

## What Happens Now? Psychosocial Care for Cancer Survivors After Medical Treatment Completion

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Submitted September 20, 2011; accepted January 10, 2012; published online ahead of print at www.jco.org on March 12, 2012.

Author's disclosures of potential conflicts of interest and author contributions are found at the end of this article.

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0732-183X/12/3011-1215/\$20.00

DOI: 10.1200/JCO.2011.39.7406

### ABSTRACT

The growing population of adults living with a history of cancer in the United States mandates attention to quality of life and health in this group, as well as to the implementation of evidence-based interventions to address psychosocial and physical concerns at completion of medical treatments and beyond. The goals of this article are to document the need for attention to psychosocial domains during the re-entry and later phases of the cancer survivor trajectory, offer an overview of current evidence on efficacy of psychosocial interventions during those phases, and offer suggestions for application and research regarding post-treatment psychosocial care.

*J Clin Oncol* 30:1215-1220. © 2012 by American Society of Clinical Oncology

### INTRODUCTION

Currently numbering 11.9 million individuals in the United States, the population living with a cancer diagnosis will continue to grow as early detection increases, medical treatments improve, and the population ages. So, too, are medical and psychosocial research bases and clinical efforts expanding to address the challenges confronted during life beyond cancer diagnosis and treatment. These developments can inform the common “What happens now?” question posed by individuals as they complete primary medical treatments for cancer. The goals of this article are to document the need for attention to psychosocial domains extending through the phases after treatment completion and into longer term survivorship, provide an overview of the evidence base on the efficacy of interventions to enhance quality of life and health with adult cancer survivors during those phases of the cancer trajectory, and identify directions for application and research.

### NEED FOR ATTENTION TO PSYCHOSOCIAL DOMAINS DURING THE RE-ENTRY PHASE AND BEYOND

The physical and psychosocial exigencies of undergoing diagnosis and treatment are well documented for a number of cancers, including evidence from prospective studies that assess large samples of individuals in the years before and after a cancer diagnosis,<sup>1-5</sup> as well as hundreds of other longitudinal and cross-sectional studies. A much smaller em-

pirical literature describes the experience of cancer during the several months immediately after completion of primary medical treatments (ie, re-entry phase<sup>6</sup>) and across the long term. Although no sharp distinction can be made between time boundaries of the re-entry phase and long-term survivorship, the re-entry phase for the purpose of this article will be defined as the point from treatment completion through 12 to 18 months, and longer term survivorship will be defined as being beyond that point (note that some researchers<sup>7</sup> view long-term survivorship as beginning at least 5 years after diagnosis). A review of this literature yields several observations, with the caveat that the preponderance of psychosocial research has been conducted with samples of patients with early-stage breast cancer.

A first observation is that individuals follow distinct trajectories of psychological and physical adjustment over months or years after cancer diagnosis. For example, a longitudinal study of distress within the first year after breast cancer diagnosis ( $n = 171$ ), which began before surgery and concluded 6 months after treatment completion, indicated four unique trajectories of general psychological distress: 36% of women reported no or minimal distress across the five assessment points, 33% experienced distress from the point of diagnosis through medical treatment and then a decline in distress, 15% experienced heightened distress beginning at treatment completion and through 6 months after treatment (ie, re-entry phase), and 15% experienced high distress throughout the study period.<sup>8</sup> Similarly, research with Chinese colorectal cancer patients ( $n = 234$ ) assessed within 3 months of cancer diagnosis

and 3 and 12 months later demonstrated that 67% scored below a clinically suggestive cutoff for anxiety/depressive symptoms across all assessments; 14% began with significant distress and then evidenced recovery; 12% experienced significant distress at the second assessment, which increased through the final assessment; and 7% evidenced clinically significant distress across all assessments.<sup>9</sup> Regarding longer term quality of life, a study of women with breast cancer beginning at 4 months after diagnosis and extending through 4 years demonstrated that the largest proportions of women evidenced positive psychological (43%) and physical (55%) health-related quality of life, which changed little over the 4 years.<sup>10</sup> Other groups demonstrated somewhat compromised functioning that evidenced no change or gradual or rapid improvement over time, and the smallest proportions (<15%) had compromised mental and physical quality of life, which declined further over the 4 years.

A second observation is that the re-entry phase brings particular challenges. As described in clinical accounts and research reports, the several months after treatment completion typically involve loss of the safety net of active medical treatment and the accompanying supportive milieu, resumption or alteration of former roles within and outside the home, a decline in interpersonal support, and lingering physical and psychological effects of diagnosis and treatment.<sup>11-14</sup> Prominent problems during the re-entry phase include fear of cancer recurrence and lingering adverse effects of particular treatments, such as fatigue/sleep disturbance, sexual dysfunction, urinary/bowel problems, and cognitive problems.<sup>11,13,15-20</sup> Little preparation for the re-entry phase by health care professionals or others is common, eventuating in prominent needs for information.<sup>12,21-25</sup> When persistent symptoms and concerns are juxtaposed against the expectation held by cancer survivors and their interpersonal network of relatively swift return to life as usual, survivors can be left without effective methods for addressing the experience and conclude that they are not recovering as they should or that the cancer remains. Again, proactive psychosocial care can aim to prevent or assuage concerns during re-entry and set the stage for adaptive survivorship.

A third evidence-based observation is that, as a group, long-term (eg,  $\geq 5$  years after diagnosis) cancer survivors often report quality of life that matches or exceeds population norms; however, even in the context of positive general quality of life, specific problems can persist.<sup>19,26-32</sup> Reviews highlight problems with fear of cancer recurrence, fatigue, sexual health, depressive symptoms, pain, financial/unemployment burden, and adverse effects of specific cancer treatments (eg, lymphedema).<sup>7,33,34</sup>

Finally, research reveals that particular demographic, cancer-related, and psychosocial characteristics predict impairments in quality of life and health in post-treatment cancer survivors. The most consistent demographic predictor of poor quality of life and unmet needs in adult survivors is relatively young age.<sup>7,10,35-39</sup> Depending on the developmental phase and cancer treatment regimen, specific challenges that are particularly acute for younger cancer survivors include managing sexual and fertility concerns, depressive symptoms, concomitants of premature menopause, intimate relationships, and career goals.<sup>40</sup> Although the relevant literature is small, some evidence suggests that quality of life is compromised in ethnic minorities diagnosed with cancer relative to their white counterparts,<sup>41-43</sup> and research is accumulating to identify mechanisms underlying this disparity.<sup>41</sup> Undergoing systemic treatments (eg, chemotherapy, endocrine therapies)<sup>16,34,44</sup> or

having comorbid diseases<sup>17,34,38,45</sup> also can magnify problems during survivorship.

Psychosocial characteristics also are important contributors to quality of life after treatment completion. High social isolation, lack of social support, and having no intimate partner intensify quality-of-life deficits in cancer survivors.<sup>7,10,17,34,37,45-47</sup> Enduring personality attributes such as optimism (ie, general expectancy for positive outcomes) predict more favorable quality of life.<sup>45,46</sup> In addition, use of active coping strategies such as problem solving, identifying benefits in the experience, and expressing emotions related to cancer can bolster psychological adjustment, whereas coping through attempts to avoid cancer-related feelings and thoughts predicts less favorable adjustment.<sup>48-50</sup>

In summary, the body of descriptive and predictive research suggests that a large proportion of individuals diagnosed with cancer can expect relatively stable, positive functioning or marked recovery over time in psychological and physical domains. Such groups are likely to recover well in their natural environments or with standard supportive care from health professionals. Other cancer survivors, however, evidence chronically compromised psychological or physical health (whether beginning before diagnosis or chronically after diagnosis is unclear) or marked decrements in quality of life during the treatment or re-entry phase, sometimes without recovery. These groups stand to benefit from more intensive psychosocial care. Research also illuminates specific problems that can persist into re-entry and longer term survivorship (eg, fear of cancer recurrence, fatigue, sexual problems), which can be productively targeted for preventive and intervention efforts. Helping individuals know what to expect at the completion of medical treatments and how to address anticipated problems effectively are vital components of psychosocial care. Research identifying risk and protective factors for quality of life and health during re-entry and longer term survivorship can contribute to evidence-based psychosocial care in at least two ways: Psychosocial care can be targeted toward cancer survivors in most need (eg, younger or socially isolated survivors), and intervention techniques can be developed that promote skills to enhance quality of life and health (eg, active coping strategies). What measures can be taken to reduce psychological and physical morbidities and promote adaptive survivorship during the re-entry phase and beyond?

#### PSYCHOSOCIAL CARE DURING RE-ENTRY AND LONG-TERM CANCER SURVIVORSHIP: CURRENT EVIDENCE

By 2005, nearly 500 unique studies, 63% of which involved randomized designs, comprised the evidence base on the efficacy of psychosocial and behavioral interventions for individuals diagnosed with cancer.<sup>51</sup> This research was most often conducted with patients in the diagnostic or active medical treatment phases,<sup>51,52</sup> spanned a range of intervention approaches often with multiple components (eg, education regarding cancer and its treatment, provision of emotional support, training in coping skills, challenging unhelpful thoughts, relaxation training), and targeted multiple outcomes (eg, quality of life, depression, physical symptoms, fatigue). Furthermore, most intervention trials included participants regardless of their baseline standing on the trial outcome. For example, a review of 60 psychosocial interventions for depressive symptoms or anxiety in patients with cancer demonstrated that only 5% of studies restricted

eligibility to patients meeting a specified threshold for depression or anxiety.<sup>52</sup> Although this recruitment approach provides the widest reach to patients with cancer who are interested in intervention, it works against detecting an effect when individuals who enter the intervention are functioning well at the outset. Indeed, a meta-analysis of 27 psychosocial interventions (12 randomized controlled trials [RCTs] and 15 single-group designs) for patients with cancer to investigate whether baseline symptoms of depression or anxiety moderated intervention efficacy revealed that effects were negligible when baseline symptoms were low and pronounced when they were relatively high.<sup>53</sup> This finding did not vary by study design or intervention type, setting, or dose, and it held both immediately after the intervention and 2 to 7 months later, although it weakened at longer follow-up.

The bodies of evidence illuminating the lingering problems after completion of cancer treatments, even in the context of generally positive psychosocial adjustment, as well as the risk of persistently compromised quality of life for individuals with specific characteristics have prompted efforts to test psychosocial interventions during the re-entry phase. Randomized trials indicate that interventions offered at re-entry (study entry up to 18 months after treatment) can be effective. For example, RCTs reveal that cognitive-behavioral, stress management (eg, relaxation, mindfulness), and psychoeducational interventions (conducted over 6 to 20 hours) can confer benefits in such domains as depressive symptoms, physical functioning, fatigue, fear of recurrence, sexual health, and general quality of life.<sup>54-62</sup> Benefits also can accrue from briefer interventions, including a peer-modeling video specifically addressing the re-entry phase<sup>63</sup> and written expressive disclosure (eg, writing about deepest thoughts and feelings about cancer or about benefits of the cancer experience).<sup>48</sup> It is essential to note, however, that relatively few trials targeting the re-entry phase have been conducted, trials primarily are confined to participants with cancers of the breast or prostate, and interventions are not uniformly effective across outcomes. In addition, efficacy of some interventions is shown to vary as a function of such factors as participants' psychological status or psychosocial resources at baseline, presence of comorbidities, education level, and adequacy of prior preparation for re-entry by the medical team.

Interventions during longer term survivorship also are accruing. Problems successfully addressed by cognitive and behavioral interventions in RCTs with survivors on average more than 1 year beyond treatment completion include insomnia,<sup>64</sup> fatigue,<sup>65</sup> fear of cancer recurrence and other cancer-related uncertainties,<sup>66</sup> post-traumatic stress symptoms,<sup>67</sup> menopausal symptoms,<sup>68</sup> and pain.<sup>69</sup> Again, the pertinent body of research is small and focused primarily on women with breast cancer.

Interventions to promote health behavior change after treatment completion also are receiving empirical attention. Cancer survivors report that health care providers are not likely to discuss physical activity, diet, or smoking with them.<sup>70</sup> However, controlled research demonstrates that interventions for health behavior change (eg, physical activity, diet, smoking) after cancer treatment can produce benefit across a number of outcomes.<sup>71</sup> For example, a review of 40 controlled trials of high methodologic quality, 86% of which targeted breast cancer survivors, documents the efficacy of physical activity interventions initiated after medical treatment across a number of domains, including bodily strength, aerobic fitness, overall quality of life, fatigue, and other cancer-specific concerns/symptoms<sup>72</sup>; note that an additional 26 trials targeted patients with cancer during medical treat-

ment. Although most of these trials involved professionally supervised non-home-based activity, more accessible programs that involve home-based activity or print materials combined with pedometer provision also can produce positive outcomes.<sup>73,74</sup> Post-treatment cancer survivors also prefer home-based programs that begin after treatment completion.<sup>75</sup> Positive physical and psychological effects from controlled trials, as well as evidence for the role of health behaviors in cancer initiation and progression,<sup>76</sup> highlight the importance of extending the research to populations with other cancers, evaluating long-term effects of health behavior change programs, and ensuring translation into practice by promoting accessibility of programs and developing cost-efficient delivery methods.

#### PSYCHOSOCIAL CARE DURING RE-ENTRY AND LONG-TERM CANCER SURVIVORSHIP: APPLICATION AND DIRECTIONS

What can the oncologist and multidisciplinary team gain to enhance clinical practice from the knowledge base on psychosocial issues and interventions in the post-treatment periods of the cancer trajectory? Promoted by many national bodies, including the Institute of Medicine,<sup>12,77</sup> the President's Cancer Panel,<sup>78</sup> and the National Comprehensive Cancer Network,<sup>79</sup> a first observation is that monitoring of patients' psychological and physical concerns is warranted. This recommendation holds not only during diagnosis and treatment, but also during the re-entry phase and beyond, in light of survivors' shifting concerns and the evidence that external sources of support erode over time, particularly for individuals who are most distressed.<sup>80,81</sup>

Individuals with cancer often want their oncologists to ask about emotional well-being. For example, in a study of patients with gynecologic cancer approximately 2 years after treatment completion,<sup>82</sup> 57% of the sample reported that they had needed help in dealing with cancer-related emotions, but only 35% had received such help; 73% believed that physicians should ask whether patients with cancer want help in dealing with emotions. Cancer survivors may hesitate to raise sensitive concerns, and physicians can play a role in routinely querying for concerns and providing resources for addressing them. An article in this special series provides a review of evidence-based screening for distress and psychosocial needs.<sup>83</sup> Whether systematically screening for distress or systematically offering all patients a chance to raise any concerns (regardless of distress level) is more effective and efficient requires study, but it is clear that screening alone is not sufficient; the availability and implementation of resources for further care are essential.<sup>84-87</sup>

A second recommendation regards offering evidence-based psychosocial care to survivors at treatment completion and later into survivorship. After completing medical treatment, survivors report that they are more likely to learn about psychological support or specific cancer information/support services on their own than from medical personnel.<sup>88</sup> A window of opportunity exists at the point of treatment completion, when oncology teams can provide psychosocial resources proactively to patients through comprehensive survivorship care, including appropriate referrals.<sup>12</sup> The first medical follow-up and cancer surveillance visits in the year after treatment completion also are opportune points for referral to and provision of psychosocial care. As described previously, evidence-based approaches to post-treatment psychosocial care are accumulating, and trials are under way to address prominent problems during the post-treatment phase (eg, cognitive-behavioral therapy and physical activity for treatment-induced menopause<sup>89</sup>; Web-based

stepped care for improving distress and functional status after autologous stem-cell transplantation<sup>90</sup>). Adequate psychosocial care will move forward as the oncology team refers patients to well-designed intervention trials and as psycho-oncology services incorporate empirically supported approaches.

Outside of academic medical centers and large hospitals or oncology practices, on-site psychological resources often are not readily available. Patients can be referred to print and online materials, such as the National Cancer Institute's (NCI) Facing Forward series and other resources for post-treatment survivorship ([http://dcccps.nci.nih.gov/oc/ff\\_series.html](http://dcccps.nci.nih.gov/oc/ff_series.html), <http://www.cancer.gov/cancertopics/coping/survivorship>; see <https://cissecure.nci.nih.gov/ncipubs> for free publications), the National Coalition for Cancer Survivorship and collaborators' Journey Forward (<http://www.journeyforward.org>), the American Society of Clinical Oncology's Cancer.Net (<http://www.cancer.net>), and the American Cancer Society (<http://www.cancer.org>). Free publications, videos, and podcasts relevant to survivorship are available from these sources. Free telephone services also are available, in which trained staff can help the caller translate and make sense of material that can seem overwhelming, as well as provide emotional support (eg, the NCI's Cancer Information Service at 1-800-4-CANCER; CancerCare at 1-800-813-4673; American Cancer Society at 1-800-227-2345; and the American Psychosocial Oncology Society's Helpline at 1-866-276-7443, which assists patients and families in finding counseling resources in their own community). Additional resources are provided in the Institute of Medicine reports<sup>12,77</sup>; for information regarding implementing selected evidence-based survivorship interventions, see Cancer Control P.L.A.N.E.T.'s survivorship page (<http://cancercontrolplanet.cancer.gov/survivorship.html>).

Just as the patient with cancer at treatment completion is likely to pose the question, "What happens now?" health care providers and researchers are grappling with similar questions with regard to the most appropriate venues and approaches for providing medical and psychosocial care to post-treatment and long-term survivors. Charged with accelerating progress to address the needs of cancer survivors, the eight LIVESTRONG Survivorship Centers of Excellence initiated approaches including separate survivorship clinics and consultative care, with movement toward integrative care in which both medical and psychosocial survivorship care is embedded within the oncology team.<sup>91</sup> Commitment by the organization's leadership and champions at multiple levels of the health care team facilitated survivorship care, whereas financial and other resources needed to provide care (eg, time to complete survivorship care plan) were barriers. All centers endorsed provision of oncology treatment summaries and survivorship care plans, as recommended in the Institute of Medicine report.<sup>12</sup> Online programs for creating survivorship care plans have been developed (eg, for professionals, the National Coalition for Cancer Survivorship and collaborators' Survivorship Care Plan Builder [<http://journeyforward.org/professionals/survivorship-care-plan-builder>]; and for individuals with cancer, the Lance Armstrong Foundation and Penn Medicine's OncoLink LIVESTRONG Care Plan [<http://livestrongcareplan.org/>]).

Regarding provision of care for long-term survivors, shared care models involving the oncology team, primary care practice, and mental health professionals are receiving attention.<sup>92</sup> Collaborative care programs involve the recognition and treatment of psychosocial problems in medical settings through professional collaboration (eg, oncologist, nurse, psychologist, psychiatrist, social worker). Such programs, which typically involve systematic screening on the psychosocial outcome

of interest, provision of evidence-based intervention protocols, structured collaboration of medical and mental health professionals, and monitoring of intervention adherence and outcomes, can be effective for depression and other outcomes in cancer survivors.<sup>93-95</sup> As the population of cancer survivors increases and access to long-term care by the treating oncologist diminishes, collaborative care models integrated into primary care warrant development.<sup>96</sup>

Many gaps remain in the evidence base on psychosocial interventions for post-treatment cancer survivors. RCTs are needed to develop and refine interventions for survivors evidencing clinically significant levels of the problem in question (eg, depression, anxiety, fatigue). Identification of mechanisms for effects of interventions will promote the creation of maximally effective approaches. 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 (eg, peer discussion).<sup>97</sup> Cancer-relevant biologic effects (eg, neuroendocrine and immune effects) of psychosocial interventions also are receiving attention, although links with ultimate disease outcomes are not established.<sup>98</sup> As evidence mounts for the role of health behaviors (eg, physical activity,<sup>76</sup> adherence to oral therapies for cancer prevention and management<sup>99</sup>) in preventing cancer recurrence and improving quality of life, controlled trials are warranted to bolster such behaviors in post-treatment survivors. Research also is needed to identify for whom and under what conditions psychosocial and behavioral interventions are most effective (ie, moderators of effects), so that psychosocial care can be targeted and tailored for those in most need. Research with diverse groups also is needed. For example, few psychosocial interventions have been tested with African American, Latino, or rural cancer survivors.<sup>66,69,94</sup> The largest group of cancer survivors in the United States has been diagnosed with breast cancer, and the substantial majority of research on psychosocial care has targeted that group; potentially distinct approaches for individuals with other cancers require study. The knowledge base on psychosocial care for individuals with recurrent and metastatic disease also merits further development.

Pathways for effective dissemination of evidence-based interventions require much more attention.<sup>100</sup> In times of financial constraint, development of maximally effective and accessible interventions is crucial. Professional education initiatives are under way to address a primary institutional barrier to survivorship care, that is, lack of knowledge on the part of practitioners<sup>91</sup>; several experts and national bodies have offered recommendations for implementing survivorship care.<sup>101-104</sup> The Internet and other efficient delivery modalities hold promise.<sup>105</sup> For example, an Internet-based cognitive-behavioral intervention to improve insomnia in cancer survivors demonstrated positive effects on several sleep parameters and fatigue.<sup>106</sup> Automated symptom monitoring and centralized telephone care management resulted in significant reductions in pain and depressive symptoms in adults with cancer from community-based rural and urban oncology practices, more than 40% of whom had completed medical treatment.<sup>69</sup> Although a place remains for the provision of evidence-based psychosocial care by the individual professional with the individual survivor, more accessible and efficient

The author(s) indicated no potential conflicts of interest.

evidence-based approaches also are needed. As the population living with a history of cancer continues to grow, creation and implementation of optimal methods for promoting the health and well-being of post-treatment survivors are critical.

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