as the meaning making and other types of coping in which they engage. Survivors' coping has been demonstrated to predict well-being in many domains across many studies (see Franks & Roesch, 2006; Park et al., 2008a), although studies of survivors' coping and health behavior change are rare (Park, Edmondson, Fenster, & Blank, 2008b).

As research on resilience trajectories evolves, we encourage integration of theoretically driven research questions, including consideration of the proposed model of resilience presented in this chapter. Using theoretically based approaches allows for identification, assessment, and targeted approaches to research and clinical practice in the growing population of cancer survivors in the United States and beyond.

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