Cancer Survivorship: Resilience Across the Lifespan
*Supplement to **Cancer***

Promoting Adjustment after Treatment for Cancer

Annette L. Stanton, Ph.D.[1]
Patricia A. Ganz, M.D.[2]
Julia H. Rowland, Ph.D.[3]
Beth E. Meyerowitz, Ph.D.[4]
Janice L. Krupnick, Ph.D.[5]
Sharon R. Sears, Ph.D.[6]

[1] Department of Psychology, University of California–Los Angeles, Los Angeles, California.

[2] Division of Cancer Prevention and Control Research, School of Public Health and Jonsson Comprehensive Cancer Center, University of California–Los Angeles, Los Angeles, California.

[3] Office of Cancer Survivorship, National Cancer Institute, Bethesda, Maryland.

[4] Department of Psychology, University of Southern California, Los Angeles, California.

[5] Department of Psychiatry, Georgetown University Medical Center, Washington, DC.

[6] Psychology Service, Veteran's Administration Palo Alto Health Care System, Palo Alto, California.

Presented at Cancer Survivorship: Resilience Across the Lifespan, Washington, DC, June 2–4, 2002.

Supported in part by Grant R01 CA63028 from the National Cancer Institute, Bethesda, MD.

Address for reprints: Annette L. Stanton, Ph.D., Department of Psychology, 1285 Franz Hall, Box 951563, University of California, Los Angeles, Los Angeles, CA 90095-1563; Fax: (310) 206-3566; E-mail: astanton@ucla.edu

Received February 28, 2005; accepted May 4, 2005.

DOI 10.1002/cncr.21246

The transition from the period of diagnosis and medical treatment of cancer to survivorship (i.e., the reentry phase) is an understudied phase in the cancer trajectory. The objectives of this report were 1) to illustrate several adaptive tasks of the reentry phase, 2) to provide examples of research on factors that predict positive adjustment during this phase, and 3) to discuss interventions that address the adaptive tasks of early cancer survivorship. Although the pertinent empirical literature is scarce, accounts from cancer survivors, healthcare professionals, and qualitative researchers converge to suggest several themes in adaptive tasks during reentry. Drawing from the authors' work and that of others, the authors have described common expectancies held by many individuals approaching reentry (e.g., "I shouldn't need support"), typical concerns during this phase (e.g., concern over cancer recurrence), and personal and contextual factors that can facilitate and hinder adjustment. Promising psychosocial interventions have been developed for individuals in the reentry period. Continued research will be necessary to characterize this important phase of cancer survivorship. ***Cancer*** **2005;104(11 Suppl): 2608–13.** *© 2005 American Cancer Society.*

KEYWORDS: cancer, survivorship, quality of life, reentry.

"Now, every little thing has me petrified! Any ache means the cancer is back…but, then, I worry that, if part of my mind still believes the cancer will come back, maybe it will. Just trying to think positively can cause stress. I think the hardest part of this week has been the sense of loss I've felt being finished with treatment. You spend so many months doing everything you can to fight the disease, even just relaxing to fight it, and then the doctors have completed all of your treatments. How do I pick up the pieces?"

These words from a breast cancer research participant[1,2] who recently had completed medical treatments vividly capture some of the distinct challenges that can accompany the phase of transition from "cancer patient" to "person," that is, the period of early survivorship that constitutes the several months after the completion of primary treatments for cancer. The objectives of this report were 1) to describe adaptive tasks of the posttreatment phase, 2) to illustrate research on factors that predict positive adjustment during this phase of reentry, and 3) to provide examples of promising interventions designed to address the adaptive tasks of early survivorship.

It is important to note that most individuals who confront a cancer diagnosis adjust well. On general measures of psychological adjustment and quality of life, it is often found that cancer patients are indistinguishable from the general population by 1 or 2 years after diagnosis, given that treatment is complete and the cancer controlled.[3–7] Within this context of overall positive adjustment, however, two points deserve mention. First, there is substantial variability in adjustment. The majority of patients do well, and a subset are at risk for high distress and life disruption.[4,7] Second, rather than producing

TABLE 1
Myths of Treatment Completion

I should be celebrating
I should feel well
I should be the precancer me
I should not need support

global dysfunction, cancer may engender what Andersen et al. have called "islands" of disruption that occur in particular life domains and at particular points in the cancer trajectory.[8] We focus here on the posttreatment phase as one potential island of disruption. Research focusing on this phase is sparse compared with that on the earlier phases of diagnosis and treatment; however, as one woman with gynecologic cancer said, the treatment period is only the first chapter.[9] Furthermore, extant research primarily targets women with breast cancer. Although no standard exists for defining the boundaries of this transition, and individual variability in its experience is likely, we view the year after completion of primary medical treatments (i.e., surgery, radiotherapy, chemotherapy) as constituting the reentry phase.

The Adaptive Tasks of Reentry

Cancer patients themselves and the clinicians working with them alerted us to the distinct challenges accompanying the reentry phase. Twenty years ago, Dr. Fitzhugh Mullan, Chief Medical Officer of the Office of Medical Applications of Research at the National Institutes of Health, wrote about his own experience with cancer and what he called the "reentry" phase.[10,11] The themes Dr. Mullan described in his process of the resumption of life as an active adult[10] are remarkably similar to those that were identified by other cancer survivors,[12,13] healthcare professionals,[9,12–15] and qualitative researchers[16–19] over the next 2 decades. An important point made by those writers was that the challenges faced during reentry often are unanticipated and leave the individual feeling ill-prepared to manage them.[12] Instead of being able to predict the challenges, many patients and their intimate others hold expectancies that we may describe as the "myths of treatment completion" (see Table 1).

The first myth is the expectation that the end of treatment should be celebrated. Although treatment completion represents a major milestone in the cancer trajectory and often is accompanied by relief and positive emotions,[17] many also discover that the work of processing emotions and finding meaning are just beginning. For instance, one research participant said that treatment just "flew by" and that she was not hit with the reality of having cancer until the end of treatment. Furthermore, treatment provides a vehicle for control, a focus for the patient's energy, and a way to cope through active engagement. At treatment completion, the individual may be left with the looming question, "…what do I do now?"

A second common expectation is that the individual should recover soon after the completion of treatment. After all, medical treatments are supposed to leave you feeling better. If lingering fatigue or other physical compromises come as a surprise, then they may prompt self-imposed demands to push past their own physical limits too quickly or misattributions, such as a fear that the cancer is still there. The interpersonal circle also can promote such expectations in communicating an assumption that the individual will return promptly to old roles once treatment is completed. Patients sometimes perceive that individuals on the outside assume that, once the patient is cured, they will be ready to return to whatever they did before with the full vim and vigor they had before cancer, as though nothing had happened.[16]

A third expectation is that the patient should return quickly to their prediagnosis sense of self. However, an altered sense of self is possible. In one report, a breast cancer patient commented that, when she stood in front of a mirror, she was bothered less by the missing breast than the fact that her hair color was different: She still saw a sick person when she looked in the mirror, which was a reminder of what she went through during treatment.[17] In addition to confronting physical reminders of the cancer experience and a new sense of vulnerability, however, individuals with cancer also may experience an enhanced sense of self and the world after treatment. Consistent evidence demonstrates that cancer patients find benefit in their experience. For example, Sears et al.[20] observed that, shortly after the completion of treatment, 83% of a sample of breast cancer patients cited at least 1 benefit in their experience, enjoying a new sense of personal strength (9% of benefits cited), spiritual growth (6%), life possibilities (11%), life appreciation (12%), attention to health behaviors (13%), and enhanced relationships (46%).

A fourth myth is that the patient no longer should need support after treatment is over. Both the interpersonal support system and the medical treatment team rallies around the affected individual during the acute diagnostic and treatment period. Cancer patients often comment on the relatively sharp downturn in active support once they complete treatment.[16,19] Patients sometimes have no one to talk with once their treatment is over.[16] The motivation of loved ones to see the patient as cured, the lack of regular contact with other cancer patients while awaiting medical treatment, and the medical team's congratulatory "I'll see you in 3 months!," all can contribute to a sense of isolation once treatment ends. The comfortable net of safety and support can diminish quickly. Schnipper[13] observed clinically that individuals are more likely to seek a support group after treatment completion than in the phases of diagnosis and treatment.

Counter to the expectation that treatment completion and full recovery of health and well being occur simultaneously, the literature suggests that treatment completion can be disruptive psychologically. For example, Beisecker et al.[17] reported that, 6 months after the completion of treatment, the majority of their breast cancer patient sample had not anticipated the lingering effects of chemotherapy. Furthermore, Ward et al.[21] found that 30% of a sample of 38 breast cancer patients reported that treatment completion was upsetting, and some in our own group have observed that 27% of patients rated the end of radiation and 48% rated the end of chemotherapy as moderately or extremely stressful in a study of 160 women with breast cancer.[22] In a longitudinally designed study, McQuellon et al.[23] found that energy levels had recovered to only 70% of normal at 1 year after bone marrow transplantation.

We suggest that the individual completing treatment often confronts adaptive tasks in four domains: emotional functioning, physical functioning, interpersonal relationships, and life perspectives. These domains resemble those identified in quality-of-life research.[24] However, the content and relative importance of the facets within each domain are the factors that are likely to vary as a function of the specific point in the cancer trajectory. Central concerns of participants in a completed trial illustrate these domains. Our randomized, controlled trial tests a structured, educational intervention (Moving Beyond Cancer) for women who are beginning the reentry phase after breast cancer treatment. We used behavioral self-regulation[25–27] and stress and coping theories[28,29] to guide our hypothesis that gaining preparatory information on what to expect during the phase of cancer recovery and instruction and encouragement in the use of coping strategies oriented toward actively approaching the adaptive tasks will contribute to positive adjustment in the four life domains, perhaps moderated by perceived preparedness for reentry. Women were registered for the trial shortly after they underwent surgery for breast cancer, and they completed baseline measures and were randomized (n = 558 patients) to 1 of 3 intervention arms within approximately 3 months after the completion of primary medical treatments. In one arm, women participated individually in two structured sessions with a trained educator. Women reviewed their own concerns in the four domains as part of the first session; then, they identified a primary concern for which to develop an action plan.

Fully 51% of the women in this trial arm had central concerns in the emotional domain, with 39% reporting fear of cancer recurrence as their dominant concern. The physical domain was of most concern for 26% of women (e.g., weight gain, menopausal symptoms). Of course, the content of these facets would change given a different sample. Incontinence and erectile dysfunction would be included for men with prostate cancer, for example.[30–32] Eleven percent of women reported primary concerns in each of the domains of interpersonal relationships (e.g., partner, work relationships) and life perspectives (e.g., lifestyle change, finding meaning). Only five women identified no major concern for the reentry phase.

Additional evidence suggests that individuals with cancer confront specific concerns during the reentry phase, with accompanying information needs. Luker and colleagues[33] found that 105 patients with breast cancer reported gaining useful information at the time of diagnosis from medical professionals. At an average of 21 months later, however, this sample reported gaining information primarily from the popular media and often reported discomfort in requesting information from medical providers. The majority (66%) reported information needs that had not been met at follow-up (e.g., information about the likelihood of cure of breast cancer and about the risk to family of developing cancer). In a sample of 223 women who were treated for early-stage breast cancer within the prior year,[34] the most frequent concerns were fear of cancer recurrence, pain, death, harm from adjuvant treatment, and medical bills. In a sample of 231 breast cancer survivors[35] (note that most had been diagnosed 3–5 yrs earlier), 48% reported moderate-to-high unmet needs for information on dealing with fears about cancer recurrence, the most frequently endorsed unmet need among 52 rated information needs. Younger patients with breast cancer reported greater information needs in the psychological arena than older women. The evidence that many cancer patients encounter unanticipated and lingering difficulties in multiple life domains during this phase signals the importance of identifying factors that contribute to positive adjustment in the year after treatment.

Predictors of Positive Adjustment During the Reentry Phase

Stress and coping theories[28,29] provide a general conceptual framework for identifying contributors to positive adjustment after cancer treatment. Figure 1 shows that such contributors to adjustment in the four domains can arise from the interpersonal and environmental context; attributes of the individual; dis-

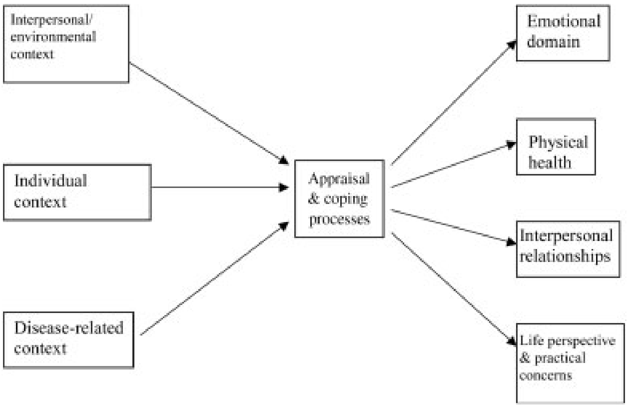

FIGURE 1. This chart illustrates the conceptual framework for posttreatment adjustment.

ease and treatment characteristics; and what the individual thinks and does in response to the cancer experience. Little research has focused specifically on predictors of positive adjustment during the reentry phase.

Stanton and colleagues[1,36] have conducted two studies focusing on the reentry phase in patients with early-stage breast cancer. In the first study,[36] they followed 92 patients with breast cancer from shortly after treatment completion through 3 months, with an additional assessment at 1 year. It was hypothesized that approach-oriented coping strategies (i.e., coping directed toward active engagement with the stressor, such as planning, problem-solving, emotional expression, and positive reappraisal) would promote enhanced physical and psychological health across time. The roles of coping through emotional expression and through positive reappraisal were of particular interest. The investigators predicted that these strategies would be particularly useful for women in receptive social contexts and for women high in hope, which is a sense of goal-directed determination and ability to generate pathways to meet goals.[37]

Analyses revealed that coping through emotional expression maintained consistent relations with the dependent variables, controlling for initial values on the dependent variables and participant age.[36] Specifically, women who, at treatment completion, reported coping with their cancer experience through expressing their emotions demonstrated enhanced physical health, had fewer medical appointments for cancer-related morbidities, and reported lowered distress and increased vigor over the next 3 months compared with women who were less expressive emotionally. Coping through positive reappraisal predicted increased vigor and enhanced self-reported health at 3 months and at 12 months as well as greater self-reported posttraumatic growth at 1 year.[20]

Personal and social factors also were important during this reentry phase. Emotionally expressive coping predicted a decrease in distress and fewer cancer-related medical appointments for women high in hope, and it predicted improved quality of life for women in receptive social contexts. Furthermore, approach-oriented coping strategies mediated the relations between hope and positive outcomes.

These findings suggest that positive social contexts, personal attributes, and particular approach-oriented coping strategies can contribute to adjustment in several domains during the reentry phase. Other research has suggested that good candidates for predictors of cancer-specific adjustment problems in this phase may be younger age,[36,38] receipt of chemotherapy,[39–42] and use of more avoidant coping processes.[36,43] Continued research will aid in identifying additional protective and risk factors for adjustment in the reentry phase, revealing whether predictors of positive adjustment during this phase bode well for adjustment over the long run and determining the utility of these findings for the development of clinical interventions.

Interventions to Promote Posttreatment Adaptation

Longitudinal research has demonstrated that coping through emotional expression and positive reappraisal predicts positive adjustment across time, but a stronger test of the utility of these coping strategies involves an experimental design. An example of such research is a small, randomized, controlled trial of a writing intervention to promote reentry adjustment.[1] In that trial, the researchers hypothesized that inducing women to write about either their deepest thoughts and feelings about their breast cancer experience or the positive aspects of their experience would promote positive psychological and physical health outcomes compared with writing about the facts of their experience with cancer. A second hypothesis was that women who tend to avoid their thoughts and feelings regarding cancer may benefit more from focusing on the positive aspects of their experience, whereas women who are low in avoidance may benefit more from full expression.

These hypotheses were tested in a trial of 60 patients with early-stage breast cancer who were randomized to 1 of 3 writing arms shortly after they completed medical treatment and engaged in 4 writing sessions, with 1-month and 3-month follow-up assessments.[1] With regard to psychological outcomes, the writing intervention was effective differentially for women high and low in cancer-related avoidance, whereas the conditions revealed main effects on physical health outcomes. Specifically, as hypothesized, women who were high in avoidance became less distressed if they wrote about the positive aspects of their cancer experience, and less avoidant participants became less distressed if they wrote about their deepest thoughts and feelings. With regard to physical outcomes, the expressive disclosure condition produced a significant decrease in self-reported somatic symptoms relative to the fact control (i.e., writing about facts of the breast cancer experience). In addition, both the expressive disclosure and benefit-finding conditions were superior to the fact control on another health-related outcome, yielding fewer medical appointments for cancer-related morbidities over the following 3 months.

The demonstrated effectiveness of the benefit-finding condition deserves mention. We agree strongly with Holland and Lewis[44] and others[45] who have cautioned against the tyranny of positive thinking[44] for cancer patients. Characteristics of this trial may have allowed for this condition's effectiveness. First, women on average had been diagnosed for several months when they entered the trial and likely had the opportunity to express negative emotions during that time. Thus, the benefit-finding condition may have prompted balanced emotional expression. Asking women to describe benefits immediately upon cancer diagnosis may have produced very different outcomes. Second, we did not prescribe particular benefits to women but, rather, encouraged women to identify the positive aspects of their experience on their own. We also note that the expressive disclosure condition did show a narrow advantage over the benefit-finding condition on health outcomes, suggesting that full emotional processing may be particularly effective. Of course, emotional expression is likely to be more beneficial for individuals with particular characteristics in specific contexts, and these potential moderators require further study.

We also implemented a reentry intervention in the Moving Beyond Cancer randomized, controlled trial described above. This is a multisite trial that was designed to promote realistic expectancies and approach-oriented coping for women in the breast cancer reentry transition. The three arms involved combinations of written material, a peer-modeling video, and brief, structured psychoeducational sessions, which included identification of a target concern, development of an approach-oriented action plan for addressing the concern, and implementation and evaluation of the plan. The objective is not only to address the target concern but also to promote approach-oriented planning for other concerns encountered in the reentry transition. Findings from this trial and another reentry trial are now available.[46,47]

Summary and Directions for Research

To summarize, most individuals who face cancer report positive global adjustment at reentry, although treatment completion and the ensuing months are likely to constitute an island of disruption, with effects in multiple life domains. Contributors to positive adjustment during this phase are beginning to be identified, and promising interventions are being developed. However, we have far to go in understanding the reentry transition. Although clinical and qualitative writings provide a rich description of the problems of the reentry phase, little empirical work is available. Longitudinal research documenting the experience of reentry is needed, with assessment of cancer-specific outcomes and of positive indicators of adjustment as well as pathology. It also should be noted that the reentry transition may be very different for individuals with early-stage disease versus those with poorer prognoses, for whom the end of treatment often is demarcated less clearly and the transition to survivorship is less certain.

Theoretically driven research to identify protective and risk factors for adjustment in multiple domains is essential as data accumulate to characterize the nature of the reentry transition. Translation of this work into randomized, controlled trials of interventions to promote reentry adjustment in diverse groups of cancer patients and their loved ones also is needed. The findings that personal and contextual factors influence cancer-related adjustment suggest that such factors may moderate the effects of psychosocial interventions on outcomes[48] and that interventions may be targeted most productively to those at highest risk for poor adjustment. Finally, evaluation of the links between aspects of the reentry experience and long-term health outcomes is vital. Such research may establish the reentry phase as a pivotal transition that sets the stage for adaptive long-term survivorship.

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