

Posttraumatic Growth in Adolescent Survivors of Cancer and Their Mothers and Fathers

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Objective To describe posttraumatic growth (PTG) following childhood cancer survival and its association with demographic and disease/treatment variables, perceived treatment severity and life threat, and posttraumatic stress symptoms (PTSS). **Method** Adolescent survivors of cancer ($N = 150$, ages 11–19), at least 1 year after treatment, and their mothers ($N = 146$) and fathers ($N = 107$) completed self-report measures of perceived treatment intensity and PTSS and a semistructured interview designed to identify posttraumatic responses and indicators of PTG including perceived positive changes for self, relationships, and life goals. **Results** A majority of adolescents and their mothers and fathers reported PTG. Greater perceived treatment severity and life threat, but not objective disease severity, was associated with PTG. PTG and PTSS were positively associated for the adolescent cancer survivors. Diagnosis after age 5 resulted in more perceived benefit and greater PTSS for adolescent survivors. **Conclusion** Clarification of the concept and measurement of PTG after childhood cancer is warranted, as are prospective studies of the association of PTG and PTSS and the role of demographic variables and illness-specific appraisals.

Key words adolescents; childhood cancer survival; families; posttraumatic growth; posttraumatic stress.

A traumatic stress framework is helpful in understanding the long-term psychological sequelae of life-threatening medical conditions including childhood cancer (Stuber, Kazak, Meeske, & Barakat, 1998). Although clinical rates of posttraumatic stress disorder (PTSD) are modest (e.g., between 5 and 10% for adolescent survivors of childhood cancer, around 20% for young adult survivors, and between 10 and 25% for parents), much higher rates of posttraumatic stress symptoms (PTSS) have been reported in survivors, their parents (Barakat et al., 1997; Brown, Madan-Swain, & Lambert, 2003; Hobbie et al., 2000; Manne, DuHamel, Galleli, Sorgen, & Redd, 1998) and siblings (Alderfer, Labay, & Kazak, 2003). For example, moderate to severe PTSS have been reported for 44% of mothers, 35% of fathers, 18% of adolescent survivors (Kazak et al., 2004), and 32% of siblings (Alderfer et al., 2003). Appraisals of the illness and treatment experience, including perceived treatment

intensity and life threat, have been shown to be related to PTSS.

However, posttraumatic responses are not necessarily negative. Parkes (1971) described trauma as a life transition resulting in both positive and negative changes. The existential writings of Frankl (1963) and others discuss a positive shift in perspective and priorities that can occur when faced with one's mortality. These writings underlie the concept of posttraumatic growth (PTG). Data supporting the overall well-being and psychological health of childhood cancer survivors and their parents (Barakat, Kunin-Batson, & Kazak, 2003) suggest that facing a life-threatening trauma such as childhood cancer may result in PTG as well as distress. Indeed, in an earlier study, we reported that childhood cancer survivors and their mothers identified positive changes after cancer treatment had ended (Kazak, Stuber, Barakat, & Meeske, 1996).

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PTG been defined as the cognitive process by which those who have experienced trauma apply positive interpretations to and find meaning in the traumatic event. This process results in restoration of pretrauma schema and positive changes in one's sense of self, relationships, and philosophy of life (Calhoun & Tedeschi, 1999; Tedeschi & Calhoun, 1995; Ullrich & Lutgendorf, 2002). In general, although measured in a number of ways, some standard and some specific to study samples (Evers et al., 1997; Tedeschi & Calhoun, 1996), assessment involves asking survivors whether they perceive benefits or whether positive changes have resulted from the trauma.

Studies of PTG typically involve samples comprised of survivors of sexual assault, natural disasters, or a variety of traumas (Frazier, Conlon, & Glaser, 2001; Frazier, Tashiro, Berman, Steger, & Long, 2004; McMillen, Smith, & Fisher, 1997; Ullrich & Lutgendorf, 2002); however, some researchers have investigated this phenomenon in adult health populations and bereaved parents (Affleck, Tennen, & Gershman, 1985; Cordova, Cunningham, Carlson, & Andrykowski, 2001; Evers et al., 2001; Polatinsky & Esprey, 2000; Weiss, 2002). Cordova et al. (2001) documented an increased sense of personal strength and positive changes in priorities for women with breast cancer compared to a demographically matched comparison group. Weiss (2002) confirmed PTG for women with breast cancer and their husbands and found that spouses corroborated women's reports of positive changes particularly of appreciation of life. Similar findings have been reported for parents of ill newborns and parents whose children have died, a majority of whom reported the experience to bring some benefits including closer family relationships, emotional or spiritual growth, and appreciation of the child (Affleck et al., 1985; Polatinsky & Esprey, 2000).

Among these studies, both positive and negative changes following trauma were acknowledged, and PTG was more likely to occur in the context of severe stressors and for those with higher incomes, more time since treatment, greater optimism, and higher levels of social support (for a review, see Calhoun & Tedeschi, 1999). For the breast cancer survivors, subjective severity of the disease was associated with PTG, but objective disease severity variables were not (Cordova et al., 2001). Additionally, findings suggest that perceived benefits or PTG following a trauma are associated with lower levels of distress or PTSD over time (Davis, Nolen-Hoeksema, & Larson, 1998; Evers et al., 2001; Frazier et al., 2004; McMillan et al., 1997; Ullrich & Lutgendorf, 2002).

To further understand PTG in a pediatric sample, this study describes adolescent survivors' and their

mothers' and fathers' reports of positive changes for themselves, their relationships, and their life goals following successful treatment for childhood cancer. It was hypothesized that more time since treatment and higher perceived treatment intensity and life threat would be associated with greater PTG. The association of PTG with age at diagnosis for the adolescent survivor was examined to address developmental aspects in processing this traumatic stressor, with the expectation that those older at diagnosis would report more PTG. Finally, also expected was a negative association of PTG with concurrent PTSS.

Method Design

Data presented in this article were collected in an Institutional Review Board-approved randomized clinical trial of the Surviving Cancer Competently Intervention Program (SCCIP; Kazak, Alderfer et al., 2004). Eligible families included an adolescent childhood cancer survivor who was at least 1 year after treatment with no history of relapse. For recruitment, families were sent a letter of inviting participation in a study with two assessment points, before and after an intervention and a brochure describing the intervention. Additional details regarding the full study and recruitment procedures are available elsewhere (Kazak, Alderfer et al., 2004).

Participants

Across the 150 families, data were collected from 150 teen survivors, 146 mothers and 107 fathers. The teen survivors ranged in age from 11.1 to 19.3 years ($M = 14.7$, $SD = 2.4$) and had completed treatment, on average, 5.3 years ($SD = 2.9$) before participation. Roughly half of the teens were female (52.0%). Diagnoses included: leukemias (30.5%); solid tumors (35.1%); lymphomas (21.2%); and other (13.2%). The mean age at diagnosis was 7.9 years ($SD = 4.3$; range, 3 months to 16.4 years). Most of the survivors were White (84.7%) with 9.3% Black, 4.7% Hispanic and 1.3% Asian. Mean parental age was in the early to mid-forties (Mothers $M = 43.2$, $SD = 5.6$; Fathers $M = 45.7$, $SD = 6.0$). Median household income was in the \$50,000–75,000 range, consistent with census tract data for the hospital's catchment area (U.S. Census Bureau, 2002). Educational attainment of the parents completing the study was as follows: 22.6% of mothers and 17.0% of fathers completed grades 9–12; 24.0% of mothers and 17.9% of fathers completed some college and/or vocational school; 48.0% of mothers and 52.0% of fathers received at least a degree from a 4-year

college. Demographic characteristics of this sample, of ethnic background, parent education, and family income, are similar to those attending the cancer survivor clinic at the hospital from which they were recruited (Kazak, Alderfer et al., 2004).

Procedure

When enrolling in this study, families agreed to complete two data collection sessions at their home (baseline and post-intervention) and a separately scheduled, day-long psychological intervention at our hospital. Written informed consent was secured from all participants. Interviews were conducted privately with individual family members. The data presented within this paper were collected before the intervention.

Measures

Perceptions of Changes in Self

PTG was measured using the Perceptions of Changes in Self (PCS) scale from the Impact of Traumatic Stressors Interview Schedule (ITSIS; Kazak et al., 1996, 2001), a semistructured interview with 45 items that include open-ended questions, dichotomous card sorts, and Likert-type scales. To minimize response bias, the PCS scale begins with an open-ended question stating, “Some people think that having cancer [a child with cancer] and going through treatment changes people. Some of these changes you may like. Some you may not like. Do you think you are different than you would have been if this had not happened? How are you different?” The focus of this study is the questions that follow, consisting of nine cards and reflecting ways in which the participants may have changed in response to their cancer experience (the nine items are listed in Table I). For each item, participants indicate whether or not they have changed in that area, and if so, whether the change was for the better or for the worse. From these items, the total number of positive changes was calculated

(possible range: 0–9). The Kuder-Richardson 20 internal consistency coefficient for the PCS score ranged from .70 to .73 across the survivor, mother, and father samples.

Demographic Variables

Parents completed a demographic questionnaire assessing background characteristics including age, gender and ethnicity of the adolescent, marital status and educational level of parents, and family income. Information was also collected about the child’s diagnosis, date of diagnosis and date of end of cancer treatment.

Intensity of Treatment Ratings (Hobbie et al., 2000; Kazak, McClure et al., 2004)

To provide an objective rating of treatment intensity, each participant’s chart was abstracted and rated by a pediatric oncologist and nurse practitioner. These clinicians were blind to the identity of the participants but were informed of treatment protocol numbers, medications, and treatment modalities. The rating scale included four points: 1 (surgery/enucleation only or surgery plus short-term chemotherapy protocols); 2 (low or standard risk protocols); 3 (multiple modalities of treatment and high risk protocols); and 4 (metastatic disease or stem cell transplantation). Discrepancies in the ratings were identified and discussed until consensus was reached.

Assessment of Life Threat and Treatment Intensity Questionnaire

To assess perceptions of life threat and treatment severity, participants completed the Assessment of Life Threat and Treatment Intensity Questionnaire (ALTTIQ) (Stuber et al., 1997). Two items assess perceptions of life threat in the past and present (i.e., “I thought I [my child] would die when I [he/she] had cancer”; “I [My child] could still die from cancer”) and two items assess cancer-related hardship (i.e., “My [My son’s/daughter’s] cancer was scary [hard] for me”) on a five-point Likert-type

Table I. Percent of Sample Endorsing Posttraumatic Growth (PTG) Items from the Impact of Traumatic Stressors Interview Schedule [ITSIS; Perceptions of Changes in Self (PCS) Scale]

	n (%) reporting positive change		
	Teen survivors (N = 150)	Mothers (N = 146)	Fathers (N = 107)
The way I treat other people	50 (33)	84 (58)	51 (48)
The way other people treat me	48 (32)	34 (23)	16 (15)
How I make friends	36 (24)	45 (31)	15 (14)
How careful I am	61 (41)	73 (50)	42 (39)
The quality of my work	18 (12)	35 (24)	14 (13)
How I behave at school/work	14 (9)	36 (25)	18 (17)
How my family treats me	44 (29)	38 (26)	14 (13)
My plans for the future	63 (42)	68 (47)	36 (34)
How I think about my life	79 (53)	100 (86)	66 (62)

scales. The two life threat items were used independently; the two hardship items were moderately correlated (r s ranged from .55 to .69) and averaged to form a perceived treatment intensity score.

Impact of Events Scale-Revised

To assess PTSS, all participants completed the Impact of Events Scale-Revised (IES-R) (Weiss & Marmar, 1997), a 22-item scale assessing intrusive thoughts, avoidance, and hyperarousal symptoms consistent with PTSD. Respondents were asked to focus on the cancer experience as the stressful event. Each item was rated for frequency of occurrence in the past 7 days on a weighted four-point Likert-type scale (0 = not at all, 1 = rarely, 3 = sometimes, 5 = often). Across survivor, mother, and father samples, internal consistency for the IES-R total score ranged from .91 to .95.

Statistical Approach

Descriptive statistics were used to characterize the PTG of our sample as reported on the PCS. Directional Pearson product moment correlations were used to determine the relationship between PTG and demographic characteristics, disease/treatment variables, perceived life threat and treatment severity, and posttraumatic stress. To correct for the number of analyses, criterion for significance was set at an alpha level of .01. When the distributions of the variables were examined, skew was found for multiple measures. Appropriate transformations were applied to the data; however, these transformations did not impact the pattern of results. Therefore, for ease of interpretation, non-transformed data were used.

Results

PTG

A majority (84.7%, $n = 127$) of adolescent survivors of childhood cancer reported at least one positive consequence of having had cancer (Table I). Nearly one third (32%, $n = 48$) reported four or more positive changes. On average, the adolescent survivors reported nearly three positive changes ($M = 2.8$, $SD = 2.2$) with a modal response of two positive changes. Over half of the adolescent survivors (53%, $n = 79$) reported a positive change in how they think about their life (Table I). Slightly more than 90% ($n = 131$) of the mothers of adolescent survivors of childhood cancer reported at least one positive outcome of the cancer. Almost half (44.8%; $n = 65$) reported four or more positive changes. The modal number of positive changes was 3 ($M = 3.5$, $SD = 2.2$). Eighty-six percent of mothers reported that

the cancer had a positive impact on how they think about their life, 58% reported that it had a positive impact on the way they treat other people, and half reported that it had a positive effect on how careful they are. Among the fathers of adolescent survivors of childhood cancer, slightly over 80% ($n = 87$) reported at least one positive effect of the cancer and slightly over one fourth reported 4 or more positive changes. The modal number of positive changes was 2 ($M = 2.6$; $SD = 2.1$). Again, the most frequently noted positive change, reported by 62% ($n = 66$) of fathers, was how they think about their life; nearly half of the fathers ($n = 51$) reported that the cancer changed for the better the way they treat other people.

PTG and Demographic and Disease/Treatment Variables

PTG among adolescent survivors was positively correlated with age at diagnosis but negatively correlated with time since treatment (Table II). A similar negative correlation with time since treatment was found for fathers. Perceptions of greater life threat were related to PTG for survivors. Perceptions of greater treatment intensity for both survivors and fathers were associated with more PTG. Across survivors, mothers and fathers, there were no significant associations between PTG and income, survivor's current age and objective ratings of treatment intensity.

PTG and Posttraumatic Stress

Contrary to prediction, PTG and PTSS were positively correlated for survivors (Table II). They were unrelated for mothers and fathers.

Table II. Correlations Between Posttraumatic Growth (PTG) and Other Study Variables

	Survivors ($N = 150$)	Mothers ($N = 146$)	Fathers ($N = 107$)
Demographic/treatment			
Survivor's age at diagnosis	.28**	.08	.20
Survivor's current age	.17	.04	.01
Time since treatment ended	-.29**	-.07	-.25**
Intensity of treatment ratings	.13	.08	.12
Household income	-.09	.02	-.06
Perceptions of disease/treatment			
Perceived past life threat	.32**	.02	.19
Perceived current life threat	.22**	.12	.11
Perceived treatment intensity	.20*	.12	.30**
Posttraumatic stress	.35**	.13	.14

* $p < .01$ (one-tailed). ** $p < .005$ (one-tailed).

Exploratory Follow-up Statistical Analyses

Our data revealed two unpredicted findings that we explored with follow-up analyses.

First, time since treatment was inversely (rather than positively) associated with PTG. We wondered if age at diagnosis could explain this. Indeed, the correlation between age at diagnosis and time since treatment was strong ($r = -.71, p < .001$). We then truncated the sample using age 5 at diagnosis as a cutoff given that children under 5 are typically unable to remember or understand their diagnosis and their treatment experiences. In addition, age 5 seems to demarcate a shift in cognitive functions that allows children to better process and reflect on their experiences (Alderfer et al., 2003). Children under age 5 ($N = 48$) reported fewer positive consequences of having had cancer compared to those 5 and older ($N = 102$) at diagnosis (younger: $M = 1.7, SD = 1.8$; older: $M = 3.2, SD = 2.3$), $t(148) = 13.45, p < .001$. Only three (6.3%) of the children under age 5 at diagnosis reported more than three positive changes whereas 45 (44%) of the survivors who were aged 5 or older at diagnosis reported more than three positive changes, $\chi^2(1, N = 150) = 21.5, p < .0001$. After truncating the sample to those 5 and older at diagnosis, PTG was no longer significantly correlated with time since end of treatment ($r = -.09, p = .40$).

Second, the positive relationship between PTG and PTSS among the survivors was also unexpected. We examined correlations between PTSS and perceptions of life threat and treatment intensity as both PTSS and PTG have been positively related to these constructs in past studies. PTSS were significantly and positively associated with perceptions of life threat ($r = .30, p < .001$) and treatment intensity ($r = .33, p < .001$). To determine if the relationship between PTG and PTSS was an artifact of these associations, a hierarchical regression equation was calculated. In an equation predicting PTG, age at diagnosis was controlled by entering it on Step 1, perceptions of life threat and treatment intensity were entered on Step 2, and PTSS was entered on Step 3. PTSS added significantly to the equation (change in $R^2 = .05, p < .005$) and was significantly associated with PTG over and above age at diagnosis and illness-specific appraisals ($\beta = .25, p < .005$).

Finally, we investigated whether the 5 and older subsample reported higher PTSS than those younger than 5 at diagnosis and whether differences in report of PTG and PTSS would impact their correlation. The 5 and older subsample did report more symptoms of PTSS than the younger group, $t(131) = 3.1, p = .003, M_{old} = 27.1, SD = 21.4, M_{young} = 18.1, SD = 13.8$. However, PTG and PTSS remained significantly correlated for both the older ($r = .29, p = .003$) and the younger ($r = .36, p = .01$) subsamples.

Discussion

PTG, measured as positive changes in self, relationships with others, and plans for the future, was reported by the majority of adolescent survivors of childhood cancer and their mothers and fathers. These families identified multiple positive changes, with endorsement of growth particularly high for how they think about their life, plans for the future, and how careful they are. Many adolescent survivors and their parents also noted changes for the better in how they treat others and how family members and others treat them, whereas positive changes in specific activities or behaviors were less frequently cited. These findings corroborate earlier results with a smaller sample of children and mothers (Kazak et al., 1996) and suggest that survivors and their families have positive beliefs about the impact of their experiences with childhood cancer and its treatment.

The findings for the adolescents may be the most interesting and unique from this report. For the teen survivors, perceptions of greater current and past life threat and their perception of the intensity of the treatment were associated with identifying positive aspects of the experience. And, PTSS and PTG were positively associated, above and beyond the associations between PTG and perceptions of life threat and treatment severity. The likely relationship of this with age at diagnosis helps to clarify an understanding of PTG in this sample as those who were older than age 5 at diagnosis reported more PTG and PTSS than those who were younger than 5. That is, adolescent survivors who are more likely to recall their treatment experiences (e.g., were age 5 or older at diagnosis) appear to perceive both challenging and adaptive aspects and impacts of the cancer. These patients are likely to have had greater realization of the seriousness of their illness and thus have more PTSS. However, they are also more likely to understand and appreciate the support and encouragement they received during treatment and to understand that they showed strength in the face of treatment-related adversities, resulting in more positive outcomes (PTG). These findings are consistent with the developmental tasks and challenges of adolescence and suggest the importance of understanding how adolescent survivors process their experiences and formulate longer-term cancer-related beliefs.

In this relatively large sample of mothers and fathers, the relatively few associations of parental PTG with demographic and disease/treatment variables is noteworthy. The data suggest that endorsement of growth items such as positive changes in oneself and relationship with others are independent of their child's treatment and also of PTSS. Recent studies have highlighted

the important role of perceived control over the current situation in predicting PTG (Frazier et al., 2004), and this may relate directly to parents' perceived control over cancer treatment and survivorship. Mothers and fathers may play very different roles in their child's treatment and in their families; they may cope differently with the various acute and chronic stressors resulting from the cancer diagnosis, treatment and survivorship. Moreover, in coping with childhood cancer, parents may struggle to come to terms with aspects they can and cannot control in treatment and outcome. It may be that PTG is associated with outcome for those parents who have regained a sense of control over daily aspects of dealing with the disease and survivorship. Furthermore, these data reinforce the importance of including multiple family members in studies of posttreatment sequelae.

Regarding limitations and goals for the future, the measure of PTG used in this study was not standardized, positive changes were not validated by other informants, and reliability statistics can be considered moderate at best. Additionally, although instructions were devised to minimize demand characteristics for endorsements of positive change, response bias may have occurred. Conceptually, PTG has been presented as the result of cognitive processing that may reduce symptoms of posttraumatic stress over time. However, it may be that posttraumatic responses are multifaceted and represent changes for both better and worse in one's view of self, relationships, and the future. For pediatric cancer samples, it may be that PTG is more a measure of active coping efforts than that of an outcome as suggested by Cordova et al. (2001). If this is the case, PTG may be an indicator of resilience in survivors who are recovering from the major adversity of childhood cancer and may progress to highly competent outcomes (Masten, Best, & Garmezy, 1990). Adaptation of a standard measure of PTG for a pediatric population holds merit. Clearly, a prospective research design is needed to tease out the associations of psychosocial variables with PTG and the interplay of PTG with posttraumatic stress over time.

Emerging is a picture of families who may experience significant symptoms of distress as well as growth or perceived positive changes in response to childhood cancer. Taken together these findings suggest that stress follows those with childhood cancer into the survivorship phase; furthermore, those who experience distress during survivorship may adjust their expectations of themselves, the world, and their future by finding positive meaning in their experiences.

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