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Abstract

Some cancer survivors report positive subjective changes they describe as “life transforming.” We used a grounded theory approach to identify the content, underlying process, and identifying characteristics of self-defined “life-transforming” changes (LTCs) reported by 9 cancer survivors. To actualize their hopes for improvement, participants used a self-guided process centered on pragmatic action: researching options, gaining experience, and frankly evaluating results. Many participants discovered unanticipated personal abilities and resources, and those became highly useful in coping with other challenges apart from cancer. This made the increased personal abilities and resources “life transforming” rather than being substantially limited to reducing cancer-related problems. The action-oriented features and processes of LTCs seemed to be more fully described by experiential learning theory than by posttraumatic growth and coping. Supportive intervention to facilitate positive change processes could decrease suffering and enhance positive psychosocial and spiritual outcomes for cancer survivors.

Keywords

cancer, psychosocial aspects; coping and adaptation; healing; illness and disease, life-threatening / terminal; lived experience; palliative care; resilience; self-efficacy; survivorship

Supportive care teams attempt to reduce physical pain, nausea, depression, and other noxious subjective experiences of hospital patients across a wide variety of disease stages and trajectories (Berger, 2006; Sanft & Von Roenn, 2009; Taylor, 1998). Some patients have reported to their caregivers that a valuable positive psychological, social, and/or spiritual change has taken place within them during the course of their illness (Andrykowski, Lykins, & Floyd, 2008; Folkman, 2008; Heffernan, Grealy, & Mutrie, 2009). Such positive changes might indicate a substantial increase in adjustment ability. A more limited but still significant number of these patients reported that their positive changes had been “life transforming.” There has been little research focused specifically on positive changes of this magnitude among cancer patients. Should such changes be understood as the benefit of a sobering wake-up call about mortality, or lessons from suffering, or healing from psychosocial/spiritual wounds, or an epiphany/enlightened insight? In what cancer-related circumstances do these changes occur—diagnosis, treatment, or recovery?

The purpose of this article is to answer the following questions: What is the nature of self-reported subjective changes among cancer patients and survivors that are so

positive as to be life transforming? What is the process that led to such changes? Strong positive changes can help counteract a patient’s negative subjective experiences, and might also help promote health (Salovey, Rothman, Detweiler, & Steward, 2000). Both of these benefits might reduce the cost of medical care (Smith & Cassel, 2009). Strong positive changes therefore represent a valued outcome that can extend well beyond the cure or management of a serious disease or medical condition (Berger, 2006; Sanft & Von Roenn, 2009; Taylor, 1998).

We recognize that positive psychological, social, and spiritual outcomes reported by patients can take many forms, have been documented in many disciplines, and have been identified with many constructs. These include coping (Carver, Scheier, & Weintraub, 1989; Folkman & Lazarus, 1980; Pearlin & Schooler, 1978), “healing”

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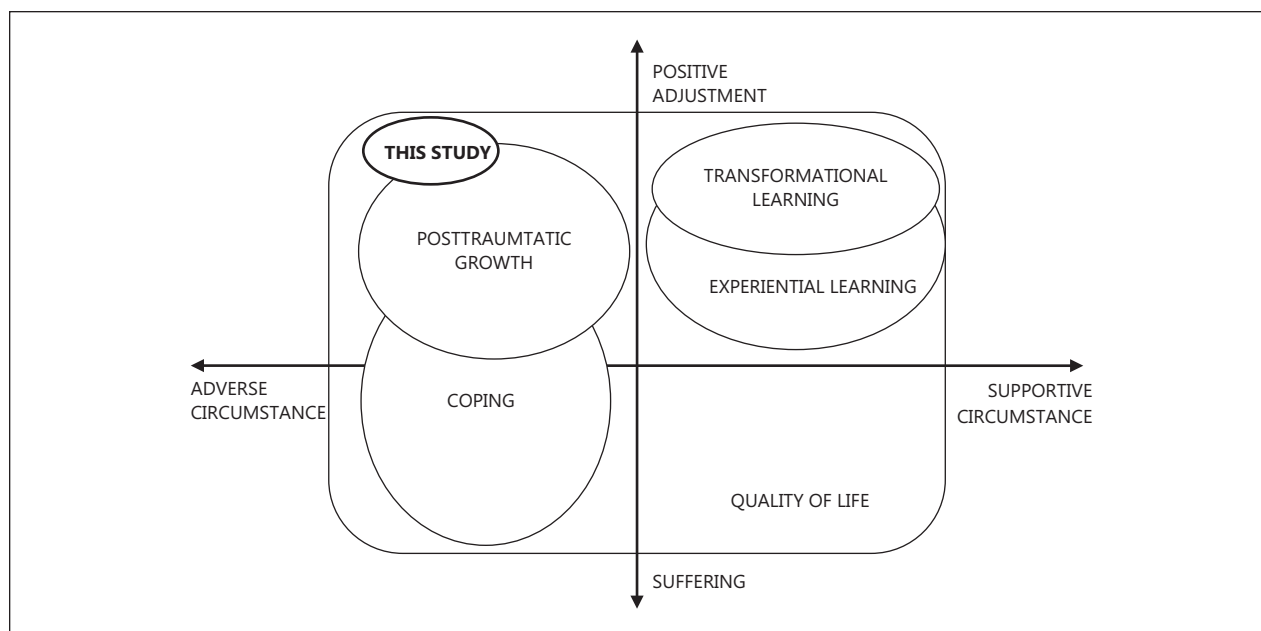


Figure 1. Comparison of population domains.

(Johnson, 2000) of psychosocial and spiritual pain in palliative care (Berger, 2006), posttraumatic growth (Tedeschi & Calhoun, 1996, 2004), stress-related growth (Park, Cohen, & Murch, 1996), benefit-finding (Helgeson, Reynolds, & Tomich, 2006; Linley & Joseph, 2004), resilience (Masten & Coatsworth, 1998; Reich, Zautra, & Hall, 2010), subjective well-being (Diener, Suh, Lucas, & Smith, 1999; Watkins, 2008), and self-actualization (Noble Walker, Richert Sechrist, & Pender, 1987).

We obtained and analyzed data from participants without presumptions of construct or theory (Parkes, 1971) apart from an operational eligibility criterion: self-reported “life-transforming” positive subjective change in the context of cancer. As a result, the Results section is grounded in our data and is not made to conform to any pre-existing theories. It is only in the Discussion section that we place our results in the context of well-established theories. In that section we discuss the implications of our results for other theories and show how our results can be framed in terms of well-established theory. Our intent in the Discussion is to use existing constructs as much as possible to provide a framework for the life-transforming change (LTC) process. We assumed there would be no need to develop new constructs.

Methodology

Recruitment and Informed Consent

We obtained National Institutes of Health (NIH) Institutional Review Board approval of the study’s

protocol prior to participant contact. Recruitment sites were both in the greater Washington, DC, area: a nonmedical holistic services organization (HSO; offering psychological, social, and spiritual support to cancer patients and survivors), and a nonprofit hospital. Candidates were selected and introduced to the study by the heads of supportive care at these organizations. The appropriateness of their selections was supported by both the lack of any screening failures and the richness of data obtained.

Purposeful selection by these staff was based the protocol’s eligibility criteria and on their previous observations of candidates’ articulate and credible self-reports of life-transforming positive changes in relation to their cancer experience. The eligibility criteria were (a) experiencing cancer-related, self-reported, life-transforming positive subjective change which began more than 6 months prior to interview; (b) being age 18 or older; (c) being a cancer survivor (undergoing current or prior cancer treatment; Rowland, 2008); (d) being at a low distress level at screening; and (e) providing audiorecordable English speech. Our LTC eligibility criteria provided a tightly focused population domain (represented as a relatively small ellipse in Figure 1) near the extremes of adverse circumstance (cancer survivors) and positive adjustment (life-transforming change). By selection of participants who had both dominant circumstances and high levels of adjustment, other factors in the participants’ lives were expected to have a less confounding influence on the data.

In contrast, the population domains in much of the related constructs literature have been relatively diverse

both in terms of the circumstances facing the participants and in terms of the range of adjustment in response to those circumstances. These populations are represented qualitatively as relatively large ellipses and a rounded rectangle in Figure 1. The relevance of transformational learning and experiential learning were not anticipated at the beginning of analysis. They are included in this figure because their relevance emerged later in analysis, when constructing a framework for the LTC process.

Interested candidates were given an information packet by staff, including the protocol's informed consent form. The staff assured candidates that their care would not be influenced by participation in the study. Each candidate then met with the NIH interviewer, who answered study-related questions prior to consent. All 9 candidates chose to participate and signed the informed consent form.

Research Session Structure

A 2.25-hour private research session was conducted at the host institution immediately after finalizing consent. The research session consisted of (a) simultaneous screening and preinterview questionnaires, audio recording setup, and establishing rapport (20 min); (b) a semistructured interview (60 min); (c) a 10-minute break; and (d) a questionnaire (Garcia et al., 2007) and structured interview to guide future development of an assessment instrument (45 min). All forms and audio recordings used in the research session were identified by code number only, and in this article participants are identified only by pseudonyms.

A 0-to-10 visual analog scale similar to the distress thermometer (Jacobsen et al., 2005) was used for self-rated distress-level screening. Nine out of 9 participants passed screening. Each participant's preinterview questionnaire included demographic and experiential forms. Participants briefly wrote in their own words up to three positive changes that were related to their cancer, and indicated whether the change was life transforming. On the experiential form participants were also asked whether prior to their cancer they had had traumatic events or serious life challenges, and whether they felt healed (Johnson, 2000) from those events.

The 1-hour semistructured interview typically began with a question about motivation: When you first heard about this study, what made you want to take part? Throughout the remainder of the interview the interviewer sought to elicit descriptions of the participant's concrete experiences (Wertz, 2005). When a participant entered into opinions, beliefs, interpretations, or generalizations regarding his or her positive change, the interviewer asked the participant to describe an actual situation. Descriptions of actual situations provide data that is more concretely rooted in the process of change.

Demographics

Three of the 9 participants were in cancer treatment: 2 in recurrence and 1 in a research protocol after the first course of treatment had been unsuccessful. The range of time since first diagnosis was between 3 and 29 years. One of the participants was under age 46, 4 were between 46 and 65, and 4 were 66 and over. Two of the participants had experienced multiple primary cancers. Participants included 8 women and 1 man; 1 self-identified as Asian, 1 as Black, and 7 as White. All participants were college graduates and 8 had earned a postgraduate degree; 5 were married, 2 were divorced, 1 was widowed, and 1 was single. Participants' religious backgrounds were predominantly Jewish ($n = 4$) or Christian ($n = 3$). Among the 5 participants who identified themselves as employed, 2 were full time and 2 were disabled because of incomplete recovery after cancer treatment. Four participants were retired and 5 engaged in volunteer work. Eight participants were recruited from the HSO and one from NIH. Four had previously enrolled in an HSO-led, 4-day, in-residence healing retreat program.

Analysis

We used a grounded theory approach to develop the LTC process from qualitative interviews and analysis (Charmaz, 2006). Processes of personal change often depend on the interconnection of many steps (Prochaska & DiClemente, 1983; Prochaska & Velicer, 1997); therefore, interview transcripts and written statements were analyzed for both LTC content and process steps. Interview transcripts were read multiple times during analysis as we identified the features and process of participants' LTCs. Once a potential feature of the positive change process was identified in one participant's transcript, other participants' transcripts were examined for the same feature. If a feature was present in the majority of transcripts, it was accepted as a part of the positive change process.

To create a framework for the LTC process, we then attempted to match the features and process of each LTC to existing constructs of adaptation or change in the literature (e.g., coping, posttraumatic growth). Our strategy was to understand participants' LTCs using existing change-related constructs with documented processes. We considered creating a new process or construct only if this effort exhausted the possibilities among existing constructs and associated processes. When each feature and process of LTC from the participants' transcript data was accounted for by a single construct or small set of constructs, this was considered a satisfactory match. Obtaining a satisfactory match required us to consider a broader range of personal change-related constructs than we had anticipated.

Table 1. Cancer-Related Life-Transforming Change (LTC) Scale and Content Categories.

| Domain | Category Of Change |
|------------------------|---|
| LTC scale category | Reduction of negative subjective experiences (toward zero) Increase of positive subjective experiences (away from zero) |
| LTC content categories | Self-care/lower stress Relationships/roles Spirituality/being true to myself Personal strength Priorities/purpose |
| LTC content separation | Multiple LTCs listed by a participant are not easily separable |

Initially it was not known if there might be more than one positive change process represented in our data. One way to classify changes is in terms of scale properties. Different scale properties can correspond to different underlying processes; therefore, scale properties are central to accurate, meaningful measurement of patient-reported experiences (Bartoshuk et al., 2003). Scales for subjective positive change are of two basic types: decrease of a negative experience (e.g., suffering) or increase of a positive experience (e.g., strength). The first type of scale is characterized by a reduction toward zero. The other type of scale is characterized by an increase away from zero.

Results

We analyzed our data three ways: in terms of LTC scale category, content category, and process; this section is divided into corresponding subsections. The LTC process subsection is further divided into four parts: precancer response to trauma, initial responses to cancer (medical and nonmedical), adaptation, and transformation.

LTC Scale Categories

Among patient-reported outcomes in the psychosocial illness impact domain, positive outcomes such as growth have a significant degree of independence from negative outcomes such as suffering (Dees, Vernooij-Dassen, Dekkers, Vissers, & van Weel, 2011). In Table 1 we therefore categorized participants' self-reported LTCs according to two scale types: reduction-toward-zero of negative experiences (e.g., suffering) and increase of positive experiences (growth and other gains). Twenty-two self-reported LTCs were obtained from the 9 participants' written responses to questions on the preinterview experiential form. In the context of what several participants described as highly adverse cancer treatment and recovery, it was quite striking to us that only 7 of 22 (32%) of participants' LTCs could be associated with the reduction toward zero scale. Participants' descriptions of these

LTCs included "less anxious," "react to [more effectively reduce] stress," and "I am more mindful of what is healing for me." Subjective healing in palliative care can be operationally defined in terms of reducing psychosocial or spiritual suffering until a patient indicates, "I'm okay now." Using this definition, only about one third of the participants' LTCs should be considered "healing"—much less than we anticipated.

Fifteen of the LTCs (68%) exhibited the scale characterized by increase of a positive experience away from zero. LTCs on this scale were associated primarily with increased positive psychosocial and spiritual abilities and resources. Participants' descriptions included "sense of inner strength," "deepened relations," "much more connected spiritually," and "life is more purposeful, meaningful." LTCs with this scale type often appeared to be broad gains in life that extended well beyond the issues of cancer.

We sought evidence regarding whether participants' multiple LTCs occurred by independent processes. As a starting point for their respective interviews, 2 participants were asked to choose for discussion any one of the three LTCs they had listed. These participants had listed LTCs in more than one content category, and at least one LTC of each scale type. One participant responded, "They're all kind of interconnected in a way, so I don't know how easy it will be for me to split out each one." The other said, "Well, I mean they all work hand in hand." These responses are consistent with one underlying process for LTCs.

LTC Content Categories

The LTC content categories that emerged were diverse, and similar to categories developed in the context of well-established constructs that are expected in this population (e.g., coping, posttraumatic growth, benefit-finding). The most common category involved attention to self-care and lowering of stress (7/22 LTCs). The other four categories were fairly equally represented in the count: relationships/roles had five, spiritual/being true to myself had

four, personal strength had three, and priorities/purpose had three. One participant's newfound personal strength discovered in the context of cancer was applied elsewhere in life to go through a divorce. Another participant used newfound personal strength to help sustain her marriage. The experience of increased strength in one context (cancer) could change how the individual appraised unrelated yet challenging life situations. It could enable major life changes or resilience that would otherwise be too difficult for the individual; therefore, the increased strength could be life transforming in behavior and outcomes.

LTC Themes and Process, Part 1: Precancer Trauma and Healing

In Table 2 we summarized results obtained from participants' written responses to the precancer questions on the preinterview experiential form. Eight out of 9 participants responded "Yes" to a question asking if they had faced traumatic or very challenging situations before their cancer. However, only 2 of those 8 participants indicated they had been successful at healing those precancer psychosocial and spiritual wounds. This is consistent with the fact that at some point in their attempts to cope with cancer, most of these participants sought help from an HSO.

LTC Themes and Process, Part 2: Initial Responses to Cancer

Initial response to the medical challenges of cancer. Participants' subjective responses to cancer were highly varied in content but similar in certain process elements. One common process element was that participants devoted substantial attention to not one but two main concerns: saving their lives physically, and keeping themselves going psychosocially and spiritually. Typically, 30% to 50% of participants' interview transcripts were related to discussion of their cancer and the associated disruption of their normal lives (see Table 2). Their negative physical experiences of cancer were typical of those described in articles reporting adverse sequelae of cancer patients and survivors (Schag, Ganz, Wing, Sim, & Lee, 1994). The first response to the medical challenge of cancer was most often to learn everything possible and find the best medical care available: "I am a data person. I really need data. So when I was diagnosed I read furiously. I read everything I could get my hands on." This learning response was consistent with the participants' high levels of education.

Initial response to the challenges to normal life. The participants reported experiencing common emotional hardships related to cancer. Participants well understood that they could (or would) die, despite best efforts to save them.

One participant said about hearing a cancer diagnosis, "It's a shock, a tremendous shock. Very disorienting. Because you think that this is a death sentence. I mean, that's what cancer is." Other participants explained: "Of course your first thought is that it only has the potential to ruin your life. You never think that it's going to have the potential to improve your life." "It's only that, well, I could die. Oh, what could be good about that?" The initial shock could reverberate day after day: "You wake up in the morning and the sudden realization hits you again, and, you know, that, 'Oh my God, I have cancer!'" We did not detect any avoidance or denial of the seriousness of cancer among the participants. They also did not express any anticipation that a positive personal change might co-occur with their cancer.

LTC Themes and Process, Part 3: Adaptation to Cancer

Adaptive response to the psychosocial and spiritual challenges to normal life. As their distress lowered, participants recognized they could choose to direct their attention to adapting their personal lives. Their appetitive motivational systems (Elliot & McGregor, 2001; Krieglmeier, Deutsch, de Houwer, & de Raedt, 2010) could become much more active, supported by strong self-efficacy (Bandura, 1982) in the midst of adverse circumstances. Participant Pat explained:

That's the way it is with this disease. It's like you've got a big hill to climb, and if you're lucky you get there and then you get a remission for a while. Then you can go celebrate life and recognize the beauty: "Wow, look at this, I'm off medicine, I can go," knowing it's going to come at some future time. But you put it on the shelf. And you put it on the shelf and then just go at it. And celebrate one day at a time and be grateful for it while [at] the same time you're suffering and you're scared.

Participants used the intensity of their individual situation to their advantage. It was a spur to creative problem solving, adaptation, and focusing on getting desired results. One participant commented, "It's going to sound really bizarre, but in a way that intensity was one of the most creative and fruitful periods of my life even though I was faced with my own mortality." This creative learning process might occur more readily for patients who possess substantial tolerance for dissonance between opposed factors (Bonanno, Papa, Lalande, Westphal, & Coifman, 2004), such as the threat of death vs. becoming "better than before" as a person.

Adaptive beliefs. Beliefs played a key role in enabling participants to attend to positive experiences in the midst of

Table 2. Life-Transforming Change (LTC) Process-Related Themes.

| Domain | Category | Themes |
|--|---------------------------|--|
| Precancer | Trauma and healing | Precancer very challenging situation |
| Cancer | Debilitation | Healing of precancer very challenging situation Cancer: Symptoms, struggle for physical survival, physical fatigue Treatment: Side effects, physical fatigue, body appearance, medical bills, recovery |
| | Challenges to normal life | Intensity of situation was high and ongoing It's not just about the cancer (#1): Life apart from cancer was highly affected Uncertainty: Sometimes overwhelming doubt and confusion, and yet had to make decisions Heightened awareness: Vigilance; sensitivity to pain, physical sensations/symptoms Separation from routine (psychosocially, spiritually), isolation, disconnection, loneliness Vulnerable: Out of control, threatened, faced debilitation and death with fear Loss: Broken, wounded, grief, loss of energy, loss of normal life Benefit unexpected: Did not anticipate becoming a better person than before cancer |
| Adaptive beliefs and attributes | Coping | Distress lowered enough to enable learning Learn everything about this cancer and how to fight it Find medical solutions: The right treatment and the right doctors Distress lowered enough to think about other aspects of life besides cancer |
| | Personal life | Personal life can be maintained: Kept some parts of life normal despite debilitation and disruption (e.g., connection with children) Imperative: Had to find a way to "keep myself going" (keep interest in personal life) Tolerant of dissonance: Acted on good opportunities for life as well as serious problems that threatened death; able to have some genuine enjoyment while also suffering Compensation: A loss in one highly valued area of life was compensated by gain in another highly valued area of life Mastery oriented: Expected that some important aspects of life status could be improved during cancer treatment if the right way could be found |
| Pragmatic actualization: Turning hope into reality | Hope | Hope based on substantial interest in personal life (approach-type motivation), not only avoidance of death (avoidance-type motivation) Highly protective of hope: Changed friends or caregivers to protect hope, because approach and mastery motivations were weakened to the degree that hope was diminished Hope made resilient by grounding it in "my truth" (something positive and personally true for me whether I am healthy, sick, or dying) |
| | Exploring | Highly experiential three-part cycle: Might require multiple cycles, long time Learning what might help me, very proactive, research, then choosing what to try Active experimentation: Trying it out and seeing what truly happens |

(continued)

Table 2. (continued)

| Domain | Category | Themes |
|----------------|---------------------|--|
| | Resources | <p>Frank, honest evaluation of both positive and negative outcomes; not pretending something is helping or being persuaded by others' opinions</p> <p>Apply new resources and abilities to cancer-related issues, lessen impact of the illness</p> <p>Confidence developed, got a grip, looked back for a view of the whole, wisdom, understanding</p> <p>Gathering resources: Getting wide variety of support, giving support, more meaningful relationships: "Oh, I had a village [of supporters]. I really did. . . help came in all sorts of different ways."</p> <p>Unexpected resources, opportunities, abilities, and ways of functioning discovered by experience during actualization.</p> <p>Resource subthemes:</p> <p>Relationships: New or much expanded</p> <p>Strength to persevere, to make changes as needed; found it in myself, didn't create it</p> <p>Spiritual: New or expanded side of life, use it to heal, source of wisdom, might struggle to explain and integrate into life</p> <p>Conserve personal resources: The demand on personal resources is up (e.g., physical and mental energy) and the supply is down</p> <p>Have support during recovery (still feel sick but getting much less care from doctors)</p> |
| Transformation | Extend to noncancer | <p>Highly experiential cycle of applying new ways to noncancer issues</p> <p>It's not just about the cancer (#2): Successful outcomes from applying new resources, abilities, and ways of functioning to noncancer life made them life transforming</p> <p>Gratitude, appreciation, and joy over new ways; empathy for others in crises</p> <p>High value: Some would even go through cancer again rather than forego their most valued new ways; might lead to a new high-interest pursuit</p> <p>Challenge of integration of new ways with old ways that re-emerge if the crisis abates</p> |

negative circumstances. Frequently they identified one or more positive turning points in relation to psychosocial and spiritual challenges of cancer, and these were associated with adaptive beliefs. For example, one participant was the mother of a preschool child when she was diagnosed with an aggressive form of breast cancer. Ann was given a prognosis of living 18 months before death, with or without treatment. She described how her adaptation began and how she arrived at her own key belief:

I was turning myself over to the medical team that I had selected and they were phenomenal. I was fortunate enough to be in a part of the country where I had great medical care, and felt confident about that. But this was so huge, so enormous for me, I just couldn't just sit there and just dutifully go to my doctor's appointments. I had to be [doing] something for myself as well. . . . I remember very clearly

within the first week of diagnosis sitting on my couch waiting, starting chemotherapy the following week, and thinking, "How am I ever going to get through this? And do what's expected of me by or recommended of me/to me by my doctors?" The way they were describing the chemotherapy was pretty brutal. [Pause] I really kept asking myself over and over again, "If I am going to go through this and if I die, if there's any way of getting the maximum out of it in terms of learning something from it or [Pause] growing as a spiritual being." That's what I wanted.

Hope and maintaining approach-type motivation. Hope was an essential, practical support for participants' motivations and corresponding actions (Folkman, 2010), both in fighting cancer for survival (medically) and in "keeping myself going" (psychosocially or spiritually). Ann wanted to keep herself going through a difficult medical

regimen, the loss of opportunity to raise her daughter, and a dying process. Relying on maternal motivation alone would likely have left her in anguish. She needed an additional motivation that could be substantially rewarding to her even in dying, and which might also help improve her chances of living by minimizing the draining effects of a loss of all hope (Dees et al., 2011). Based on a single dramatic spiritual experience during a diagnostic test, she hoped that spiritual growth and learning from her cancer experience would fulfill that need for her. Finding and developing an additional motivation, beginning with a key belief, was a part of the LTC process in which constructive rumination could be quite helpful (Watkins, 2008). Constructive rumination was suggested by Ann's phrase, "I really kept asking myself over and over again."

Participants strongly protected their hope by rejecting doctors or even long-time friends who did not support it. Such individuals were viewed as an intolerable drain on personal energy and motivation. Participants consciously sought to both block negative energy from others and conserve their own limited energy. In part, this might be understood as a way to conserve much-needed personal resources for the accomplishment of their goals (Hobfoll, 1989, 2002). It might also have helped them maintain a sense of control. Participant Yael commented,

There was one woman [friend] who's pretty neurotic, really. And her life was just like living in fear. And I felt like once I got my cancer, I was six feet under in her mind. And so it was negative energy, which I just needed to get away from.

Pat expressed in strong terms how an HSO-led retreat helped cancer survivors clarify and organize their thinking about their own hope and motivation: "What do you have to shed from your life?" and "What do you have to bring into your life?" became a very central issue [during the HSO retreat]. What are you living for? And what are you fighting for?" Leslie considered that for any patient with life-threatening illness, the hope and motivation for adaptation could begin in much more modest ways: "The strength, I guess, in the sense comes from just the experience of waking up every day and saying, 'Oh, I'm still here. And what am I going to do with this day?'"

Pragmatic actualization: Turning hope into reality. Among the participants, active exploration (and what we later came to recognize as experiential learning) turned hope into reality. One participant believed that learning or growing spiritually could be substantially rewarding to her even while dying. This became her additional motivation, and she cautiously but diligently explored any opportunity to actualize it that came her way. It was a form of self-actualization that did not depend on having more basic needs met:

I ended up getting into this whole exploratory research mode of integrative cancer care. And it didn't feel like that was coming out of a sense of panic; it was more that that's kind of just the way I am. I started spending as much free time as I could exploring some of these [complementary] therapies. And I was very cautious about it, as I said, coming from a science background and being a left-brainer. Um, a lot of the stuff was a little too "out there" for me. But there were a lot of things that—I weighed it in and it a, became kind of my research mode.

LTC Themes and Process, Part 4: Transformation

Participants sometimes extended new ways of functioning to noncancer challenges. For example, when they began discussing what made their LTC important, they turned the discussion away from cancer and toward their personal life before cancer. The changes that ultimately became life transforming very often (but not always) directly addressed psychosocial or spiritual challenges prior to cancer. Some of the participants' better ways of functioning with cancer were so broadly useful and meaningful that continued development of them took on an importance beyond cancer. The two main LTCs listed by Leslie were "sense of inner strength" and "ability to make needed changes." During her cancer treatment she found a core strength that she had not previously known within herself, and later she applied that strength to make needed changes personally and professionally that were unrelated to cancer:

If you had said to me before I was diagnosed, "How would you handle a cancer diagnosis and all that goes along with the treatments and the recovery and everything?" I would have said, "Oh, I would just be a wreck." You know, unable to function. . . . And it wasn't that way. Not at all. You know, parts were very hard. Radiation was beyond miserable as it went on, but physically. Once I recovered from surgery, I went back to work and just continued to live my life and deal much as I could. So that was, I guess, Number One on the list—just finding a core strength that I would not have predicted was there. . . . I mean, deciding to leave the marriage was hard. But once I made that decision it was like, if I can make that decision—if I can choose again to be alone and be okay with that and give up some of the security and some of the good parts of marriage—I can probably make other difficult, other hard decisions. So that when I was starting to have some challenges in my previous job, it was like, "Okay, this isn't working anymore. It's time to make a change." And I did. . . . So yes, just being able to say, "This is not working. This needs change," and setting about to change it. It did start with the cancer. You know, where I saw, "Okay, I'm handling this. I'm doing it. I'm not just lying in bed with the covers over my head. I'm out there living life and putting one foot in front of the other."

Discussion

We prefer to understand participants' LTCs using well-established, change-related constructs with documented processes. In general, successful adaptation among seriously ill patients and their caregivers has frequently been characterized in terms of coping (Folkman & Moskowitz, 2000) and posttraumatic growth (PTG). It is useful to consider the LTC process of the participants (who were not a representative sample of cancer survivors as a whole) in relation to specific models of coping (Folkman, 2008) and PTG (Tedeschi & Calhoun, 2004) that have been widely considered in studies of cancer patients and survivors.

Ample evidence of ways of coping (Folkman & Lazarus, 1980) was found throughout each participant's interview transcript. It can be said without any reasonable doubt that the participants engaged in coping as described in Folkman's classic (Folkman, 1984) and revised models of coping (Folkman, 2008). At the same time, they displayed unusually high levels of learning and transformation in the context of coping. Not only were these features toward the extreme adaptive end of the spectrum of coping behavior, but often they tended to persist and even expand after the crisis was over. It is not logical for coping to increase after the taxing situation that motivated it has ended. Therefore, although coping is necessarily and quite usefully a part of the LTC process, it does not satisfactorily account for the features of learning and transformation.

Tedeschi and Calhoun (1996) developed both the Posttraumatic Growth Inventory (PTGI) assessment instrument and a model of the PTG process (2004). The factors of the PTGI overlap strongly with content categories of LTC (see Table 1), as well as the transcript contents. However, the strong emphasis on rumination in the PTG model contrasts with the active experimentation and ongoing experiential learning that were so prominent in our study. LTC's highly experiential (behaviorally oriented) process does not satisfactorily match PTG's rumination-based (cognitively oriented) process.

LTC and Experiential Learning

Obtaining a satisfactory match for the LTC process required us to consider a broader range of change-related constructs than we had anticipated. In particular, we found a much better match for the LTC process in experiential learning (Cramer et al., 2011; Kolb & Kolb, 2009; Timmann et al., 2010) and transformational learning literature. Experiential learning (EL) is not the same as formal classroom learning (Kolb, 1984); it applies to more unfamiliar, uncontrolled, complex, real-life situations. It is often self-guided and self-taught, and therefore it requires more mature judgment faculties than learning by classroom instruction. It is generally more successful in

well-motivated adults. These characteristics make EL widely suitable for business training, but the same characteristics are also apparently suitable for helping patients meet many of the psychosocial and spiritual challenges associated with cancer.

The classic form of EL is a cycle with four parts: concrete experience, reflective observation, abstract conceptualization, and active experimentation (Kolb & Kolb, 2009). The three-part "exploring" cycle (see Table 2) could readily be restructured into the four-part EL cycle without compromise of data integrity. Also, themes from Table 2 can readily be organized into a larger, more comprehensive four-part EL cycle that encompasses nearly all of the themes. For example, concrete experience in EL corresponds to themes of cancer experience, life disruption, and experiencing the results of active experimentation within exploring.

Jarvis (1992) placed EL in the wider context of all adult self-learning by constructing a three-level typology of learning (Levels 1 to 3 of Figure 2); EL appears at the third level: reflective learning. In Jarvis' typology, we have noted, higher levels correspond to higher levels of learner attention and appetitive motivation. It is appropriate to ask what might happen in a more intensely motivated learning situation, such as the participants' efforts to find ways to "keep myself going." Could the learning process extend beyond the level of reflective learning, and what new features would characterize such a level?

One such feature could be the transformation phenomenon of LTC. Such transformation is characterized by the generalization of experiential learning to domains of life that are unrelated to the original learning context. Within the discipline of learning there is an analogous phenomenon referred to as transformational learning (Jarvis, 2008; Taylor, 2007). In the educational domain it refers to a learner's discovery of an entirely different way to conceptualize the experiences he or she has in everyday life, and how nature functions as a whole. LTC and transformative learning both appear to be EL carried to the point of transformation, having both a cognitive and a behavioral impact that extend well beyond the original context of experiential learning. We have therefore inserted transformative learning as a fourth level on top of Jarvis' typology of learning.

The four levels of this typology can be used to understand how coping, PTG, and LTC might be related to each other in the same patient. The majority of a cancer patient's day-to-day responses to medical challenges and life disruptions can be well described as coping. In the learning typology this corresponds to activity on Levels 1 to 3. Coping responses might often begin at Level 1 (non-learning) because Level 1 requires the least effort, and rise as high as the third level if the situation demands reflective thinking (requiring more effort and more

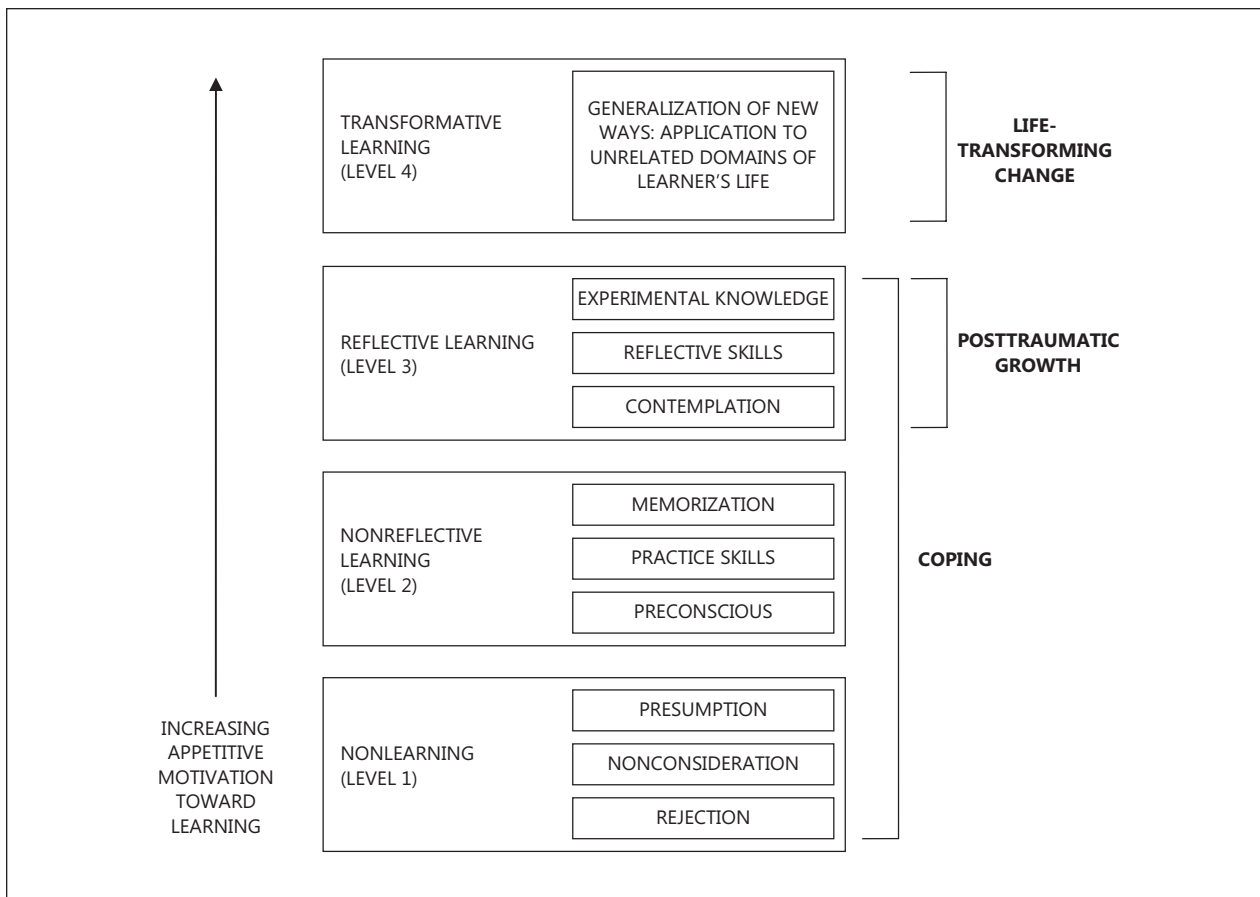


Figure 2. Typology of learning. (Adapted from Jarvis, 1992).

motivation, which could be aided by the intensity of the situation). In a smaller number of situations additional reflection (rumination) at the third level might lead to PTG, consistent with Tedeschi and Calhoun’s (2004) model. In a yet smaller number of situations the learning activity might rise to the fourth level, transformative learning.

When a new way of functioning is learned experientially in one context (e.g., among the challenges of cancer) and is then applied with substantial benefit in noncancer domains of life (e.g., workplace challenges), this is transformational learning. Transformational learning was typical of LTC as reported by 8 out of 9 participants (1 participant’s self-identified LTC did not meet the criteria of transformative learning because it was not applied in a noncancer domain). The exemplar quote in the Transformation subsection of this article is an example of transformative learning. The participant applied increased personal strength (discovered in the context of cancer) to make needed changes concerning two difficult life problems that did not arise in relation to cancer: a

marriage that was persistently unrewarding and a job that became too stressful.

This understanding of experiential learning in the context of cancer can be combined with the LTC process outline to create a model of the LTC process (see Figure 3). The intensity, disruption, and debilitation of going through cancer meant that participants were highly concerned about their cancer and their medical treatment. Successful coping with medical issues lowered distress sufficiently to enable them to meaningfully engage in aspects of their life other than medical survival. They saw “keeping myself going” psychosocially or spiritually through treatment and subsequent recovery or dying as an important tool in their overall strategy.

Supported by key beliefs and the ongoing intensity of the situation, participants used a highly pragmatic and effective process based on experiential learning and resilient hope to find ways to keep going. Based on their effective use of the experiential learning process, they were sometimes not only able to keep going, but found greater personal abilities and better ways to function in

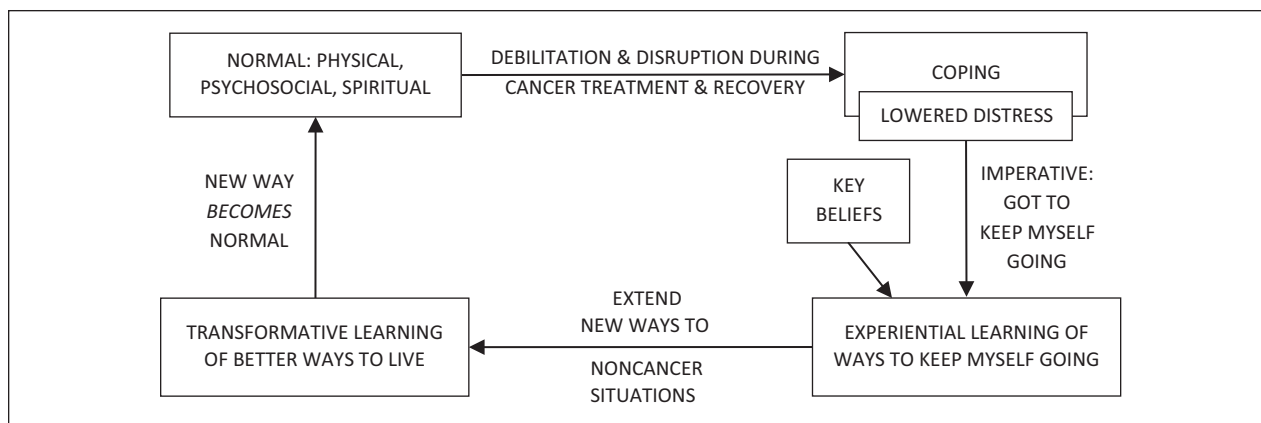


Figure 3. Cancer-related life-transforming change process.

life (often unexpectedly). Application of these abilities and better ways of functioning could result in improved relationships; greater spiritual depth; increased personal strength; and much clearer priorities, purpose, and meaning in life. Some of these were so appealing and broadly useful in participants' lives that additional development of them took on an importance beyond cancer. They not only helped participants "keep going" in the context of cancer; they became life transforming.

Strengths and Weaknesses

Life-transforming positive change was used as a self-reported eligibility criterion. The advantages of studying this population include: (a) they represent successfully adaptive outcomes with highly positive subjective value, and (b) it is easier to delineate the features and processes of such change because of its relative strength. As expected, some participants did have strong experiences of "healing" (Johnson, 2000). However, other LTCs were frequently found that did not involve healing of a psychosocial or spiritual wound. The ability of qualitative analysis to discover and characterize an unexpected type of LTC is also a strength.

The study population was quite limited in certain demographic categories. The number of women (8) far outweighed the number of men (1). The educational background of participants was highly skewed toward higher education. Greater socioeconomic, educational, and racial diversity are needed to broaden the applicability of the results. In addition, it would be desirable to interview participants with diseases and serious medical conditions other than cancer. Also, our focus exclusively on participants who had life-transforming positive changes also carries limitations. Participants who have a different outcome (no life-transforming positive changes) might be expected to experience different process

pathways compared to participants in this study (Bonanno, Westphal, & Mancini, 2011; Carver, 1998)

Conclusions

LTC, as described by the participants, was neither an anomaly nor a fantasy, nor the result of rare heroics; it was the natural though often unexpected culmination of a systematic, rational, and pragmatic process of psychosocial and spiritual self-care. It involved frequently and intelligently applying an ordinary experiential learning process in ongoing and intense circumstances that helped sustain high motivation, and this sometimes yielded extraordinarily valuable results. Engaging in the LTC process would likely aid the adjustment of most patients, whether they utilize the full process or just a part of the process. Facilitation of the LTC process could be made one of the core competencies of supportive care teams, holistic services organizations, and oncology-related specialties.

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