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OF THE LITERATURE AND OUR
EMPIRICAL WORK

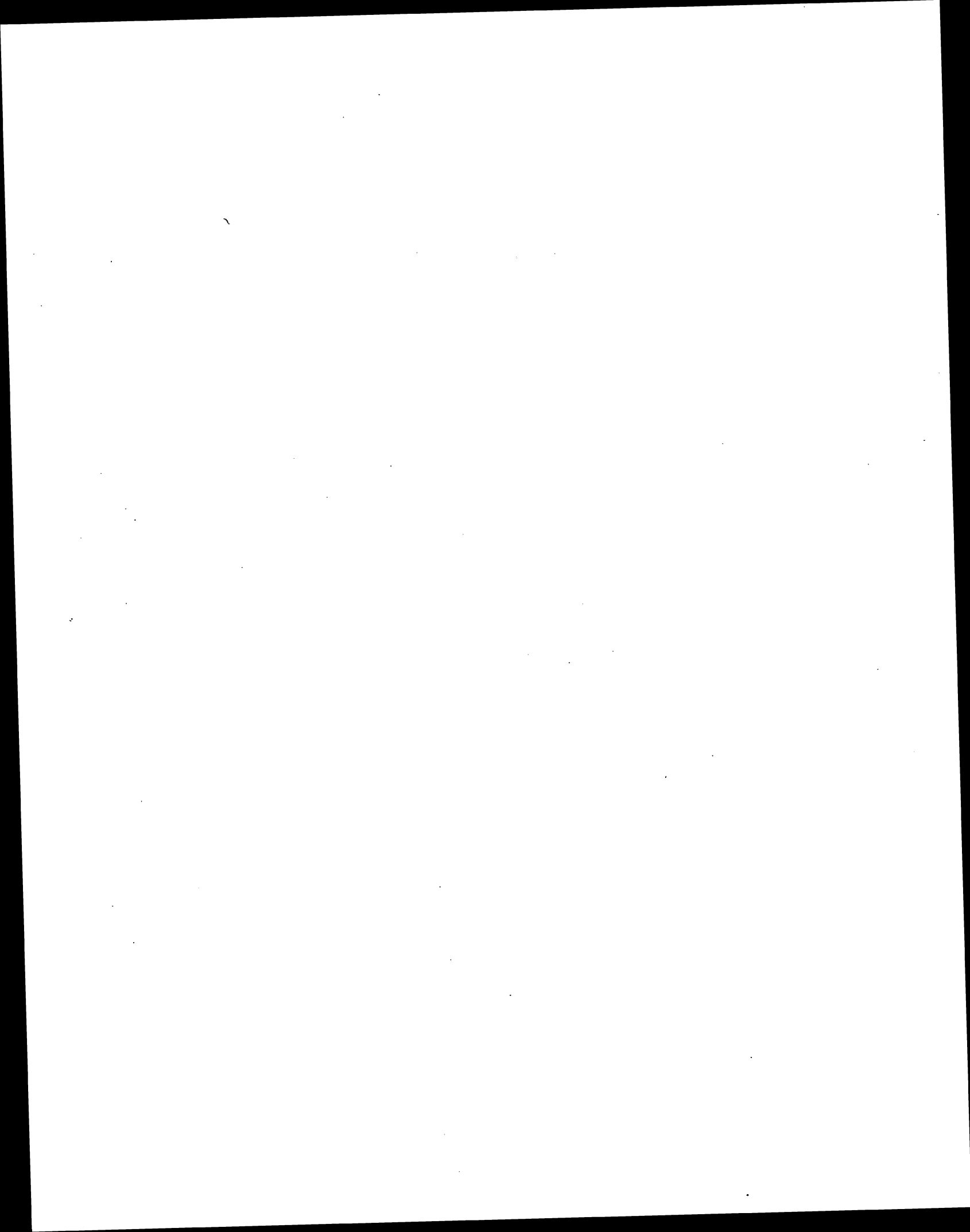
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SOME SURVIVORS OF CHILDHOOD CANCER ARE "THRIVING" – ILLUSION OR REALITY? A SYNTHETIC REVIEW OF THE LITERATURE AND OUR EMPIRICAL WORK

Mark Chesler
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A recently emerging literature on stress, threat and trauma provides us with a different paradigm for examining and understanding responses to these situations. It raises the possibility that people may not only survive such stress and trauma, they may "thrive" as a result, and they may create a higher quality of life than prior to the stress. In this paper I review some of this material and integrate it with our findings about the lives of young people surviving (or thriving from) childhood cancer (and their parents). My goal in this paper is not to conduct an exegesis on the concept of thriving for survivors of childhood cancer (the literature review and conceptual analysis of terms and measures is partial at this stage), nor to prove its empirical reality (although I will provide descriptive evidence of its probable existence), but to explore this concept, to order some of this literature, and to set the stage for its deliberate application to studies of survivors of childhood cancer.

I. Background to a discussion of thriving

The history of psychosocial research on stress and trauma, and on serious medical conditions, has emphasized the potentially negative and debilitating effects of such events and situations. But as Folkman & Greer (2000, p. 11) argue, the focus on "psychiatric symptoms, such as anxiety and depression... obscures the struggle for psychological well-being and the coping processes that support it." Perhaps even more dramatically, Paterson et al. (1999) discuss how some people can transform their lives by responding to an illness in ways that enhance the quality and meaning of their lives. In their words, living with (or beyond) a chronic illness enables some "individuals to experience life, themselves, and others in a way that was inaccessible previously; that is, they can be transformed by the experience of living with a chronic illness to

experience positive and rewarding outcomes (p. 786).” What does this mean? Is it Pollyannaish to talk about positive outcomes and higher quality of life in the context of recovery from serious and chronic illness? In what kinds of traumatic situations is thriving more or less likely – or possible? What do/can people do to create this transformation – surely it does not just “happen” to them? There must be some kind of personal or collective agency involved – what is it and why/how do some people find/create it and others don't? What is this new paradigm about?

What is thriving?

“Thriving” is the general term for a number of recently coined psychological constructs, including thriving (O’Leary et al., 1998; O’Leary & Ickovics, 1995), transformation (Paterson et al., 1999), transformational coping (Aldwin, 1994), and post-traumatic growth (Tedeschi & Calhoun, 1996). The last term is particularly ironic, (probably deliberately), as it challenges the only slightly less recent attempt to apply the diagnosis of “post traumatic stress” or “post traumatic stress syndrome/disorder” to the same situations of long-term outcomes of trauma. There also are referents in the literature to terms such as “efficacy”, “courage”, “resilience” and “stress resistance”.

Carver (1998) and O’Leary (1998) establish similar continua of sorts to describe people’s potential responses to trauma. The range includes:

Succumbing – giving up or otherwise being unable to function effectively

Surviving - continuing to function although at a reduced rate

Recovering – being resilient and returning to a prior level of functioning, regaining homeostasis

Thriving – transforming the threat into a challenge and ending up functioning at a higher level than before the trauma

The core issue is that in the face of threat (stress or trauma) people may have many different kinds of responses. Collins et al. (1990, p. 264), discussing cancer explicitly, note that such trauma “shatters the perception of personal invulnerability” and, in so doing, “alters one sense of self-worth and world meaning.” Tedeschi et al. (1998, p. 2) put it slightly differently: “Trauma calls into question the basic assumption of one’s future and how to move toward that future, and therefore produces massive anxiety and psychic pain that is difficult to manage.” In particular, the overwhelming scholarly and

public interpretation of the cancer trauma has been that it will create significant negative psychosocial reactions and negative long-term outcomes.

Taylor (1983) was one of the first scholars to make the general argument that positive outcomes could flow from stress responses. She developed a theory of cognitive adaptation to stress that focused on: (a) a search for meaning – about why what happened happened, about its impact and its implications; (b) seeking mastery – to manage both the immediate situation and its implications; and (c) enhancing self-esteem damaged/threatened by the event – by feeling good despite what happened and/or engaging in social comparisons. Andrykowski et al. (1993) note that “In working with cancer patients, it is not uncommon to encounter individuals who flatly state that having cancer was the best thing that ever happened to them (p. 262).” What might account for people’s different responses to cancer and other threats; stress or trauma?

Thriving is a form of coping.

Thriving requires the individual to actively cope, or mobilize “individual and social resources in response to risk or threat, leading to positive mental or physical outcomes and/or positive social outcomes (Ickovics & Park, 1998, p. 237)”. Part of this process involves reevaluating the negative and threatening event as positive by: (Thompson, 1985): (a) finding side-benefits - related positive outcomes, such as feeling closer to one’s family, becoming more aware of others and life goals; (b) social comparing – seeing others doing less well; (c) imagining worse situations - and feeling lucky; (d) forgetting the negative (although that may come close to denial); and/or (e) redefining the situation – changing self-expectations and therefore being satisfied with lesser or perhaps just “different” outcomes. The attached Figure A, from Thompson (1985), provides some examples of these processes in the form of statements by trauma “victims” who have focused on the positives. Affleck & Tennen (1996) talk about this general process as “benefit finding”, including “devictimizing” oneself and “resolving the challenge to taken-for-granted and set the stage for deep-seated personal change” (p. 906). There is a vast and often disorganized literature on coping strategies in general, and the work (still minimal) that links coping strategies to thriving

is still vague and often fragmented (e.g., discussions of "active coping" and "problem-solving coping" are some of the natural starting points, but thriving as a postulated outcomes goes far beyond these descriptors).

A central element of any of these coping strategies or outcomes related to thriving is the process of meaning-making, either referring to making new meaning out of a situation that is/was traumatic/stressful, or making new meaning out of one's larger life. Collins et al. (1990, above) implies this when referring to the way the trauma alters one's "sense of self-worth and world meaning". Similarly, Thompson's (1985, above) discussion of reevaluating the traumatic event as positive clearly requires making new meaning, as does O'Leary's focus on "re-examining meaning" (1998). Paterson et al. (1999) suggest that the key to this process is the ability to convert a threat into a challenge (described by Finfgeld, 1999, as "courage"). This involves a cognitive shift whereby people reframe or reinterpret both their illness experience and themselves (from victim of the traumatic situation to creator of a new situation or life stance and response). Many of us go through life and work not feeling as if we are the masters of our own ship, the architects of our life path. The destabilizing and challenging impact of trauma may permit us to trim our sails and grab the rudder, taking over the direction of our lives (even if that life is somewhat more circumscribed in certain ways now than previously).

Dirksen (1995) emphasizes the importance of the search for meaning among adult survivors of melanoma. She locates this phenomenon within "attribution theory", wherein "individuals initiate a causal search for events in their lives which are unexpected, sudden and/or stressful, in an attempt to understand and gain control over their lives (p. 628)." The effort seeks to "comprehend why an event occurred and... the personal significance of that event (p. 628-9)." This issue is addressed squarely and in greater detail by Park & Folkman (1997). They discriminate between making new "global meaning" (referring to new life goals, understanding of fate and/or the order of self in the universe) and making new "situational meaning" (referring to making new appraisals of the stressful event, understanding its implications and coping with it). These authors suggest that new meaning making requires: (a) reevaluating the event

as positive (at least partially); (b) developing an answer for why it happened or why it happened to me (hopefully an answer that does not blame oneself, since that seems to lead to depression, emotional abasement and paralysis); (c) changing one's life; and (d) making sense or finding life meaning in the event and response (a and b clearly are more "situational" while c and d are more "global").

Successful meaning making requires refitting the situational and global senses of the event either to alter one's global life outlook to fit the event or to reinterpret the event to fit into one's life schema. O'Leary et al. (1998) also help in this regard, distinguishing between notions of change in one's "core self-identity" and one's "reflective-self"; the latter is where meaning making usually enters. But meaning making also can enter for the former, changes in self-identity, and Harvey (1996, p. 13) argues that meaning making leads to, for some, "embracing a survivor mission... transforming the experience into creative pursuits or determined social action."

Carter (1993), studying breast cancer survivors, explicitly identifies several stages of meaning making that help people make sense of their disease within the context of their lives: (a) interpreting the diagnosis (and its meaning for themselves); (b) confronting their mortality; (c) reprioritizing (changing life styles and goals); (d) coming to terms (acceptance of the situation and integrating necessary changes); (e) moving on (with one's life and putting cancer in the past); and (f) flashing back (revisiting and reliving some experiences). Given the preeminence of psychological researchers studying both meaning making and thriving as intra-psychic processes, it seems important to emphasize the crucial relevance of the social environment as a source of stimulus and reinforcement. Significant others' in one's social network clearly have impact on all the above processes, influencing a survivor's ability to reinterpret, reprioritize, revisit and move on, as well as supporting courageous and/or transformative responses.

Finally, as a methodological note, Massey et al. (1998) argues that if meaning making is what we think is important we must engage in in-depth qualitative studies! We may profit from insights and evidence about relative functioning gained from standardized physical (motoric and sensory) measures, psychometric tests and large-

scale attitude or outlook surveys. But that doesn't tell us what the "meaning" of such functioning is for the individual, and thus the full impact of functioning for a person's life (Haase et al., 1999, distinguishes in this regard "function studies" from "meaning studies"). For instance, as a result of trauma/illness a person may lose a degree of ambulatory function. But if that same person finds greater possibilities for emotional or professional expression even without mobility, the loss of ambulatory function may not matter much – it may even have facilitated this inner growth. The process of meaning-making, and the content of new situational or global identities and interpretations of the world, can only be retrieved from open-ended and intense conversations and observations of people engaged in such acts. Moreover, as we engage people in generating and sharing their narrative reports it is clear that such story-telling itself can create greater coherence. As Robinson (1993) argues, the telling of one's story doesn't just reflect life, it orders it. Thus, as we engage with informants in the (co-)story telling process we are helping to create responses to stress and threat just as we are retrieving them. Individual self-reports, managed and organized substantially by informants themselves, rather than by a standardized series of a priori questions, are always open to question. But they are the clearest expression of informants' ways of thinking about and presenting themselves. Our role as scholars is to listen to and reflect upon these self-reports, "test" them for accuracy or unreliability, for defensiveness or obfuscation, and for internal contradiction. Indeed, in our own research (discussed further below), we conducted open-ended interviews, group interviews and surveys with large numbers of informants. In these interviews/conversations we often challenged informants' self-presentations, asking for clarity about vague responses, self-serving voices and apparent contradictions. We also shared our data and early interpretations with informants, inviting survivors' corrections, reactions and co-theorizing. The combination of several studies of different groups of childhood cancer survivors, conversations with survivors and their parents and their siblings, probing interviews, and survey questions as well as interviews, provide us with a sense of the credibility and trustworthiness of our preliminary findings (reported below).

Thriving as process v. thriving as outcome.

Sometimes the literature makes it difficult to distinguish between descriptions of the process of thriving and the results of thriving. The term thriving, and others like it, sometimes are used as descriptions of a coping process and sometimes of a coping outcome. Indeed, some of the empirical research is basically tautological, predicting from quality of life to thriving or thriving to personal adjustment or to well-being or mental health or whatever. Affleck & Tennen (1996) acknowledge some of this difficulty in trying to distinguish between “benefit-finding” as an outcome indication and “benefit-reminding” (sort of like Thompson’s search for positives) as a coping process (but some of this may be the difference between a passive noun form and an active verb form). By the same token, sometimes meaning-making is used to describe a coping strategy and sometimes it is used to describe an outcome (see above).

Despite this confusion, Cella & Tross (1986), report that their sample of survivors of Hodgkin’s disease “clearly showed greater appreciation of life than the comparison sample (p. 620),” lending support to the notion that one can create benefits or otherwise thrive from the cancer experience. More specifically, some of the reported indicators or results of thriving (or maybe its processes) include, according to Tedeschi & Calhoun (1996): (a) changes in oneself; (b) changes in one’s relationships with others; and (c) changes in one’s philosophy of life. These same indicators also are conceptualized by Tedeschi et al. (1998) as outcomes or as indicators of “post-traumatic growth”:

Personal outcomes

- Moving from victim to survivor mentality (an identity change)
- Self-reliance (“If I can survive this I can survive anything”)
- Vulnerability (awareness of mortality and preciousness of life)

Interpersonal outcomes

- Emotional openness (disclosure and expressiveness)
- Compassion for others

Philosophical outcomes

- New priorities of life
- Sense of meaning
- Spiritual development
- Wisdom

Specific items capturing these indicators are presented in Figure B, from Tedeschi & Calhoun (1996).

Collins et al. (1990) summarize outcomes such as those above as changes in one's daily activities, relationships with others, and views of self and the future. In a somewhat more conceptual, but empirically less distinct, manner O'Leary et al. (1998) further suggest that the results of thriving include: (a) new skills (empathy, self-understanding, activism); (b) better relationships; and (c) changed life perspectives (new priorities, life goals, meaning and purpose). And Carver (1998) suggests a closely related set of outcomes (or indicators) of thriving that include: (a) new skills and knowledge; (b) confidence and mastery; and (c) stronger personal relations

With particular respect to cancer-related issues, Curbow et al. (1993) note that bone marrow transplant survivors often report positive life changes in relationships and in existential/psychological areas, "positive change...in beliefs about what is important in life (p. 437)." Dirksen's (1995) research with melanoma survivors rests on the assumption that once positive meaning has been made of the cancer experience people can achieve outcomes such as "a heightened sense of awareness, living in a more meaningful and conscious way, and a restructuring of values and priorities... enjoy(ing) life more fully having faced death (p. 629)." And Gotay & Muraoka (1998) review Sorensen's report that breast cancer survivors "reported a number of positive outcomes, including increased emotional intimacy, increased value of life, and a discovery of emotional strength and resilience (p. 660)." A substantial list of life change outcomes reported by cancer patients awaiting Bone Marrow Transplantation, is provided by Andrykowski et al. (1993), included as Figure C. The primary negative changes include a lessened ability to be physically active and to plan for daily and future activities, including a greater sense of aloneness and lack of enjoyment. At the same time, even in the midst of this very serious medical situation, positive changes are reported in several relationship areas (spouse, children, friends) and in self-respect and life outlook (Andrykowski notes that these reports of positive change may not be quite as positive as they may seem, since some of them are also reported by healthy control samples). Other researchers have reported similar positive and negative

outcomes among people surviving coronary heart disease (Newman & Moch, 1991), myocardial infarction (Johnson & Morse, 1990), spinal cord injury (Yoshida 1993), diabetes (Paterson et al., 1993; LeMone, 1995), AIDS (Coward & Lewis, 1993), advanced forms of breast cancer (Coward, 1990; Luker et al., 1996), and testicular cancer (Gritz et al., 1990). And the list goes on.

It is worth mentioning that the perspective of the observer (scientist or otherwise) is an important issue here. For instance, one might see greater expressions of emotional openness and vulnerability, or new and less material pursuits, as do Tedeschi et al. (1998; and others, see Eiser, 1998), as positive and indicative of psychological growth; others may see these as negative reports and as indicative of psychological loss. Of course informants reporting such change almost always see them as positive, as an unhooking from prior socialization into materialistic achievement patterns and as an entry into new ways of living and relating with others.

Discussion of some of the correlates or predictors of thriving should help us refine and target our understanding of this phenomenon, even while it re-raises the question of tautologies. There is too much of this literature to deal with here, especially since our primary concern is not with generic issues but with their relevance to studies of survivors of childhood cancer. But, for instance, in Curbow et al.'s (1993) study of 171 survivors of bone marrow transplants, the following predictors of "secondary benefits" or "positive life change, were discovered: (a) nature of the disease and treatment; (b) social status and social support; and (c) subjective psychological attributes. O'Leary et al. (1998) adds that thriving also depends on (d) developmental stage. Ickovics & Park (1998) add the importance of (e) one's location in the social hierarchy (e.g., race, class and social status) and Rutter's (1987) research with stress-resistant children adds the variables of (f) personality (pre-existing self-esteem); and (g) family cohesion. And O'Leary et al. (1998) pull together lots of this in Figure D.

Thriving is neither fixed nor uniform.

Massey et al. (1998) add an important qualifier to this discussion, noting that "Thriving is not fixed, one experiences inevitable ups and downs (p. 340)." Thus,

thriving can come and go. Many others, including Cella & Tross (1986) note that just because one demonstrates thriving, or that research demonstrates thriving, does not mean that people report only positive changes and outcomes: negative outcomes and pain can occur at the same time as thriving or “stress related growth” (Park et al., 1996). And Curbow et al. (1993) report the simultaneous existence of “problems flowing from a negative life event” (i.e. bone marrow transplant) as well as “secondary benefits”.

In addition, several researchers argue that people can report positive change or growth on certain life dimensions (most notably life outlook and spiritual commitment), but loss on others (most notably physical health and activity level, see again Figure C, from Andrykowski et al.). Gotay & Muraoka (1998) provide several examples of each in their review of the literature on survivors of adult-onset cancers. These commentaries emphasize the point that thriving is not a unitary but a multidimensional concept (Cohen et al., 1998).

Are these reports of positive outcomes, however framed and measured, believable?

Some scholars suggest that these apparently positive outcomes are really evidence of denial, low self-awareness, lying or faulty instrumentation. Shedler et al. (1993) directly challenge Taylor’s early article on “cognitive adaptation”, and her discussion of the positive function of “illusions”, as self-serving distortions and biases that go hand in hand with poor mental health. They argue that defensive denial is costly and that it is not hard to fool oneself and observers (e.g., self-reports or others’ reports or clinicians’ observations are less reliable than physiological measures). They conclude that, “standard mental health scales appear unable to distinguish between genuine mental health and the facade or illusion of mental health created by defenses (1993, p. 1117).” Further, they argue that these “scales are valid when they indicate distress but ambiguous when they indicate health” (p. 1121), leading to a subgroup of apparently healthy people who have “illusory mental health” but bad physiological indicators like coronary reactivity (and I suppose sweaty palms). It is particularly interesting that Shedler et al. argue for the existence of only a one-tailed error (why are

these scales valid for negative outcomes but potentially invalid for positive ones – might they not be equally valid or invalid in both directions and might not observers be fooled in either way?)!

Although this is one of the strongest attacks, others raise important questions of a similar sort. Park et al. (1996) ask “Is there validity to self-reported outcomes not grounded in concrete measurable changes (p. 73).” And I remember how cautious I and my colleagues have been to not broadly report or publish our early (Chesler, 1988) findings about the positive changes and outcomes reported by survivors of childhood cancer. Affleck & Tennen (1996) try to respond to this question by arguing that their observations of “benefit-finding” do not necessarily involve denial of harm, and others report negative as well as positive comments (and scores) from informants.

As a partial contrast, Matt et al. (1988) argues (as do others) that denial itself is not necessarily bad (except for researchers trying to argue that it is not “real” but only “illusory” mental health). Of course, if denial leads to refusal to acknowledge a medical diagnosis, and an insistence on inappropriate risk-taking, it may well be dangerous. Aside from these extremes, however, a moderate level of denial may allow for a period of adjustment, permit individuals to maintain a sense of self-esteem, and be an effective emotion-focused coping strategy. More interesting than the debate over denial, per se, is the possibility raised by Andrykowski et al. (1993) that survivors may “recalibrate” their internal reference system when responding to inquiries: this downward “response shift” may be a function of changed standards for oneself and life goals (in this context see Tedeschi et al.’s 1998 list - and see below). As we suggest later, this is a particularly important line of interpretation for our concern with populations of adolescent and young adult survivors, people in the midst of coming to clarity and engaging in reality-testing about their identities, core values and life goals.

All this does raise the question of just what is a “measurable change” in situational perceptions or life goals, and the related question of how to measure such change. Cohen et al. (1998) provide some assistance: while suggesting that we “be skeptical of victims’ self-reports (p. 329)”, they encourage corroboration via reports from significant others, use of multiple measures, and use of control groups. They also

ask who decides what is a benefit or a gain (so corroboration may be very tricky), and thus highlight the inherent subjectivity of this phenomenon (the broad phenomenon not only of thriving but of wellness, QOL, positive adjustment or mental health itself). Such subjectivity is not generally addressed directly by the use of standardized measures generated and tested by scientists or the reports of others in the person's environment. Still, a number of scholars argue for the use of multiple observations or reporters on quality of life measures (e.g., patient and spouse evaluations of patient's functioning, or child and parent and physician and teacher rating of child's physical functioning or mental health). This is another particularly potent issue in research with young children who may not read or understand well (under the age of 12 perhaps), where some researchers call for the use of "proxies" such as parents for such ratings. Landgraf (1999) poses the question of whether the child's own report, or the parent's report of the child's situation, is the true "gold standard" in such research. She also advises us to limit our search for truth in such proxy or comparative reports; and consider the degrees of agreement or discrepancy between them as a variable in and of itself.

At least two other issues bedevil the researchers working on these issues: (1) problems of selection bias (do people with certain psychological orientations not participate in such studies, thereby skewing the results) and (2) social desirability in responses (Madan-Swain et al., 1994), or informants' desires to self-present in certain ways (for internal or external purposes) - or perhaps even "political correctness" in current day language.

II. Thriving among survivors of childhood cancer...and our own work

The argument that childhood cancer is an exemplar of a trauma or threat is well documented in the literature and in our own work (clearly a life-threatening and chronic threat to our most cherished and vulnerable family member). More specifically, we used previously a stress-coping-social support paradigm to study these issues in the family context of childhood cancer (Chesler & Barbarin, 1986). We developed therein a five-fold set of psychosocial stresses that family members (parents and children) face: intellectual or informational, practical, emotional or intrapsychic, interpersonal or social,

and existential or spiritual. Coping responses must attend to each of them, depending upon their impact on any single person, and thriving must account for each of them.

The overall threat and particular stresses of childhood cancer can continue well after treatment ends, as is made clear by the many studies that document long-term physical impacts of the disease and treatment, or "late effects". A number of recent researchers have begun to develop measures of Health Related Quality of Life (HRQL), explicitly to study survivor (mostly physical) functioning (Feeny et al., 1992; and summarized in Calaminus & Kiebert, 1999; Van Schaik et al., 1999). Note, however, that in Haase et al's (1999) terms this line of research has focused much more clearly on studies of "function" than on "meaning" - the meaning of a loss or change in function for the individual is typically not assessed.

It is clear that the psychosocial stresses of childhood cancer (as other serious and chronic illnesses) also can continue long after treatment ends. Interestingly but not surprisingly, the history of research on chronic and serious childhood illness has emphasized issues of psychological and emotional distress and/or deviance (Tavormina et al., 1976), and the early perspectives on childhood cancer certainly fit this model. The initial psychosocial studies of childhood cancer survivors emphasized the presence of psychopathology, adjustment problems and school/career deficits. In fact, Koocher & O'Malley (1981) argued that perhaps 33% of childhood cancer survivors were at risk for serious psychosocial problems. Other studies more or less repeated this dominant theme, confirming what many medical and psychosocial clinicians believed to be the case (see a summary in Chesler & Zebrack, 1997).

Van Eys posed a forward-looking theoretical and interventionist challenge to this line of thinking in his book, *THE TRULY CURED CHILD* (1997), and some of the earliest serious empirical counter-evidence was provided by Cella & Tross (1986). In their study comparing adolescent and young adult survivors of Hodgkin's' disease with a control sample, Cella & Tross reported that survivors were at least as well adjusted, showed both more positive affect and negative affect, and felt more personal control over their lives than did their peers without a cancer history. A series of studies followed that verified the finding that the majority of childhood cancer survivors were

relatively well-adjusted psychosocially, that some small portion (10%-15%) were psychologically distressed, and that a sizable portion were coping more positively than their peers (see a summary in Chesler & Zebrack, 1997). Haase et al. (1999), in particular, now propose to study positive coping in the context of a model of courageousness and adolescent resilience!

Perhaps the state of research on this issue can best be summarized by Smith et al.'s (1991) observation that the experience with cancer necessarily alters the way survivors view themselves and their world, and that these alterations can be positive or negative and both positive and negative. This sets the stage for the current inquiry agenda, one involving researchers from different medical and psychological backgrounds and orientations, using different methods and measures, often with different samples of survivors (of different ages, diagnoses and length of time since the end of treatment); some with and some without control or comparison groups. Moreover, current research is being conducted in a medical context where survival from/with childhood cancer is no longer a rare or singular phenomenon: in the 1960s and 1970s, for instance (which is when survivors studied in a 1981 report would have had to have been diagnosed and treated), survival was still relatively rare (perhaps 10%-20% in the 1960s and 40-50% in the 1970s for all types of childhood cancer combined, contrasted with 65%-75% - or even 90% for some diagnoses - in the 1990s), not many youngsters survived, and those who did were seen as medical "miracles" – and without peer survivors. This cohort effect alone may be assumed to have a significant effect on the psychosocial outlooks of current day survivors.

As an example of the more recent and more optimistic research findings, Gray et al. (1992) report results showing "survivors expressing significantly more positive affect, less negative affect, more perceived control in life situations, and more satisfaction with the amount of control they experienced in situations (compared to controls)... suggestive of better mental health in survivors compared with their peers (p. 2718-19)." Gray et al. also report finding improvements in survivors' relationships with family and friends. Findings from several other studies point to the expression of various positive psychological, interpersonal and existential/spiritual outcomes of the

childhood cancer experience (Apajasalo et al., 1996; Fritz et al., 1988; Kazak et al., 1994; Kupst et al., 1998; Zeltzer, 1993). Many of these results mirror the gains in life appreciation, goal reprioritization, compassion and relationships with others that have been reported in the general literature on “thriving”. This is not to “deny” or overlook the series of studies reporting negative outcomes (or even the negative outcomes accompanying some of the positive outcomes in the above-cited studies), but that is a matter for a more detailed review (see Chesler & Zebrack, 1997).

Woodgate & Clement’s (1997) review of coping strategies that may lead to such positive outcomes include: imagining or actually having a positive appearance, being active, believing one is special or different in comparison to peers, believing that one is adaptable and resilient, and making sense of their experience. Other reports confirm the positive utility of these coping strategies and add others. However, some of this work prompts repetition of my earlier concern about whether and how coping is being treated as a process variable (as in a strategy leading to an outcome), as an outcome variable itself (as in thriving), or as both.

Our current work

Findings from our own studies also demonstrate positive as well as negative outcomes for adolescent and young adult survivors of childhood cancer. Since my purpose here is not to characterize or analyze the range of such outcomes, nor their predictors, but explicitly to explore the case for thriving among some in this population, that will be the focus of the remainder of this paper. For instance, consider Figures E and F, containing tables adapted from Chesler & Zebrack (1997). These Figures compare samples of long-term survivors of childhood cancer with samples of similar-age adolescents and young adults without a cancer history. One set of data (LTS-I and Comp-I) were gathered in 1988-89 and another set (LTS-II and Comp-II), in a different venue, in 1995-96. Both tables demonstrate substantial similarity in the responses of the LTS-I and LTS-II samples, arguing for good reliability of the questions. In Figure E, with regard to a series of questions about general health worries, worries not related specifically cancer, more survivors report worrying less than the comparison sample (an apparently positive outcome). When we ask about health issues reasonably

impacted by a cancer diagnosis and treatment, however, more survivors report higher levels of worry than does the comparison sample (an apparently realistic self-assessment). The evidence that childhood cancer survivors worry more than the comparison group about issues that are realistically related to their cancer experience makes good sense: it also gives us added confidence in the credibility of their complementary report that they worry less than the comparison group about the more general series of health issues.

In Figure F the survivors more often report being different than other young people their age than does the comparison sample with regard to feeling “more mature” (although that finding for LTS-I is not repeated for LTS-II) and having a more positive and “clearer existential sense”. The survivors also report (viz ups and downs) more often feeling different in being “physically less healthy.” One reason the LTS-II informants show a major difference from LTS-I in their “no answer” reports is an artifact of a change in the exact wording and placement of this question in the survey. Both these Figures suggest some positive outcomes.

Some excerpts from our interviews with survivors may provide a further flavor of their outlooks, when asked if there were any positive or negative outcomes of their cancer experience. Some survivors talked about negative outcomes, primarily regarding their physical health status.

I can't do what everyone else can do. Like the things you take for granted I can't do, like run and stuff.

I'm afraid about infertility. And I'm a little worried that once I have children, what are the chances of them getting cancer. I think about that. I'm really worried about being able to have children, that's my biggest fear.

These comments clearly reflect the cancer-specific worries reported in Figure E and the negative physical health differences reported in Figure F. Other survivors reported negative outcomes focused on their relations with peers or their social comfort.

I'm close to my friends but I was before. And now, it's like a lot harder for me to get close to people. Or to trust them, you know. I'm a little more superficial.

I used to be really, really outgoing. And I'm not anymore. I mean I used to be like always smiling and always, you know, very bubbly. I mean it's probably part of growing up too. I got older, but I think I just changed more quickly.

But the majority of survivors interviewed, like the majority of their responses to the survey questions, reported positive outcomes.

I think about the fact that I had cancer and that if I could get through cancer then I should probably be able to get through anything.

The experience made me more mature, more than older guys. I'm serious about what I say and do, and have no reason to play around. I know I'm mortal, as funny as that sounds. But a lot of people are living for the day, which is great, but I don't know as thought they appreciate what they've got.

These comments seem to illustrate Tedeschi & Calhoun's (1998) categories of acknowledged "vulnerability" and "self-reliance".

Several other informants commented on an increased sense of empathy with or "compassion for others" (Tedeschi & Calhoun, 1998).

My life is now inspiring people. I do things for someone else.

I consider myself fairly empathic. I pick up on others' feelings pretty easily...being alone in a room for hours on end, yeah it'll tend to help you turn inward.

I feel I respect other people more and listen better. I also try hard to help others and spend more of my time doing things for others.

Another category suggested by Tedeschi & Calhoun (1998) includes "philosophical outcomes", such as "new priorities" and "spiritual development", or in Park & Folkman's (1997) terms, new "global meaning". This was such a common and powerful set of responses that I provide several examples.

I learned so much. And I really learned it fast. It brought me much closer to God and it made me a stronger person. I know for sure what I believe and what I want out of life. So I would say it (cancer) really strengthened me a lot.

I feel I've learned good lessons from it (my cancer). You know, I've learned how to be, not to take things for granted, I've learned that my family and social life are very important to me, and that I shouldn't judge people based on how they act some of the time.

I realize what is important in life and I don't take everything for granted. I want to live life to its fullest.

There's not enough time to tell you all of them (the changes cancer has made in my life). I think the most important is 'I live for today because no one promised me tomorrow'.

I feel I'm more perceptive toward people with special needs. And I have a 'one day at a time' philosophy which helps me enjoy life more. I also tend to be

serious and without leaning toward conceit, I feel that I'm more mature about my general outlook toward life than my contemporaries.

We coded most of this last set of comments as "positive existential" change (see Figures G and H); they seem to reflect a new and different appreciation of one's life situation and the development/expression of a coherent outlook on the meaning of (one's) life. They express in some detail what Curbow et al. (1993) refer to in their report of survivors' newly developed sense of "what is important in life".

One might argue, at this point, that some of these expressions reflect appropriate developmental-stage growth of adolescents and young adults, and that they are not necessarily linked to their cancer experience. This is a difficult argument to respond to, but we can begin to address it in two ways: (1) when we asked similar questions about life change to comparison samples they did not as often respond in this "positive existential" category, nor were their statements in any category as well-developed and articulate as were the survivors'; and (2) sometimes the survivors stated quite clearly how they thought their new outlooks were related to their cancer history/experience. For instance:

I guess I've been through something totally different than most people my age and I think it gives me, you know, a really different outlook on life. You know, I know a lot of people who are like, 'Oh, let's go and drink and party.' And I'm just like I don't take my health for granted. I really value my health.

I think that because of the cancer I am a better writer, and I'm now into creative writing. Because of what happened when I was a little kid made me notice different things about life and what was really important and what isn't important.

I think I'm stronger. I am very independent now. I set my mind to doing something and I do it. I think that part of me has definitely been impacted by the fact that I've had cancer. There are a lot of go-getters out there, but when you've accomplished something like that (surviving the cancer and treatments), when you've gotten through something like that, it just gives you a determination, a drive, to achieve well in school and to do well in life.

Having faced the idea of dying has made me look at life in a different way – to respect life and what I have each day.

These statements clearly are different from (more than) the normal development progress of young people. They reflect the impact of a life-threatening trauma, one that

permitted and/or caused many of these young people to “experience life, themselves, and others in a way that was inaccessible previously (Paterson et al., 1999, p. 786... quoted previously). In metaphoric terms, many of these young people have walked or been pushed to the edge of a deep chasm, have looked over into the depths of fear and the face of death itself, and they have returned. They have had experiences that many of us, much older, have not had. And these experiences have changed, strengthened and transformed many of them.

Figure G presents survey data (in contrast to the above interview data) on survivors' assessments of their life changes (similar to the chart from Andrykowski et al., 1993). Note the constant report of positive life changes (life better now) for all items except comparative physical health. Of course, it is unclear from these reports, despite the focus of the question, whether informants were reporting changes from before their illness to now or from the midst (nadir) of their illness/treatment period to now. But once again, the combination of both positive and negative reports, the ways the data in Figure G fit with Figures E and F, and the excerpts provide above do suggest positive change overall.

Shall we interpret the data from Figure E, F, and especially G, and the excerpts above, as evidence of thriving? If thriving is more than positive outcomes, more than recovering or surviving, if it is being better off now than before the illness, then both Figure G and several of the excerpts are powerful indicators.

Are these data to be believed?

Apajasalo et al. (1996) is one of many reports that question the finding of positive outcomes for childhood cancer survivors with the notion that “denial is likely to be involved (p. 1357).” Many of these reports express concern about the mental health of “denyers”, and caution against believing the evidence of positive outcomes on their face because of the assumed prevalence of denial. But it is not clear whether and how often or how much denial really is at work. Moreover, some of these same reports discuss the potentially positive utility of denial as a coping mechanism, while wondering about its existence (or degree of existence), thus bemoaning its confusing effect on

scientific inquiry. Closely related to concerns about denial, Elkin et al. (1997) discuss the possible presence in survivors of a "repressor personality style" a stable personality trait developed or exacerbated by the need to repress memories of unpleasant trauma.

Another series of interpretations that questions the "face value" of positive outcome reports focuses less on internal psychic defenses and more on survivors' external self-presentations. For instance, Madan-Swain et al. (1994) discuss the high levels of social desirability in their samples of childhood cancer survivors, suggesting that as a similarly complicating factor in unraveling the "true" nature of mental health outcomes. Moreover, Madan-Swain et al. (1994, p. 457) point to the "desire to appear 'supernormal' (that) may lead these youth to acknowledge less responsibility for the negative aspects of their lives." Gray et al. (1992) acknowledge the literature that argues that apparent mental health in this population may be defensive, "a kind of bravado coping style masking underlying suffering and maladjustment (p. 2719)," but conclude that there is no evidence for this interpretation.

Among the interpretations that do accept the possibilities of positive mental health outcomes in this population, Eiser (1998), Gray et al. (1992) and Hagan et al. (1972) point to survivors' potential development of new and improved coping skills. Their argument is that as young people learned to deal and live with this trauma they learned new ways of coping (reflecting earlier discussions of "problem-solving coping", "benefit finding", etc.). As a result, they have turned an objectively disadvantageous situation into one from which they have gained some sense of satisfaction and growth.

Eiser (1998) also discusses the possibility that as survivors' reflect on their experiences and respond to assessment efforts they may alter their internal referents or calibrations of traditional versions of success or of the good life. She notes we should not "make the assumption that all individuals aspire to the same gold standard of achievement... (and take into) account the fact that the experience of cancer may change an individual's view of what is important in life (p. 626)", and lead to less materialistic, more empathic, and different perspectives on life. Two striking examples of just such a transformation are reported by survivors/thrivers we interviewed:

I don't have a desire anymore for the material things, the things that other teenagers want, cars, that kind of stuff – no interest. I pay attention to other things now: trees turning colors, first snow, ants on the ground. I have an appreciation for life that others my age don't have.

If I hadn't gotten cancer I probably wouldn't be as nice a person. I'd probably be a jerk actually. I'd be an alright guy and everything, but I'd probably be more stuck on looks and more superficial things.

Several comments presented previously also express survivors' newfound appreciation of what they have, rather than what they might seek to obtain in traditional achievement terms.

In this sense (as in Thompson, 1985), it is important to distinguish between "lowered" life goals or expectations and "different" ones! "Changing standards" is not the same as "lowering standards" or a "downward response shift", although once again it is clear that much of the eventual evaluation of coping outcomes is a matter of judgement – in the eye of the researcher, so to speak. It seems to me especially important to listen carefully to what these survivors themselves say, and to be cautious about (not automatically accepting but also not quickly rejecting) how we interpret and reinterpret their expressions. The issue of different standards and transformations in life outlooks and goals has special import when we are talking about adolescents and young adults, people whose values, life goals and even identities are still very much in the process of formation.

All of us conducting such research wonder about the validity of young informants' self-reflections and reports. One strategic option is to use parents (or other adults – teachers, medical staffs, psychologists) as raters of the child's condition, adaptation or general quality of life. But such proxies are problematic in their own right, as external assessments of an informant's subjective internal reality. The issue facing us in the psychosocial realm is not simply an objective confirmation of "function" but an indication of the "meaning" of function as well. Moreover, rather consistently across a series of illness conditions, comparisons of child and parent (or others') reports show low agreement, with parents reporting more symptoms (Achenbach et al., 1987; Elkin et al., 1997; Levi & Drotar, 1999; Sawyer et al., 1999). Depending on your point of view, this is interpreted as "child under-reporting" or "parent over-reporting", but there is as

yet no compelling evidence to assert whose report is likely to be more "accurate" (whatever accuracy might be taken to mean in this context). However, Landgraf (1999, p. 148) approvingly reports Seid's argument that "adolescents, at least 12 years of age, can provide information that is reliable, valid and defensible when compared to relatively objective criteria...". And Guyatt (1999) reports that after age 11 parental ratings added little information to children's ratings of their illness situation or its impact on their life.

Another approach is to raise these questions of validity directly with informants, especially informants who are sufficiently mature to respond intelligently and meaningfully. Our focus on adolescents and young adults make this process of prompting self-reflection and self-interpretation especially reliable and useful and we continually ask individual survivors and panels of childhood cancer survivors to help us interpret some of the above results (charts E, F and G). We explicitly inquire into the possibility of denial or distortion or self-presentation (like social desirability). Overwhelmingly (not universally but overwhelmingly), our efforts at "member validation/verification" have resulted in emphatic suggestions by survivors that denial is not at work, advice that we should believe these results at "face value", that these reports represent "real change", sometimes accompanied by elaborate reasons why we should do so. Some examples of their explanations that provide this line of interpretation follow:

After dealing with the huge worries about cancer - Are you gonna get better? Will I stay in remission? It's not worth the effort to worry about the little things. And everything else is little.

It becomes an issue of priorities. When you've experienced issues of life and death it becomes difficult to take seriously anything less. The main concerns of survivors are, therefore, those relating to relapse, infertility, death, etc.

I came out of my ordeal a stronger person. I think that having cancer put me in my place, so to speak, or maybe showed me that there are better things in life than worrying about 'little things'. I suppose worrying about dying isn't a little thing, but, well, all I can say about that is that I conquered it and that being exposed to the idea of it, being faced with it, I am better prepared for it....I am overjoyed to be over my cancer and ready to get on with the important things in my life. I wouldn't change a thing that has happened to me. Yes, it is ironic, I wouldn't change it now. But when first

faced with it I did not want to fight or accept the burdens of my diagnosis. This, most of all, shows the changes I have gone through. I am a totally different person now.

Because the experience of dealing with cancer can be so profound, the more superficial things in life, such as appearances, become less important. However, such things as procreation and the recurrence of illness, which are directly affected by the original diagnosis and treatment, quite naturally take on a more substantial role. I believe that when (young) people encounter the possibility of death, their focus of concerns begins to narrow in order to deal with the issues that might impact their lives the most.

Several of these articulate and powerful comments suggest “not to sweat the little things”, and that the “profound” experience of childhood cancer has led these young people to (re)evaluate what they see as really important to them in life. The “little things” referred to are, for the most part, the general health worries in Figure E and the social differences in Figure F. The “huge worries”, the big things, are the cancer specific worries in Figure F, including relapse and infertility. These reports of changes mirror the positive existential differences described in Figure F and the prior excerpts discussing changes in philosophy of life and global outcomes (see also Tedeschi & Calhoun, 1998; Park & Folkman, 1997); they are examples of the process of reprioritization and of changed core values and life goals referred to earlier.

To be sure, not all long-term survivors said these kinds of things. For instance:

I believe it is a case of self-presentation. When you're in the hospital on treatment it is 'socially required' to have a positive attitude. If you don't have one naturally you have to pretend to. That's what I did. That way people would talk with you more when you had problems and would generally be more attentive to your needs. I felt like a big fraud, but I got used to it. I'm still acting in that pseudo-positive fashion even though I hate it and know it's phony.

This young man uses language and an interpretive frame that clearly supports the notion of self-presentation and social desirability, rather than fundamental change. But he also reflects another key dynamic in these youngsters' medical and social interactions; the situational demand to be a “good patient” – to “be up”, not to complain, to conform to positive expectations. This is not quite the same as “social desirability”

(Madan-Swain et al., 1994), but it does alert us to the ways in which others in the environment influence verbal reports of one's status and even, on occasion, physical behavior. Some survivors also report similar behavior in their interactions with their parents, as a way of protecting their parents from additional worry. Thus, the relevance of the context and of changes in situational coping, for positive or negative coping outcomes, is once again highlighted.

In addition to the use of comparative samples (e.g., Figure E and F), as previously noted we also gathered corroborative data, in the case of Figure H, by repeating the same questions posed in Figure G to three different samples of survivors of childhood cancer, at different times and in different venues, with remarkably similar results. These data, coupled with survivors' reports of their worries, and of some of the ways in which they differ "negatively", verify the notion that positive and negative outcomes can exist simultaneously, and that they can differ according to the life dimension or specific issue at stake (see also other studies with negative or positive and negative outcomes). These repetitions of self-reported complexity should further reinforce the notion (although certainly not settle the issue) that the data are relatively believable on their face.

The nature of meaning making for childhood cancer survivors/thrivers.

With regard to meaning making, I think the experience of cancer, especially childhood cancer, creates the opportunity for more alternatives in meaning making than some other traumatic events. This is not just because it is a serious and chronic disease with major and lasting life impact that challenges the assumptive world of health and of childhood innocence. In addition, because childhood cancer, especially, has quite mysterious origins (few known directly causative hereditary or environmental agents), the door is wide open for speculation about why it occurs, and to whom. Indeed, we have previously documented how parents of children with cancer often wonder "Why has this happened to me – and my child?" (Chesler & Barbarin, 1986). In part this is a practical inquiry, a search for information about the mysterious origins or causes of this disease. And in part it is a Job-like cry of pain and anger. Thus, such

wonderment and confusion represents either or both intellectual or existential/spiritual stress on the part of parents (and a search for meaning in either situational or global terms as a response): no doubt children, especially older children, have the same question.

Moreover, because children's cognitive and meaning making systems (and probably their basic psychology) are more in the formative process, and thus more malleable than are adults', it is even more possible for their "core identities" and "self-reflected identities" (or "situational" and "global" identities) to grow or change (in any direction but hopefully positive) as a result of trauma. In the case of children surviving cancer, the possibilities of situational redefinitions in a positive direction, and hence thriving, are greater because there is little possibility that they themselves have contributed (via smoking, diet, drunk driving, etc.) to the onset of their situation (and hence little realistic reason to personalize or internalize blame for trauma causation).

The social system surrounding children diagnosed with cancer also creates the opportunity for new forms of meaning making (as in the prior excerpt wherein the young man talks about presenting himself in socially approved ways to the hospital staff). For instance, I suspect it is now often the case that at the point of diagnosis and early treatment, more and more physicians and family members (emboldened by rising "cure" rates) now tell the newly diagnosed child several things that have enormous implications for their thriving potential: "We are all going to help you and love you", "You are going to beat this", "You are a little hero, you are so brave", "You are special to us", "You will be a survivor." In the context of narrative formation, Robinson suggests that through comments such as these, "Health care professionals are powerful significant others to the storying process (1993, p. 20)"; obviously, parents and close family members also play this role, especially for young children. In addition, an enormous amount of nuclear and extended family (and sometimes community) love and attention is focused on the ill child and celebrates her/his recovery and survival (often to the detriment of siblings). Finally, now many young patients have the opportunity to meet other children with cancer and other survivors of childhood cancer; their

encounters with these "veterans" and role models of success can be very powerful as well. The combination of these supports almost amounts to a process of resocialization.

Fortunately for our research interests, informants in this age group can speak directly about their reactions, concerns, feelings and outlooks: we have not had to rely solely on "proxies" (although we have gathered such data from parents and are examining their comparability) and have been able to involve these informants directly in co-interpretive conversations and co-meaning making, both through previously noted open-ended and dialogic interview processes and "member verification" activities.

Given the above factors, it is no wonder that in interviews many of the survivors report having at least a partial identity as a cancer survivor (Harvey, 1996), and we currently are analyzing some of the meaning making processes accompanying or leading to these reports. Perhaps a few examples of their perspectives will provide a flavor of this process/outcome.

I really strongly believe that everybody has something coming to them to teach them a lesson. For some reason I got leukemia. And I feel that I've learned good lessons from it. You know, I've learned how to be, how not to take things for granted. I've learned that my family and my social life are very important to me. It has taught me some lessons.

There was a voice in my head – 'You want to die?' I woke up in the recovery room and then I really started believing there's a purpose for me to be here and it was my destiny to find out. I began to feel emotions and feelings about a lot of things that changed my life. I was deeper into my feelings. I'm an inspiration to my family. Even my mother sometimes looks at me, like, 'Where's all that wisdom coming from?'

I'm interested in what are the unknowns. Cancer had to do with that, cancer is an unknown and made me interested in other unknowns, like space or what's on the bottom of the ocean.

I think survivor is a pretty good term for it because to call yourself a victim would be kinda ridiculous. You're definitely not a victim. And you're obviously a survivor because you got through it and not everyone survived.

As these young people think and talk about who they are, who they want to be, how they are different (different now from before and different from their peers), some are taking on an identity as a cancer survivor, or are incorporating their cancer survivorship as part of their broader identity. And it appears that some of them are taking on and expressing a public identity as a survivor. Harvey also draws attention to the situation

wherein some survivors adopt not only a survivor identity but a “survivor mission”. One young woman made her survivor mission very clear.

I've always been very visible with my cancer history. I've been active, I was active with the American Cancer Society, on their speakers' bureau, and in counseling cancer patients.

In a similar vein, several survivors have joined our research project to help us (and themselves) study these issues and advocate for survivor services, some serve as volunteers or peer counselors in childhood cancer hospitals or clinics, and some have served on the staff or National Board of the Candlelighters Childhood Cancer Foundation and like agencies. Moreover, numerous others have reported their educational and future goals as leading to careers as physicians, social workers and in general advocates – especially for cancer patients and children but more generally for people with “special needs”.

Madan-Swain et al. (2000, p. 108-109) discuss the mature state of adolescent “identity achievement” as referring to “those youths who have experienced a period of questioning and exploration and consequently have formed commitments to a personal set of values and beliefs.” This is certainly what appears to be occurring and is reflected in the above comments (even though Madan-Swain and colleagues explore these issues in the useful but more limited context of highly structured psychometric measures). Further, Gregory et al. (1998), discuss such outcomes as a “new sense of self”, once again related to new ways of interpreting or coming to terms with their illness situation and their global outlook on who they are and their life values and goals. So perhaps what we have here is the development of an identity as a “cautious conqueror” of trauma and threat!

But over and above the matter of identity, per se, the several sets of comments I have presented reflect more than “survivorship”. Many of these young people are not just talking about surviving their cancer experience, they are talking about ways in which they have grown positively thereby – as young people who are “thriving”!

In one of the few prior empirical discussions of these issues for childhood cancer survivors, Weigers et al. (1998) review Smith et al.'s (1991) conclusion that the positive or negative outcomes for childhood cancer survivors “depends upon the meaning

survivors ascribe to their experience – that is, their subjective outlook or understanding of their experience (p. 5).” Similarly, our current and future reports (Weigers et al., 1998; Zebrack, 2000; Zebrack & Chesler, 2000) are pursuing the medical, demographic and psychosocial correlates/predictors of different levels of positive and negative outcomes for long-term survivors of childhood cancer. We have data on many of the variables identified as important in understanding who is likely to thrive (see p. 9 of this paper; Curbow et al., 1993; Ickovics & Park, 1998; O’leary et al., 1998; Rutter, 1987; and especially Figure D attached). These include: (a) diagnosis and time since treatment ended; (b) social support received and support services desired; (c) worries and future outlook; (d) age and educational status; (e) parental status; (f) self-esteem; and (g) family structure and integration.

A note about collective and communal coping

It is clear from this discussion, and from much of the literature, that no one copes alone, and certainly that no one survives or thrives alone. The research literature often discusses the importance of the context within which coping takes place. In the particular situation of children and adolescents coping with cancer, the family has crucial importance, as an arena within which interaction takes place, as a source of social support, and as an agent of (re)socialization. In that sense, the nature of parental reactions and the role of family functioning have been seen as important variables related to the child’s eventual perspectives and outcomes.

Family systems’ analysts have emphasized the importance of seeing the family as an integral unit, and thus of assessing the responses of each family member to the trauma (e.g., Kazak & Christakis, 1996). In addition, Lyons and her colleagues (Lyons et al., 1998) have developed the notion of communal coping, which emphasizes the operation of the family as a social unit. This means more than assessing the reactions of various family members, but of somehow aggregating and combining these reactions to gain a measure of the collective response of the family. In their words, “Communal coping occurs when one or more individuals perceive a stressor as ‘our’ problem (a social appraisal) vs. ‘my’ or ‘your’ problem (an individualistic appraisal), and activate a

process of shared or collaborative coping (p. 583).” Thus, “pooling resources”, which also implies “pooling the trauma” (i.e., whose problem is this – ours – as well as whose responsibility is it to respond – ours), certainly fits the conception of childhood cancer as a “family disease” (Chesler & Barbarin, 1986). The focus of communal coping analyses, then, would not be on the child’s trauma but on the family’s trauma, and not on the child’s or the parents’ coping responses but on the family’s responses; similarly, we might begin to talk about “thriving families”.

This is another focus of future analysis for us: we have collected survey data from many of the parents of the survivors of childhood cancer discussed here (the parents of sample LTS-II) and have conducted interviews with a sub-sample of these parents and with a sub-sample of siblings of the survivors. We are interested in analyzing the mutual associations between survivors’ views and parents’ views, the relationship between the family context and the survivors’ reactions, and the possibility of raising the level of analysis of issues of surviving and thriving from an individual to a family (micro-social system). Such an approach would also mean that instead of treating all differences between survivor and parent outcomes as sources of contradiction or error, they also could be treated as variables indicative of a phenomenon (process or outcome) in the social system of the family.

It is clear that application of the thriving concept to the lives of individual survivors of childhood cancer, and/or to their families, is a major challenge. It is a welcome one, however, one representing a necessary response to the enormous advances in the treatment of childhood cancer and the mobilization of supports that make such thriving imaginable now. It also should help influence the direction and range of services available to these survivors and their families.

FIGURE A
EXAMPLES OF FREE-RESPONSE ANSWERS TO QUESTIONS ASSESSING
FOCUSING ON THE POSITIVE (Thompson, 1985)

Others' helpfulness

I feel lucky when I realize what good friends I have.
I was fortunate to have a caring, willing family.
I learned a great deal about how wonderful people really are.

Little injury to self or others

I could have been killed or injured.
No one lost their lives.
I escaped without injuries.

Damage not worse

I could have lost everything.
I was able to save a lot of my furniture and valuables.
We saved more than was lost.

Learned a lesson

I found out that people are important, not things. Things can be replaced.
I learned not to hoard gadgets and that we all have more than we actually need.
You learn to appreciate things you once took for granted.

Got a benefit

I got new furniture.
I moved to a better apartment.

FIGURE B
 FACTOR LOADINGS OF 21 ITEMS SELECTED FOR THE POSTTRAUMATIC
 GROWTH INVENTORY (Tedeschi & Calhoun, 1996)

PTGI Item and factor	Loading
Factor I: Relating to others (17% of variance)	
6. Knowing that I can count on people in times of trouble	.67
8. A sense of closeness with others	.81
9. A willingness to express my emotions	.63
15. Having compassion for others	.70
16. Putting effort into my relationships	.61
I learned a great deal about how wonderful people are	.62
I accept needing others	.67
Factor II: New possibilities (16% of variance)	
3. I developed new interests	.76
7. I established a new path for my life	.80
11. I'm able to do better things with my life	.76
14. New opportunities are available which wouldn't have been otherwise	.76
17. I'm more likely to try to change things which need changing	.63
Factor III: Personal strength (11% of variance)	
4. A feeling of self-reliance	.62
10. Knowing I can handle difficulties	.79
12. Being able to accept the way things work out	.54
19. I discovered that I'm stronger than I thought I was	.71
Factor IV: Spiritual change (9% of variance)	
5. A better understanding of spiritual matters	.84
18. I have a stronger religious faith	.83
Factor V: Appreciation of life (9% of variance)	
1. My priorities about what is important in life	.50
2. An appreciation for the value of my life	.85
13. Appreciating each day	.59

FIGURE C
 PERCENTAGES OF CANCER SAMPLE INDICATING CURRENT STATUS WAS
 'WORSE', 'THE SAME', OR 'BETTER' THAN PRIOR TO CANCER DIAGNOSIS
 (Andrykowski et al., 1993) (n=93-133, depending on item)

CPBS item	Worse	Better	Same
Love for spouse/partner	4	28	68
Relationship with spouse/partner	14	29	57
Religious satisfaction	5	32	53
Relationship with children	7	44	49
Outlook on life	26	27	47
Relationship with friends	12	45	43
Ability to be active	66	29	5
Ability to plan a future	59	27	14
Sense of anxiety	56	35	9
Ability to be independent	42	41	17
Ability to relax	42	40	18
Satisfaction with work	41	42	17
Ability to get along with others	11	69	20
Ability to think things through clearly	19	63	18
Self-respect	8	60	32
Ability to plan daily activities	34	58	8
Satisfaction with being alone	25	58	17
Ability to handle daily events	29	57	14
Ability to express myself	9	56	35
Satisfaction with material things	17	56	27
Satisfaction with sex	35	50	15
Ability to enjoy myself	39	35	26
Sense of peace	34	33	33
Fear of death	39	33	28

FIGURE D
DETERMINANTS OF OUTCOMES SUGGESTED BY MODELS OF CHANGE AND
GROWTH (Adapted from O'Leary et al., 1998)

Personal resources

Self-efficacy
Sense of coherence
 Comprehensibility
 Manageability
 Meaningfulness
Meaning making
 Appraisal
Locus of control
Motivation
Optimism
 Self-esteem
 Internal coping
 Active coping
Cognitive status
Hardiness
 Control
 Challenge
 Commitment
Past experience
Coping style

Environmental resources

Social support
SES
Community resources

FIGURE E
WORRIES: LONG-TERM SURVIVORS & COMPARISON GROUPS*

Worry "a lot" or "some" about (%s)	LTS-I (n=303)	COMP-I (n=285)	LTS-II (n=304)	COMP-II (n=314)
Cancer-specific health issues				
Getting (another) cancer when I am older	47	39	42	38
Whether I can have children	50	38	43	28
My children getting cancer	44	21	44	16
Getting medical or life insurance	xx	xx	39	22
General health issues				
Getting a cold or the flu	16	21	14	21
How my body looks	57	73	58	84
Getting tired	22	36	30	47
Dying	24	38	29	37
Doing well in school (or at work)	52	66	60	97

*LTS-I data were collected via a questionnaire for survivors between the ages of 14-25 in the Youth Newsletter of the Candlelighters Childhood Cancer Foundation, in 1988. COMP-I data were collected from a same-age population attending public schools in Southeastern and Northwestern Michigan in 1989. LTS-II data were collected from survivors between the ages of 14-25 treated at the University of Michigan Mott Children's Hospital in 1995. COMP-II data were collected from a same-age population of students attending secondary schools and colleges in Southeastern Michigan in 1996.

FIGURE F
BEING DIFFERENT FROM OTHER YOUNG PEOPLE:
LONG-TERM SURVIVORS AND COMPARISON GROUPS*

Different in what ways? (%s)	LTS-I (n=303)	COMP-I (n=285)	LTS-II (n=304)	COMP-II (n=314)
Positive physical/health	3	5	1	2
Positive developmental/personality	29	20	22	21
Positive social	2	8	1	3
Positive existential/spiritual	18	2	10	2
N/A, neutral, non-specific difference	13	14	3	2
No answer (not different)	11	41	51	58
Negative physical/health	16	4	9	4
Negative developmental/personality	4	3	2	6
Negative social	4	4	1	2
Total	100	100	100	100

*LTS-I data were collected via a questionnaire for survivors between the ages of 14-25 in the Youth Newsletter of the Candlelighters Childhood Cancer Foundation, in 1988. COMP-I data were collected from a same-age population attending public schools in Southeastern and Northwestern Michigan in 1989. LTS-II data were collected from survivors between the ages of 14-25 treated at the University of Michigan Mott Children's Hospital in 1995. COMP-II data were collected from a same-age population of students attending secondary schools and colleges in Southeastern Michigan in 1996.

FIGURE G
**PERCENTAGES OF LTS-II SAMPLE INDICATING LIFE CHANGE IN A POSITIVE, OR
 NEGATIVE DIRECTION, OR UNCHANGED, SINCE THEIR ILLNESS (n=304)***

Life change item	Worse	Same	Better
My physical health compared to others			
my age	27	53	15
My mental health	9	53	33
My spiritual well being	3	41	52
My sense of personal control over my life	12	42	42
My willingness to join others to			
change things	6	49	40
My concern for other	4	31	60
My sense of what I as an individual			
can do	7	39	49
My sense of who I am	6	37	52
My family relationships	6	45	44
My time with friends	10	51	35
My ability to cope with tragedy	7	34	54

* LTS-II data were collected from survivors between the ages of 14-25 treated at the University of Michigan Mott Children's Hospital in 1995.

FIGURE H
PERCENTAGES OF THREE SAMPLES OF SURVIVORS OF CHILDHOOD CANCER
INDICATING POSITIVE LIFE CHANGES SINCE THEIR ILLNESS*

Life change item (% better)	LTS-IA	LTS-IB	LTS-II
My physical health compared to others			
my age	45	21	15
My mental health	45	40	33
My spiritual well being	45	52	52
My sense of personal control over my life	47	47	42
My willingness to join others to			
change things	40	42	40
My concern for other	62	60	60
My sense of what I as an individual			
can do	48	58	49
My sense of who I am	49	58	52
My family relationships	49	57	44
My time with friends	40	46	35
My ability to cope with tragedy	55	52	54

*LTS-IA data (n=94) were collected from survivors of leukemia and lymphoma in Michigan, in conjunction with a grant from the Children's Leukemia Foundation of Michigan in 1989. LTS-IB data (n=137) were collected from survivors treated at Children's Medical Center of Chicago in 1995 in conjunction with grants from the Children's Leukemia Foundation of Michigan and the Candlelighters Childhood Cancer Foundation. LTS-II data (n=304) were collected from survivors treated at University of Michigan Mott Children's Hospital in 1995.

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