

Expressive Writing Intervention for Teens Whose Parents Have Cancer

By

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Expressive Writing Intervention for Teens Whose Parents Have Cancer

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ABSTRACT

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The role of emotional expression was explored in the writings of adolescent children of parents with cancer. Participants ages 12-18 ($n=40$) were assigned randomly to write in 3 sessions about their thoughts and feelings regarding their parents' cancer (experimental condition) or their time management (fact control condition). Physical health (i.e., doctor visits, school absences, physical symptoms) and psychological health variables (i.e., internalizing and externalizing behavior, depression, anxiety, positive emotion, negative emotion, post traumatic growth) were assessed as a function of writing condition and participants' temporal orientation (i.e., the time period on which a person bases the majority of his or her perceptions of reality). Results from analysis of covariance indicated experimental condition was related to decreases in negative affect, self reported depression symptoms, parent-reported anxiety symptoms, and parent-reported internalizing problems in the adolescent participants and increases in post traumatic growth reported by the adolescent participants. Past temporal orientation was related to increased conduct problems reported by parents, increased physical symptoms, and decreased school absences. Conduct problems scores reported by parent were related to increased positive affect, increased anxiety, and decreased illness-related doctor visits. Adolescent Atypicality scores were related to increased parent-reported anxiety in the child, physical symptoms, and school absences. Problem solving coping was related to decreased anxiety, and behavioral avoidance coping was related to increased depression as reported by parent and increased internalizing problems as reported by parent. Given the significant results for the experimental condition, the findings are discussed in light of future possible research on the use of emotional expressive

writing in adolescents as well as use of emotional writing tasks as interventions for adolescent children of cancer patients.

Dedication

I would like to dedicate this dissertation to my son, Nicky. Many have assumed incorrectly that you are the reason this dissertation has taken as long as it has to reach completion. I acknowledge that having an infant, toddler, and now preschooler to feed, entertain, and care for of course takes a considerable portion of a person's mental and emotional reserves as well as time. And we both know that you will be glad when Mommy will be "done working" on this project so she can play with you more. I am so glad, though, that I've had your bright smiles and warm hugs to keep me going during this project. I am so proud to be the mother of such a loving, joyful, playful little boy.

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Introduction

When a family member is diagnosed with cancer, all family members are affected. Whereas considerable research has been conducted on counseling children with cancer and their parents, there is very little written about counseling children whose parents have cancer (Johnson, 1997). This is unfortunate because, for example, approximately 30% of women with breast cancer have one or more children still living at home (Lewis & Hammond, 1996). Research on children of persons with cancer has documented high levels of stress and increased behavioral and emotional symptomatology and coping difficulties of similar intensity to those found in their ill parents (Compas, Worsham, Epping-Jordan, Grant, Mireault, Howell, & Malcarne, 1994). This stress can affect a child's psychosocial and emotional development if not addressed.

Adolescent Children of Parents with Cancer

Adolescents may be at particular risk. Compas, et al. (1994) found that adolescent children of persons with cancer reported the highest levels of psychological symptoms of all age groups. This may be because they are better able to understand the implications of the illness but are still not as adept as adults in coping with them. Adolescents are also confronted with age-specific problems. For example, they feel the normal developmental need to assert their independence and form separate identities from their parents. At the same time, they recognize a need to be at home and close to their families during this trying time, leaving them feeling conflicted. Adolescents also often find themselves taking on additional roles and responsibilities in the household to help their parents (Faulkner & Davey, 2002). These developmental conflicts can negatively affect an adolescent's self-concept.

Although the clinical literature has explored the effects of serious physical illness on the family (Brown, 1990; Compas, Worsham, Ey, & Howell, 1996; Leedham & Meyerowitz, 1999; Rotherham, Murphy, Miller, & Draimin, 1997), this population has rarely been studied experimentally (Stanton, Kirk, Cameron, & Danoff-Burg, 2000). Children of parents with cancer are faced with particular challenges. They may have to deal with parental hospitalizations, disabilities, and sudden relapses in their parents' illnesses, as well as fears that their parents might die (Wellisch, Gritz, Schun, Wang, & Siau, 1991). Higher levels of depression, anxiety, and behavior problems and lower levels of self-esteem and social competence have also been shown in children of parents with cancer (Armistead, Klein, & Forehand, 1995; Siegel, et al., 1992).

However, other studies have cited examples of children who have overcome the stresses of the situation often through the support of other people in their lives (Brown, 1990). A parent's illness could possibly serve the positive function of bringing family members closer together, helping children learn responsibility and independence, or prompting the family to make the most of the time they have left with a critically ill parent (Armistead, Klein, & Forehand, 1995).

Adolescents and Writing

Counseling interventions with adolescents experiencing distress have taken many forms including typical psychotherapy, group supportive therapy, art therapy, psychoeducation, and journaling. However, there are few specific interventions with children of parents with cancer detailed in the literature. Journaling is of particular interest because many teenagers keep journals or diaries on their own, and journaling or writing is often a component of both individual and group psychotherapies with this age group. In one study, 86% of 191 adolescents

reported using at least one writing mode (i.e., poetry, diary entry, short story, songs) in their daily lives (Roscoe, Krug, & Schmidt, 1985). Thirty-three percent of these adolescents wrote in diaries specifically (Roscoe, Krug, & Schmidt, 1985).

The use of journals for therapeutic purposes has much in common with an experimental writing paradigm developed by James Pennebaker (1993). Studies using this paradigm have shown that inducing people to disclose feelings or thoughts about their distressing experiences in writing produces positive changes in a wide range of health outcomes including physical health, psychological well being, and general functioning (Smyth, 1998). The typical use of this paradigm asks participants in individual sessions to write about their “deepest thoughts and feelings” surrounding a personal experience, such as their most traumatic life event, or to write about a control topic such as what they did the previous day. Participants write on this topic for 15-20 minutes a day for 3-5 typically consecutive days (Pennebaker, 1993). Participants are told to write continuously and not to worry about grammar, punctuation, spelling, or organization. A meta-analysis by Smyth (1998) revealed a mean weighted effect size of $d = .47$ over 13 studies of this writing task. This represents a 23% improvement in health measures when comparing experimental groups with the control groups. A more recent meta-analysis by Frattaroli, (2006) on 146 randomized controlled studies of emotional disclosure showed a smaller average r -effect size of .075 across studies.

Early theories to explain the health benefits of writing rested on emotional disclosure and physiological disinhibition. Confronting distressing topics was presumed advantageous because it relieved the energy being devoted to holding back these emotions and not talking about distressing events (Pennebaker, Francis, & Mayne, 1997). More recent explanations of the benefits of expressive writing take the role of language in emotional processing and expression

into account. By putting their thoughts and feelings into words, participants must organize and integrate their perceptions of the event into the structure of their personal life narrative (Pennebaker et al., 1997). Initial evidence for this theory was provided by a computerized word analysis program. It revealed that the use of words that suggested causal or insight-driven thinking such as *think*, *consider*, *because*, and *reason* was related to positive changes in health (Pennebaker et al., 1997).

Initial studies also pointed to the role of negative emotion words and the combination of negative and positive emotion words in health improvements (Pennebaker, 1993). More recent studies, however, have shown that only the number of positive emotions words used is predictive of positive health changes (Pennebaker et al., 1997). The finding that insight-oriented thinking predicts benefits of expressive writing is consistent with the notion of many trauma theorists who emphasize the importance of finding meaning in the event (Davis, Nolen-Hoeksema, & Larson, 1998). The research suggests that the writing must address a topic that is central and important to the person, and it must take the form of a meaningful personal narrative.

The current study's goal was to assess the effects of the Pennebaker writing paradigm (1993) on adolescents whose parents have cancer. Little research has explored the use of narrative writing in children outside of the school setting. These school-based studies are limited in their relevance outside the school setting; or to individually-administered writing tasks as opposed to the group-administered tasks in these studies. Additionally, many of them do not have control groups. Some have control groups, but not writing control groups, further limiting the ability to compare these studies' findings with the adult expressive writing studies that fit the established, empirically supported Pennebaker writing paradigm. See Table 1 for a description of

the published expressive writing studies with child samples reviewed below and how they compare to the current study.

Daiute & Bauteau (2003) induced 3rd and 5th graders to write about social conflicts they had experienced. They had no control group. The children who, over time, described in their narratives more resolution strategies and higher levels of social relations had decreases in problem behaviors. While this study shows that children can successfully write about a stressful topic and find benefits from such writing, the lack of a control group limits the ability to discern the causal mechanism of these findings.

Springer & Pennebaker (1995) had a group of third-grade to eighth-grade students write about an emotionally upsetting event or a neutral event. They found that the 6th graders who were in the emotional disclosure condition experienced a significant decrease in the number of illness-related absences after the writing. Analyses showed a decrease in positive emotion words and an increase in negative emotion words in the writings of the 6th to 8th graders. This was related to an increase in the use of insight or causal words in the students' writings over time. Both factors were related to a decrease in illness-related absences over time.

Table 1
Expressive Writing Studies with Children

Study	Sample/design	Study Limitations/ Problems with Generalizability to Current Study	Results
Daiute & Bauteau (2002)	3 rd & 5 th graders wrote about their own social conflicts	- No control writing group - Conducted in school setting - Elementary aged children only	Children who came up with more resolution strategies had higher levels of social relations described their writing and decreases in problem behaviors
Springer & Pennebaker (1995)	3 rd -8 th graders wrote about emotionally upsetting event or neutral event	- Conducted in school setting - Elementary and young Adolescents only	6 th graders in disclosure condition had decrease in illness-related absences after writing; 6 th & 8 th graders showed increases in neg. emotion words and decreases in pos. emotion words which related to a decrease in illness-related absences across groups
Reynolds, Brewin & Saxton (2000)	191 children ages 8-13 in 3 conditions: upsetting event writing, nonemotional event writing, non-writing control group	- Conducted in school setting - Elementary and young Adolescents only	No main effects for condition
Fivush et al. (2007)	Same data as Reynolds et al. (2000)	- Conducted in school setting - Elementary and young Adolescents only	More negative words in the emotional writing group; these neg. evaluations led to higher depression, anxiety, and difficulties

Table 1 Cont.

Study	Sample/design	Study Limitations Problems with Generalizability to Current Study	Results
Horn, Pössel & Hautzinger (2010)	358 8 th graders in expressive writing + psycho-education group or no-intervention control group	<ul style="list-style-type: none"> - Conducted in school setting - No writing-based control group - Expressive writing group confounded by psycho-education intervention 	<p>Grades for experimental group increased in the short term; Neg. affect decreases in experimental condition at 3 and 6 months post; School absences decreases in experimental condition in the semester after writing.</p>
Margola et al. (2010)	20 fifteen-year-olds wrote their emotional reactions to the death of a classmate on 3 consecutive days	<ul style="list-style-type: none"> - Conducted in school setting - No control condition. - No pre-post measures besides IES 	<p>Writing analyses using the LIWC revealed 4 adjustment trajectories</p>
Soliday, Garofalo & Rogers (2004)	106 8 th graders in emotional writing or neutral topic writing	<ul style="list-style-type: none"> - Conducted in school setting - Only young adolescents 	<p>Decreases in neg. affect at 2 and 6 weeks post writing in experimental group</p>
Bray et al. (2003)	5 teenagers and adults with asthma did emotional writing	<ul style="list-style-type: none"> - No control group - Small sample size - Only 2 adolescents 	<p>Decreases in anxiety and increases in lung function after writing in 4 of 5 participants</p>
Taylor et al. (2003)	37 adolescents and adults ages 15-37 with cystic fibrosis did emotional writing or standard treatment	<ul style="list-style-type: none"> - No writing control group - Few adolescents - Different medical population 	<p>Decreases in days in the hospital in the 3 months post-writing for the writing group</p>
Warner et al. (2006)	50 adolescents with asthma wrote about stressful	<ul style="list-style-type: none"> - Different medical population 	<p>Improved pos. affect and difficulties in disclosure group; Decreases in asthma symptom and functional disability in disclosure group for participants with elevated levels on these variables at baseline</p>

Reynolds, Brewin, & Saxton (2000) had 191 children ages 8-13 write about a stressful or upsetting event, write about nonemotional events, or participate in a non-writing control condition where they discussed the life of Anne Frank. They found overall decreases in symptom levels for anxiety, difficult behaviors, and physical symptoms across groups. But, they found no specific effect for emotional disclosure on psychological health, physical health, or school attendance measures. In fact, a follow-up study on the same data by Fivush, Marin, Crawford, Reynolds & Brewin (2007) showed that children in the emotional writing group used more negative words in their writing than the control group and those children who made these negative evaluations in their writing then went on to show higher levels of anxiety, depression and difficulties, leaving the authors to question if emotional writing was a hindrance rather than helpful for this age group.

Horn, Pössel & Hautzinger (2010) had 358 German eighth graders randomly assigned to expressive writing along with a psycho-educational program or a no intervention control based on their classroom. They found that grades for the experimental condition increased in the immediate short term, negative affect decreased for the experimental condition at 3 and 6 months post, and school absences decreased for the experimental condition in the semester following the writing. However, it is possible that the psycho-education program that accompanied the writing may be at least partially responsible for these outcomes.

Margola, Facchin, Molgora, & Revenson (2010) had twenty 15-year-old Italian students in one classroom participate in expressive writing after the death of their classmate. They had no control condition. Students' writings were analyzed using the Linguistic Inquiry and Word Count (LIWC) computer program to relate their word usage to their scores on the Impact of

Events Scale (IES) at baseline, 1 week, and 4 weeks post writing. They found four adjustment trajectories that described the students' bereavement process.

Soliday, Garofalo & Rogers (2004) had 106 eighth-graders write about emotional topics versus neutral topics in the classroom. Although somatic symptoms and doctor visits remained unchanged at follow-up, subjects in their experimental condition did show a decrease in negative affect at follow-up 2 and 6 weeks post-writing.

To our knowledge, there have been only three published studies to apply the Pennebaker paradigm to children (i.e., have children write about a stressful or traumatic experience) outside of the classroom. Bray et al. (2003) examined the effects of emotional writing on teenagers, young adults, and adults with asthma. Two of their five participants were high school students. Their results showed decreases in anxiety and increases in lung function for four of their five participants. However, they had no comparison group.

Taylor, Wallander, Anderson, Beasley, & Brown (2003) examined emotional disclosure in a sample of 39 adolescents and adults ages 15 to 37 with cystic fibrosis. Twelve of the participants were ages 15 to 18. Half of the participants wrote about an emotionally distressing issue three times, while the other half received only standard care. There was no control writing group. Their results showed a significant decrease in the number of days spent in the hospital over a three-month period for the writing group.

Warner, Lumley, Casey, Pierantoni, Salazar, Zoratti, Enberg & Simon (2006) randomly assigned 50 adolescents with asthma to write about stressful events or control topics. Their experimental condition saw increases in positive affect, decreases in internalizing problems, and decreases in asthma symptoms and functional disability over their control group.

The present study will address the obvious gap in the literature by applying the Pennebaker paradigm to adolescents using a control writing group and a purely adolescent sample covering the entire range of adolescence from 12 to 18 years of age and conducting the study outside of a school setting. The goals of this study are both experimental and clinical. This research will add to the scientific literature on the Pennebaker paradigm as well as take initial steps in evaluating the role of journaling with adolescents whose parents have cancer. The results will aid in the planning and adjustment of future interventions with children of parents with cancer.

Temporal Orientation

An individual difference construct that may affect an adolescent's experience and processing of traumatic events such as the experience of parental cancer is temporal orientation or time perspective. Zimbardo defines time perspective as, "the often nonconscious process whereby the continual flows of personal and social experiences are assigned to temporal categories, or time frames, that help to give order, coherence, and meaning to those events" (Zimbardo & Boyd, 1999, p. 1271). The time period (i.e., past, present, or future) on which a person bases the majority of his or her perceptions and interpretations of reality may constitute a potent and pervasive influence on that person's behavior and thoughts (Zimbardo & Boyd, 1999).

Most research on temporal orientation has focused on the adaptive nature of a future orientation as opposed to a present orientation, while largely ignoring the effects of a predominately past temporal orientation (Zimbardo & Boyd, 1999). Some psychologists have suggested that the future perspective guides most psychological processes and that future expectations are critical in maintaining mental health and well-being (Zimbardo & Boyd, 1999).

Other theorists have emphasized the importance of “integrating past and present experience with future expectations in order to strengthen personal morale, enrich one’s sense of self, and cope effectively with adversity” (Zimbardo & Boyd, 1998, p. 1146). In the struggle to understand the event, however, the person may become “stuck” in the past, both through voluntary thoughts and involuntary intrusions of their ongoing thought processes (Zimbardo & Boyd, 1999, p.1447).

The literature on temporal orientation in adolescence has established that distinct orientations toward the past, present, and future are present by age nine or ten (Webb & Mayers, 1974). However, there are still many questions about the development of temporal orientation in childhood and adolescence. Also, there is a lack of clear information on temporal orientation’s effects on children’s lives. This is due to a number of facts, including the ever-changing concepts of temporal orientation and the use of many different questionnaires reflecting these conceptualizations in the small number of studies that have looked at temporal orientation in childhood. Research in the 1970’s did not look at the roles of past, present, and future orientation in childhood, but rather the extension of a child’s concepts of time into the past and future. More recent researchers who have used the three dimensions of temporal orientation have chosen to delete past orientation from their measures when studying children and even adolescents, despite the research that shows adolescents to have past temporal orientations.

There is a small amount of empirical information regarding how temporal orientation influences coping with stressful situations. In one study, Holman and Silver (1998) found that across three samples of subjects who had experienced a traumatic event, a past orientation was associated with heightened distress, even when rumination was controlled statistically. A previous study conducted by the present author (Laub, 2001) indicated that past and future temporal orientations were related to health outcomes for young adults writing about parental

illness. Past temporal orientation was related to increased depressive symptoms, increased negative affect and decreased positive affect over time. Future orientation was related to increases in self-assurance and decreases in depressive and physical symptoms over time.

This study was designed to address the following aims and hypotheses:

Specific Aim: To assess the effects of an emotional writing intervention for adolescents whose parents have cancer.

Additional Aims: To measure the temporal orientations (i.e., time perspectives), and levels of anxiety, depression, externalizing behaviors, and post traumatic growth in adolescents whose parents have cancer.

Main Hypothesis: Adolescents in the emotional writing condition will show decreases in negative mood, increases in positive mood, and decreases in physical symptoms and illness-related doctor visits relative to baseline whereas adolescents in the control group will not experience these changes.

Additional Hypotheses:

1. Adolescents in the emotional writing condition will report finding more meaning or benefits from (i.e., post traumatic growth) their parent's cancer than adolescents in the control group.
2. Children with a higher level of past temporal orientation (i.e., past time perspective) will have higher levels of negative mood and lower levels of positive mood than children with lower levels of past temporal orientation. Alternatively, adolescents with higher levels of future temporal orientation will show higher levels of positive affect and lower levels of negative affect.

Method

Participants

Participants included 40 adolescents and their parents; the 40 participants included 20 females and 20 males with a mean age of 13.97 ($SD=1.83$, range 12-18 years). Ninety percent of the adolescent participants were white (5% African American, 2.5% Asian, 2.5% Bi-Racial). A total of 50 adolescent participants (26 female and 24 male) initially agreed to take part in the study. Of these, ten failed to complete the entire study: three participants had parents who died before they were able to complete their follow-up for the study, one participant decided not to continue after completing her first writing session, two participants did not mail in their second or third session writings despite having completed them and thus did not move on to follow-up, and four participants did not complete their follow-up measures. One of the four moved during the follow-up period and did not leave a forwarding address or telephone number, one was no longer interested in participating in the study at follow-up, and two of the four did not respond to telephone and email prompts at the time of follow-up. Of the ten participants that did not complete the study, six were assigned to the experimental group and four were assigned to the control group indicating that assignment to the control group was not a significant factor is causing these adolescents to withdraw from the study. The analyses performed for this study included only the 40 participants who completed the study.

Parents taking part in the study were 90% Caucasian, 5% African American, 2.5% Asian, 2.5% bi-racial. While all the parents were females, 87.5% were the child's biological mother, 2.5% were the child's adoptive mother, and 10% were the child's step-mother. The family member with cancer was themselves for 90% of the parents, and their spouse for 10% of parents. Forty-five percent of parents had a college degree (17.5% high school degree, 32.5% some

college, 5% graduate degree). Ten percent of the households had yearly incomes below \$20,000 (12.5% = \$30-40,000, 20% = \$40-50,000, 20% = \$50-75,000, 37.5% = >\$75,000). Eighty percent of the parents with cancer had received chemotherapy as part of their treatment (0% = bone marrow transplant, 0% = limb amputation, 0% stem cell transplant, 62.5% radiation therapy, 67.5% = surgery, 22.5% = other treatments) with many parents receiving more than one cancer treatment. Thirty percent of parents with cancer had experienced at least one recurrence of their cancer. Age of parents in the study ranged from 34 to 57 years ($M=45.05$, $SD=5.07$); their age at diagnosis ranged from 30 to 55 ($M=42.95$, $SD=3.47$). The stage of cancer each parent was originally diagnosed with ranged from stage 1 to stage 4 ($M=2.10$, $SD=.85$). Parents rated the stressfulness of cancer they or their spouse were experiencing on a scale of 1 to 5 as an average 3.60 ($SD=.96$) with a range between 2 and 5. Parents rated the seriousness of cancer they or their spouse were experiencing on a scale of 1 to 5 as an average 3.17 ($SD=.84$) with a range between 1 and 5.

All adolescent participants met the following criteria:

Inclusion Criteria:

1. Participant must be between the ages of 12 and 18 years.
2. Participant must have a parent diagnosed with cancer within the last 3 years.
3. One or both of the participant's parents (biological, step, or adoptive) must agree to participate in the study.

Exclusion Criteria:

1. Prior to the start of the study, participants cannot have had a parent die.

Procedure

The adolescents were referred by their parents' oncologists, by their parents' oncology social workers, by the Director of Children's Programs at Turning Point organization of Kansas City (a local organization which provides support and education to persons with chronic and life-threatening illnesses and their families), by the leaders of their parents' cancer support group, by self-referral via advertising flier that was included in new patient folders at the KUMC cancer center as well as posted in various locations, or by word of mouth.

Once participants agreed to participate, the experimenter arranged to meet at the adolescent's home or at a location deemed convenient by the participant. The experimenter administered the consent and assent forms (see Appendices A-D) as well as a set of pre-experiment measures and the first 20-minute writing session. This initial session took about one and a half hours to complete. Participants received \$10 for their participation. The second and third sessions also included the experimenter meeting at the participant's home or another convenient location to administer the 20-minute writing session and post-writing questionnaires. These sessions each took about 30 minutes each, and the participant again received \$10 for participating at the end of the third session. The three sessions were approximately one week apart. Sessions took place in the participants' homes or place of their choosing to minimize the burden on the adolescents and their families. Finally, the experimenter sent follow-up measures to the participant, who returned them via the mail three months after the third (final) writing session.

Participants were randomly assigned using a random numbers table to write about their thoughts and emotions regarding their parent's cancer (expressive writing condition) or what

they did the previous day (control writing condition). There were equal numbers of males and females in each condition.

The study design is based on an experimental paradigm developed by James W. Pennebaker, Ph.D. (1993). This study used many of the questionnaires originally developed by Pennebaker and colleagues for use with this paradigm. This study used three writing sessions of 20 minutes each as is typical in the literature. Although most studies included in the Smyth (1998) meta-analysis conducted writing sessions on consecutive days, the Smyth meta-analysis found that the studies that spaced their writing sessions farther apart had higher effect sizes. Accordingly, the sessions for this study were held approximately one week apart. This also allowed for greater flexibility in scheduling participants. The three-month follow-up in the current study matches the average follow-up period found in the Frattaroli (2006) meta-analysis, and takes into account the finding of both Smyth (1998) and Frattaroli (2006) that a follow-up period of at least one month led to larger effect sizes.

Detailed procedures for each experimental session are as follows:

Visit 1:

The researcher administered consent to parent(s) and assent to the adolescent participant.

The parents then filled out the following questionnaires:

1. Parent Demographics Form (Appendix E)
2. Behavioral Assessment Scale for Children Parent Rating Scale- Adolescent (12-18)

[BASC PRS 12-18]

3. Experiences With Cancer Questionnaire (only for parent with cancer)

(Appendix F)

The child filled out the following questionnaires:

1. Teenager Demographics Form (Appendix G)
2. Dispositional Hope Scale (Appendix H)
3. Abbreviated Positive and Negative Affect Scale (Past Few Weeks) [PANAS-PFW] (Appendix I)
4. Coping Scale for Children and Youth (Appendix J)
5. Post Traumatic Growth Inventory - Revised [PTGI-R] (Appendix K)
6. Temporal Orientation Scale [TOS] (Appendix L)
7. Physical Symptoms Measure [PSM] (Appendix M)
8. Behavioral Assessment Scale for Children Self-Report (12-18) [BASC SRS 12-18]
9. Impact of Events Measure – Revised [IES-R] (Appendix N)

The child was then taken to a private room or area where the researcher read the writing instructions for the child's experimental condition (see Appendix O for exact writing instructions). The experimenter also provided the child with a written form of the writing instructions to look at throughout their 20-minute writing block. The researcher gave the child lined paper and a pen with which to write. The researcher then informed the child that he/she would be left alone to write for 20 minutes, and the researcher would come back and tell the child when his/her 20 minutes of writing were finished.

After the child was finished with his/her writing session, he or she filled out the following questionnaires:

1. Abbreviated Positive and Negative Affect Scale – present moment [APANAS-PM] (Appendix P)
2. Perceived Physiological Arousal Measure (Appendix Q)
3. Post-Essay Questionnaire – Session 1 (Appendix R)

At the end of the session, the child received \$10 for participating.

Visit 2:

The child was again taken to a private room or area where the researcher read the writing instructions for the child's experimental condition. The child again wrote for 20 minutes on the same topic. After he or she finished writing, the child filled out the following questionnaires:

1. Abbreviated Positive and Negative Affect Scale – present moment [APANAS-PM]
(Appendix P)
2. Perceived Physiological Arousal Measure (Appendix Q)
3. Post-Essay Questionnaire – Session 2 (Appendix S)

Visit 3:

The child was again taken to a private room or area where the researcher read the writing instructions for the child's experimental condition. The child again wrote for twenty minutes on the same topic. After he or she was finished writing, the child filled out the following questionnaires:

1. Abbreviated Positive and Negative Affect Scale – present moment [APANAS-PM]
(Appendix P)
2. Perceived Physiological Arousal Measure (Appendix Q)
3. Post-Essay Questionnaire – Session 3 (Appendix T)

Parents were given instructions on how to fill out the Doctor Visit Recording Sheet (Appendix U) over the next 3 months. At the end of the session, the child received \$10 for participating.

Follow-up

At the final writing session, participants' parents were asked to keep track of the number of doctor visits their child made as a result of an illness in the 3 months following their last writing session. They were then asked to mail this form back to the experimenters at the three-month follow-up. The researchers called each participant/parent at their prescribed follow-up date to remind them to fill out and return their follow-up measure. Parents filled out the following questionnaire in the packet:

1. Behavioral Assessment Scale for Children - Parent Rating Scale – Adolescent (12-18) [BASC PRA 12-18] (Appendix F)

Children filled out the following questionnaires in the packet:

2. Behavioral Assessment Scale for Children- Self Report Scale (12-18) [BASC SRS 12-18]
3. Dispositional Hope Scale (Appendix H)
4. Abbreviated Positive and Negative Affect Scale (Past Few Weeks) [APANAS-PFW] (Appendix I)
5. Coping Scale for Children and Youth (Appendix J)
6. Post Traumatic Growth Inventory - Revised [PTGI-R] (Appendix K)
7. Temporal Orientation Scale [TOS] (Appendix L)
8. Physical Symptoms Measure [PSM] (Appendix M)
9. Impact of Events Scale – Revised [IES-R] (Appendix N)

Parents returned these questionnaires along with the Doctor Visit Recording Sheet (Appendix U) using the self-addressed stamped envelope provided. When the return envelope

containing the follow-up measures was received, the child was sent an additional \$10 for participating.

The efficacy of the writing interventions was assessed by examining changes from baseline to follow-up on measures of the following: depression, anxiety, conduct problems, post traumatic growth, positive emotion, negative emotion, physical symptoms, school absences, and doctor visits.

Measures

1. Demographics Form (Teenager or Parent versions).

These author-constructed questionnaires asked participants to list their age, sex, ethnicity, education, and a self-generated subject number. Participants were also asked to briefly describe their parent's illness (Appendices E & G). Participants were asked to rate the degree of stressfulness of their experience on a 5-point Likert scale from "not at all stressful" to "extremely stressful."

2. Behavioral Assessment Scale for Children (12-18) Parent and Child Self-Report

Parent Scale. The Parent Rating Scale (PRS) is a comprehensive measure of an adolescent's adaptive and problem behaviors from their parent's perspective (Reynolds & Kamphaus, 1992). The PRS has been normed on a large national population. It includes composite scores for externalizing problems, internalizing problems, adaptive skills, and an overall Behavioral Symptoms Index. It has individual scale scores for aggression, hyperactivity, conduct problems, anxiety, depression, somatization, attention problems, atypicality, withdrawal, leadership, and social skills. There is also an *F* index as a check the validity of the parent ratings. The adolescent version of the PRS is for parents of children ages 12 to 18. The PRS

contains descriptors of behaviors that the respondent rates on a four-point scale of frequency ranging from Never to Almost Always. It takes about 10 to 20 minutes to complete.

Self-Report Scale. The Self-Report of Personality (SRP) scale is a personality measure consisting of true or false questions (Reynolds & Kamphaus, 1992). It takes about 30 minutes to complete, and the adolescent version is appropriate for children ages 12 to 18. Its composite scores include school maladjustment, clinical maladjustment, personal adjustment, and an overall composite score called the Emotional Symptoms Index. It has 14 scales that include: anxiety, atypicality, locus of control, social stress, somatization, attitude to school, attitude to teachers, sensation seeking, depression, sense of inadequacy, relations to parents, interpersonal problems, self-esteem, and self-reliance. It also includes an *F* index to assess validity.

3. Abbreviated Positive & Negative Affect Scale

This measure is an abbreviated version of the Positive and Negative Affect Schedule – Expanded Version (PANAS-X) (Watson & Clark, 1991) In a study with an adolescent population, the internal consistency reliability of the 20-item version of the PANAS Negative and Positive scales were .84 and .85, respectively (Huebner & Dew, 1995). It provides scale scores for positive affect and negative affect. This measure was used to assess positive and negative affect for the past few weeks, and at the present moment. (See Appendices I & P)

4. Post Traumatic Growth Inventory – Revised

This measure is an instrument designed to assess positive outcomes reported by persons who have experienced traumatic events. The 21-item scale has five factors: New Possibilities, Relating to Others, Personal Strength, Spiritual Change, and Appreciation for Life. The internal consistency for the overall measure is .90 (Tedeschi & Calhoun, 1996). (See Appendix K)

5. Physical Symptoms Measure

Participants were asked to indicate on a checklist with a free response option any physical symptoms they had experienced in the previous 30 days and to report the number of days they experienced these symptoms. This measure is a modified version of the Pennebaker Inventory of Limbic Languidness (PILL, Pennebaker, 1982). (See Appendix M)

6. Doctor Visit Recording Sheet (For Parent)

At the last writing session, participants' parents were asked to keep track of the number of doctor visits their child made as a result of an illness in the next 3 months. They were then asked to mail this form back to the experimenters at the 3-month follow-up. (See Appendix U)

7. Temporal Orientation Scale

Participants completed a self-report measure of overall temporal orientation during the first writing session. The Temporal Orientation Scale (Holman & Silver, 1994) is a 28-item questionnaire that combines items from the Stanford Time Perspective Inventory (Zimbardo, 1990), a set of Q-statements developed by Braley and Freed (1971), and statements made by traumatized people which were appraised by independent raters to strongly represent past, present, or future orientations (Holman & Silver, 1994). This measure yields scores representing the degree to which a person ascribes to each of the three orientations (i.e., past, present, and future). Internal reliability for these scales as measured by coefficient alphas in a previous sample of college students with a parent with a chronic illness was Past = .68, Present = .76, and Future = .71 (Laub, 2002). (See Appendix L)

8. Dispositional Hope Scale

Hope was measured by the Dispositional Hope Scale (Snyder, Hoza, Pelham, Rapoff, Ware, Danovsky, Highberger, Rubinstein, & Stahl, 1997). In this context, hope is defined as “a

cognitive set involving the beliefs in one's capabilities to produce workable routes to goals, as well as the self-related beliefs about initiating and sustaining the movement toward those goals" (Snyder et al., 1997, p.401). The scale consists of six items, including "I think I am doing pretty well" and "I think the things I have done in the past will help me in the future." For each item, adolescents used a six-point Likert scale, for which responses range from 1 (None of the time) to 6 (All of the time), to indicate how often they experience the feelings described.

The reliability of the scale in a sample of adolescent cancer survivors was satisfactory as indicated by a coefficient alpha of .89 (Thompson, 2003). Snyder et al. (1997) found that the scale exhibits internal consistency (Cronbach's alpha ranging from .72 to .84) and high-test-retest reliability [$r(359) = .71$]. (See Appendix H)

9. Coping Scale for Youth & Children

The Coping Scale for Children and Youth (CSCY; Brodzinsky et al., 1992) was used to assess adolescents' coping strategies in relation to their parent's cancer. This 37-item self-report instrument comprises five subscales, including assistance seeking (e.g., "I would ask someone in my family for help"), problem solving (e.g., "I would learn a new way of dealing with the problem"), cognitive avoidance (e.g., "I would try not to think about the problem"), behavior avoidance (e.g., "I would stay away from things that remind me of the problem"), and emotional approach (e.g., "I would allow myself to express my emotions). The adolescents indicate how often they use each coping strategy on a 4-point Likert scale, ranging from Never (1) to Very Often (4). In the sample of childhood cancer survivors, the coefficient alphas for the CSCY subscales ranged from .74 to .89 (Thompson, 2003). The measure as a whole, with the exception of the recently added emotional approach items, has been found to have a test-retest reliabilities ranging from .73 to .81, depending on the subscale being assessed (Brodzinsky et al., 1992).

Brodzinsky et al. (1992) have also found that the measure has moderate to high internal consistency, convergent validity, and construct validity. The emotional approach items (Stanton et al., 2000) have been modified and validated for an adolescent population (Thompson, 2003). (See Appendix J)

10. Impact of Events Scale – Revised

The Impact of Events Scale-Revised is a 22-item self-assessment measure used to assess symptoms of post traumatic stress disorder. It is designed to assess current distress for a specific life event. Respondents are asked to rate each item in the IES-R on a scale of 0 (not at all), 1 (a little bit), 2 (moderately), 3 (quite a bit) and 4 (extremely) according to the past 7 days. The scale contains three subscales: intrusion, avoidance, and hyperarousal. In their study of four different samples, Weiss and Marmar (1997) found that the internal consistency of the three subscales was very high, with intrusion alphas ranging from .87 to .92, avoidance alphas ranging from .84 to .86, and hyperarousal alphas ranging from .79 to .90 (Briere, 1997). Test-retest data are available for 2 of the samples in the Weiss and Marmar (1997) study. For sample 1 (n = 429), data yielded the following test-retest correlation co-efficients for the subscales: intrusion = .57, avoidance = .51, hyperarousal = .59. From sample 2 (n = 197) the correlation coefficients were considerably higher: intrusion = .94, avoidance = .89, hyperarousal = .92. Weiss & Marmar believed that the shorter interval between assessments and the greater recency of the traumatic event for Sample 2 contributed to the higher coefficients of stability. (See Appendix N)

11. Perceived Physiological Arousal Measure

Participants were asked to indicate on a scale from 1 = NOT AT ALL, to 7 = A GREAT DEAL on a checklist of 8 items any symptoms of physiological arousal they were currently experiencing. This measure was originally developed by Pennebaker & Beall (1986). The

version used in this study is a modified version of a measure designed by Richards, Beal, Seagal, & Pennebaker (2000). (See Appendix Q)

12. Post-Essay Questionnaire 1-3

Participants were asked to describe various aspects of their writing for the day on a scale from 1 = not at all, to 7 = a great deal including: how personal their writing was, how emotional their writing was, how much they held back, how much they told another person about what they wrote, how much they *wanted* to tell another person about what they wrote, if they gained any understanding from their writing, and how they felt about what they wrote. These measures are based on the measures designed by Pennebaker, Colder, & Sharp (1990). (See Appendix R)

13. Experiences with Cancer Questionnaire

This measure includes questions concerning parents' cancer diagnosis, treatment, and long-term side effects (Appendix G). Specifically, parents with cancer reported which type(s) of cancer they have been diagnosed with, how old they were when they received the diagnosis, and what treatments they received, including bone marrow transplant, chemotherapy, limb amputation, radiation, stem cell transplant, and surgery. Additionally, they reported how long their cancer treatment lasted, if and when they had a recurrence, and if they had experienced any long-term side effects of the cancer treatment.

Assessment of Subject Compliance

Subject compliance with the writing instructions was assessed by having three raters, each blind to the experimental condition the participant belonged to, rate if each essay was a product of the experimental condition (emotional writing), or the control condition (time management writing).

Results

Overview

The primary analyses to determine treatment effects took the form of ANCOVAs (analyses of covariance) with pretreatment scores on the dependent measures used as covariates. The type of writing assigned to each participant (experimental vs. control) served as the categorical independent variable. The impact of emotional writing (experimental condition) versus time management writing (control condition) was examined on the following dependent variables: internalizing problems (e.g., depression, anxiety), externalizing problems (e.g., conduct problems), positive affect, negative affect, post traumatic growth, physical symptoms, school absences, and doctor visits. In addition, temporal orientation, hope, post traumatic stress disorder symptoms, and coping style were used as additional covariates to explain variations on the dependent variables and to examine their influence on treatment outcomes. Follow-up analyses were conducted to assess the nature of significant interactions.

Preliminary Analyses

Descriptive statistics for parental illness variables assessed during the initial experimental session were first performed. Participants' mean stressfulness rating to describe the experience of their parent's illness was 2.85 (SD=.95) on a 5-point scale. The average severity they assigned to their parents' cancer was 2.85 (SD=1.00) on a 5-point scale. Parental cancer was described in 90% mothers and 10% fathers, with mothers completing the parent questionnaires for all 40 participants. Table 2 includes a list of the types of cancers reported and the percentages of participants writing about each illness.

Table 2
Frequencies of Parental Cancer Type

Original Cancer (Metastases)	<u>N</u>	%
Basaloid Carcinoma	1	2.5
Breast	30	75.0
Esophageal	1	2.5
Lung (brain)	1	2.5
Melanoma (lung/brain)	2	5.0
Pelvic/Rectal (lung)	2	5.0
Multiple Myeloma	2	5.0
Stomach	1	2.5

Preliminary analyses of variance were conducted to assess whether the two experimental conditions differed significantly at baseline on the following variables: participant age, past temporal orientation, present temporal orientation, future temporal orientation, APANAS negative affect, APANAS positive affect, Physical Symptoms Measure, all 17 of the BASC self-report scale and composite scores, the BASC self-report Emotional Symptoms Index, child's school absences in the last three months, child's days of illness in the last three months, and all 14 of the BASC parent-report scale and composite scores. The experimental conditions differed significantly on only two variables: BASC parent-report Conduct Problems scale and BASC parent-report Atypicality scale. Participants in the control condition had higher BASC parent-report Conduct Problems scale (a measure of rule-breaking behavior) scores ($M=51.10$, $SD=8.37$) than the experimental group ($M=46.25$, $SD=5.80$), $F(1, 39)=4.54$, $p<.05$. Participants

in the experimental condition had higher BASC parent-report Atypicality scale (a measure of immature or odd behavior) scores ($M=49.95$, $SD=6.67$) than the control group ($M=44.95$, $SD=6.86$), $F(1, 39)=5.47$, $p<.05$. Therefore, BASC parent-report Conduct Problems scale scores and Atypicality scale scores were used as covariates in subsequent analyses.

Analyses of variance were also conducted to assess whether the children of women with breast cancer differed significantly from children of parents with other types of cancer at baseline. No significant differences were found. A third analyses of variance were also conducted to assess whether scores of sibling groups taking part in the study differed significantly from non-sibling participants at baseline. Again, no significant differences were found between these groups of participants.

A manipulation check was conducted to determine whether participants' essays conformed to the experimental condition instructions. Essays were ordered randomly, and three independent raters read and assigned each essay to the emotional expression condition or the control condition based on essay content. The readers correctly identified the experimental condition for all three of the essays written by 39 of 40 participants (97.5% of total, 100% of the emotional expression group, 95% of the fact control group), and 2 of 3 essays for the fortieth participant. These data suggest that participants were able to follow the writing instructions for each condition such that emotional content did not confound the fact control group, and emotional content was indeed present in the emotional expression experimental group.

Temporal Orientation

Means and standard deviations on each of the types of temporal orientation (past, present, future) at baseline are displayed in Table 3. Participants showed higher temporal orientation scores overall than in 2 previous research samples. Also, the participants showed higher levels

of present temporal orientation relative to past and future orientation. Previous adult study samples have favored future temporal orientation over present and past orientations (Holman, 1997). Using their scores for each of the three temporal orientation subscales (past, present, future), the primary temporal orientation of each participant was determined by using their highest subscale score (See Table 4). Again, present temporal orientation was the primary temporal orientation for the most adolescent participants with 50% in that category.

Table 3

Means and Standard Deviations For Temporal Orientation Scale By Study Sample

	Current Study <u>M(SD)</u>	UCI Undergrad <u>M(SD)</u>	Fire Survivors <u>M(SD)</u>
Past	3.93(1.03)	2.79(.63)	2.59(.77)
Present	4.29(.83)	2.64(.61)	2.87(.65)
Future	3.98(.83)	3.33(.64)	3.54(.62)

Note. Numbers for the UCI undergraduate sample and the California fire survivors sample are drawn from Holman (1997).

Table 4

Primary Temporal Orientation Ratings For Adolescent Participants

	Frequency	%
Past	7	17.5
Past or Present	1	2.5
Past or Future	1	2.5
Present	20	50.0
Present or Future	2	5.0
Future	9	22.5%

Analyses on Psychological Health Dependent Variables

Analyses on dependent variables in general assumed the same form: analyses of covariance were conducted with the initial value of the dependent variable, and past temporal orientation, BASC parent-report Atypicality score, and BASC parent-report Conduct Problems score as continuous predictors, and experimental condition as the categorical independent variable. Gender of the adolescent participant, breast cancer vs. “other” cancer diagnosis of parent, and whether the participant was part of a sibling group to participate in the study were also included as variables in the initial analyses to assure that these variables did not cause undue influence on the results. As none of these variables showed significant effects in the initial analyses, they were deleted in subsequent analyses. Results that follow represent analyses that do not include these variables.

Follow-up analyses to assess the role of present and future temporal orientation as well as hope, coping, and post traumatic stress symptoms were conducted by substituting each of these variables for past temporal orientation in original analysis. Means and standard deviations on

each psychological measure at baseline and follow-up for each experimental condition are displayed in Table 5. Please note that subsequent findings refer to significant statistical effects and are not intended to imply causation except in the case of main effects due to experimental condition.

APANAS Positive Affect.

An analysis of covariance was conducted on APANAS positive affect scores obtained 3 months post-writing. Pre-writing APANAS positive affect scores predicted follow-up APANAS positive affect scores, $F(1, 34)=21.74$, $p<.001$, with positive affect increasing over time. No significant effects were found for experimental condition, $F(1, 34)=.21$, $p=.65$. BASC parent-report Conduct Problems had a significant effect on PANAS-X positive affect, $F(1, 34)=4.40$, $p<.05$, with higher conduct problems related to increased positive affect.

APANAS Negative Affect.

An analysis of covariance was conducted on APANAS negative affect scores obtained three months post-writing. Pre-writing APANAS negative affect scores predicted follow-up APANAS negative affect scores, $F(1, 34)=8.59$, $p<.01$, with negative affect decreasing over time. A significant effect was found for experimental condition, $F(1, 34)=7.71$, $p<.01$, with the experimental group showing less negative affect at follow-up than the control group.

Table 5

Means and Standard Deviations For Psychological Measures by Experimental Condition

	Condition 1		Condition 2	
	Baseline <u>M(SD)</u>	Follow-up <u>M(SD)</u>	Baseline <u>M(SD)</u>	Follow-up <u>M(SD)</u>
APANAS				
Pos. Affect	3.33(1.05)	3.39(1.15)	3.25(.84)	3.26(.93)
APANAS				
Neg. Affect	2.25(.96)	1.60(.65)	2.23(.97)	2.20(.95)
BASC self-report				
Depression	47.25(7.70)	44.65(4.07)	48.60(9.59)	49.55(8.81)
BASC self-report				
Anxiety	46.25(9.06)	46.05(11.01)	50.15(10.48)	51.85(10.60)
BASC parent-report				
Atypicality	49.95(6.67)	47.74(7.16)	44.95(6.86)	45.70(6.23)
BASC parent-report				
Conduct Problems	46.25(5.80)	47.89(9.92)	51.10(8.37)	50.80(9.16)
BASC parent-report				
Externalizing Problems	46.85(6.13)	46.21(7.88)	49.20(9.18)	49.50(9.62)
BASC parent-report				
Depression	51.55(11.27)	48.89(9.46)	49.30(11.39)	47.65(9.14)
BASC parent-report				
Anxiety	55.65(11.08)	50.42(10.31)	51.85(9.31)	52.50(9.39)
BASC parent-report				
Internalizing Problems	52.10(11.18)	48.84(9.77)	49.75(11.36)	49.50(9.62)
Post Traumatic				
Growth Inventory	46.70(26.47)	54.20(27.14)	61.85(18.70)	59.30(25.58)

Note. Condition 1 = Emotional Expression, Condition 2 = Time Management Control.

BASC Self Report.

Self-Report Depression Scale

An analysis of covariance was conducted on BASC self-report Depression scale scores obtained three months post-writing. Pre-writing BASC self-report Depression scores predicted follow-up BASC self-report Depression scores, $F(1, 34)=65.02$, $p<.001$, with depression scores decreasing over time. A significant effect was found for experimental condition, $F(1, 34)=4.87$, $p<.05$, with the experimental group having a lower depression score than the control group.

Self-Report Anxiety Scale

An analysis of covariance was conducted on BASC self-report Anxiety scale scores obtained three months post-writing. Pre-writing BASC self-report Anxiety scores predicted follow-up BASC self-report Anxiety scores, $F(1, 34)=65.02$, $p<.001$. No significant effects were found for experimental condition, $F(1, 34)=.45$, $p=.50$. A significant effect was found for BASC parent-report Conduct Problems, $F(1, 34)=55.43$, $p<.001$, with higher conduct problems related to higher anxiety scores. A significant effect was also found for Problem Solving type coping, $F(1, 34)=4.69$, $p<.05$, with higher scores on the CSCY Problem Solving coping scale related to lower anxiety scores.

BASC Parent Report.

Parent-Report Depression Scale

An analysis of covariance was conducted on BASC parent-report Depression scale scores obtained 3 months post-writing. Pre-writing BASC parent-report Depression scores predicted follow-up BASC parent-report Depression scores, $F(1, 34)=38.12$, $p<.001$. No significant effects for experimental condition, $F(1, 34)=.81$, $p=.37$, were found. A significant effect was also found

for Behavioral Avoidance type coping, $F(1, 34)=6.44$, $p<.05$, with higher scores on the CSCY Behavioral Avoidance coping scale related to higher depression scale scores.

Parent-Report Anxiety Scale

An analysis of covariance was conducted on BASC parent-report Anxiety scale scores obtained three months post-writing. Pre-writing BASC parent-report Anxiety scores predicted follow-up BASC parent-report Anxiety scores, $F(1, 33)=50.05$, $p<.001$. A significant effect was found for experimental condition, $F(1, 33)=17.14$, $p<.001$, with the experimental group reporting lower anxiety scores than the control group. A significant effect was found for BASC parent-report Atypicality, $F(1, 33)=6.37$, $p<.05$, with higher atypicality related to higher anxiety scores.

Parent Report Internalizing Problems Scale

An analysis of covariance was conducted on BASC parent-report Internalizing Problems scale scores obtained three months post-writing. Pre-writing BASC parent-report Internalizing Problems scores predicted follow-up BASC parent-report Internalizing Problems scores, $F(1, 33)=50.05$, $p<.001$. A significant effect was found for experimental condition, $F(1, 33)=72.41$, $p<.001$, with the experimental group reporting fewer internalizing problems than the control group. A significant effect was found for CSCY Behavioral Avoidance coping, $F(1, 29)=5.31$, $p<.05$, with higher behavioral avoidance related to higher internalizing problems scores.

Parent Report Conduct Problems

An analysis of covariance was conducted on BASC parent-report Conduct Problems scale scores obtained three months post-writing. Pre-writing BASC parent-report Conduct Problems scores predicted follow-up BASC parent-report Conduct Problems scores, $F(1, 34)=26.83$, $p<.001$. A significant effect was found for past temporal orientation, $F(1, 34)=4.50$, $p<.05$, with higher past temporal orientation related to higher conduct problem scores.

Parent-Report Externalizing Problems Scale

An analysis of covariance was conducted on BASC parent-report Externalizing Problems scale scores obtained three months post-writing. Pre-writing BASC parent-report Externalizing Problems scores predicted follow-up BASC parent-report Externalizing Problems scores, $F(1, 33)=22.23, p<.001$. No significant effect was found for experimental condition, $F(1, 33)=.24, p=.63$.

Post Traumatic Growth

An analysis of covariance was conducted on Post Traumatic Growth Inventory scores obtained three months post-writing. Pre-writing PTGI scores predicted follow-up PTGI scores, $F(1, 32)=32.96, p<.001$, with post traumatic growth increasing over time. A significant effect was found for experimental condition, $F(1, 27.61)=9.54, p<.01$, with the experimental group showing more post traumatic growth than the control group.

Physical Health Variables

Means and standard deviations on each physical health measure at baseline and follow-up for each experimental condition are displayed in Table 6.

Table 6

Means and Standard Deviations Of Physical Health Measures by Experimental Condition

	Condition 1		Condition 2	
	Baseline M(SD)	Follow-up M(SD)	Baseline M(SD)	Follow-up M(SD)
Physical Symptoms	29.20(28.75)	27.30(24.85)	34.25(34.74)	24.53(19.98)
Dr. Visits- Illness	.85(.99)	.10(.81)	.45(.69)	.20(.52)
School Absences	2.65(2.76)	.60(1.00)	1.60(2.23)	.85(1.09)

Note. Baseline values for doctor visits are for 3 months pre-experiment. Follow-up values for doctor visits are for 3 months post-experiment. Condition 1 = Emotional Expression, Condition 2 = Time Management Control.

Physical Symptoms Measure.

An analysis of covariance was conducted with the Physical Symptoms Measures total score at follow-up as the dependent variable. Experimental condition was the categorical independent variable, and BASC parent-report Atypicality and Conduct Problems scores and past temporal orientation served as continuous predictors. Physical Symptoms Measure total score at baseline was a covariate. Physical Symptom Measure scores did not change significantly from pre-writing to follow-up. No significant effects emerged for experimental condition, $F(1, 33)=.69, p=.90$. Past temporal orientation had a significant effect on Physical Symptom Measure scores, $F(1, 33)=4.62, p<.05$, with higher past temporal orientation related to increased physical symptoms. Atypicality scores had a significant effect on physical symptoms, $F(1, 33)=4.50, p<.05$, with higher Atypicality related to increased physical symptoms.

Illness Related Doctor Visits.

An analysis of covariance was conducted with number of doctor visits in the three months following the completion of the writing as the dependent variable. Experimental condition was the categorical independent variable, and BASC parent-report Atypicality and Conduct Problems scores and past temporal orientation served as continuous predictors. Self-reported doctor visits in the three months preceding the study was a covariate. Analyses revealed no significant effects for condition, $F(1, 34)=4.00$, $p=.054$, or time. Conduct Problems scores had a significant effect on illness related doctor visits, $F(1, 34)=6.65$, $p<.05$, with lower conduct problems related to increased illness related doctor visits.

School Absences.

An analysis of covariance was conducted with number of school absences in the three months following the completion of the writing as the dependent variable. Experimental condition was the categorical independent variable, and BASC parent-report Atypicality and Conduct Problems scores and past temporal orientation served as continuous predictors. Parent-reported doctor visits in the three months preceding the study was a covariate. Analyses revealed no significant effects for condition, $F(1, 32)=3.60$, $p=.067$, or time. Atypicality scores had a significant effect on school absences, $F(1, 32)=9.05$, $p<.01$, with higher Atypicality related to increased school absences. Past temporal orientation also had a significant effect on school absences, $F(1, 32)=4.18$, $p<.05$, with higher past temporal orientation related to decreased school absences.

Discussion

Results of this study indicate that having adolescents write about their parents' cancer may lower their levels of negative emotions, depression, anxiety, and overall levels of

internalizing problems, and increase their level of post traumatic growth. These results give support to the use of expressive writing in adolescents as a research population beyond the current predominantly adult populations used for such studies. It also suggests that expressive writing may developed into a helpful clinical intervention for adolescents whose parents have cancer.

In the Main Hypothesis, we posited that adolescents in the emotional writing condition would show decreases in negative affect, increases in positive affect, and decreases in physical symptoms and illness-related doctor visits relative to baseline, whereas adolescents in the control group would not experience these changes. With the exception of positive affect, this main hypothesis was supported for the psychological health variables but not for the physical health variables.

In Additional Hypothesis 1, we posited that adolescents in the emotional writing condition would report finding more meaning from or benefits of (i.e., post traumatic growth) their parent's cancer than would adolescents in the control group. We also found support for this hypothesis with a significant effect for experimental condition such that the experimental group showed more post traumatic growth than the control group.

While our Main Hypothesis was indeed supported for most of psychological health variables, none of the physical health variables showed main effects by condition. It may be that this intervention truly did not influence physical health symptoms in a meaningful way.

However, one factor that may have made it difficult to determine the nature of this relationship was the low number of baseline school absences and doctor visits reported by the participants.

With low baseline numbers on these variables, there was very little room for the intervention to effect decreases in them. However, this does not explain the lack of effect on the Physical

Symptoms Measure, which did have an adequately high average score pre-writing but also did not show a decrease across time for either condition.

In Additional Hypothesis 2, we posited that children with a higher level of past temporal orientation (i.e., past time perspective) would have higher levels of negative mood and lower levels of positive mood than would children with lower levels of past temporal orientation. Alternatively, in Additional Hypothesis 2, we posited that adolescents with higher levels of future temporal orientation would show higher levels of positive affect and lower levels of negative affect. For this study, however, temporal orientation was related to very little. Future and present temporal orientation showed no significant effects on any of the dependent variables. Past temporal orientation did have a significant effect in relation to physical symptoms such that as past temporal orientation increased, so did physical symptoms. But paradoxically, higher past temporal orientation was also related to decreased school absences. Higher past temporal orientation was also related to higher parent-report conduct problems.

It is hard to draw many conclusions from the overall lack of significant results for temporal orientation. It may be that temporal orientation really does have little effect on psychological health variables for adolescents. There is also the possibility that since temporal orientation is in flux during adolescence (Bowles, 1999), it may not have consistent relationships with other health variables. This idea also meshes with the paradoxical relationships that past temporal orientation showed with the physical health variables in this study. Temporal orientation is an evolving, changing psychological variable during childhood and adolescence (Bowles, 1999), and, as such, it may not show the same relationships that more consistent adult temporal orientation has demonstrated in previous research.

Another possible reason for the null and confusing results on temporal orientation is the fact that the primary temporal orientation shown by the adolescents in this sample was present temporal orientation instead of the future orientation that has been shown to be the primary temporal orientation for most adults (see Table 3). Bowles (1999) also found that present temporal orientation was the primary temporal orientation in the adolescents he tested. It may be that the young age of the adolescent sample in this study (M age of 13.97) influenced the primary temporal orientation shown by this sample to be more present focused as to opposed to future oriented as has been shown in some older adolescent populations. The fact that different primary temporal orientations are affecting adolescents versus adults may mediate the different effects temporal orientation has on each of these groups. It is interesting to note, though, that present temporal orientation, even as the primary temporal orientation for this sample, did not have any significant relationships with the other variables.

Two of the parent-reported scales for the BASC also had significant results. Increased Conduct Problems scale scores were related to higher anxiety. This suggests a relationship between externalizing problems and internalizing problems, which is not unheard of in children (Hinshaw, 1987). However, the Conduct Problems scale also showed two other paradoxical results: increased conduct problems were related both to increases in positive affect and to decreases in doctor visits. The relationship with increased positive affect contradicts the increased anxiety finding as anxiety is a negative emotion, not a positive one. The finding may be anomalous, perhaps a result of chance due to the number of tests conducted. It is certainly a subject for further research.

The other parent-report scale for the BASC that had significant results was the Atypicality scale. Higher atypicality was related to higher anxiety, physical symptoms, and

school absences. It may be that atypicality could result in social problems and lower self esteem for the adolescents and this could explain the higher anxiety and increased school absences shown by those higher in atypicality. The relationship between atypicality and physical health variables (physical symptoms, school absences) suggests that the atypicality construct may have a relationship with somatization.

Two of the CSCY coping scales yielded significant results. Higher problem solving coping was related to lower anxiety. It seems that active thinking and planning toward fixing a problem could be related to decreased anxiety over said problem as possible solutions generated can give the adolescent a sense of control and plan of attack that may alleviate his or her worries about the problem.

Behavioral avoidance coping is the second coping scale that showed significant results. Higher behavioral avoidance coping was related to higher depression and internalizing problems. Just as actively facing a problem may decrease negative emotions, actively avoiding a problem may possibly increase negative emotions and distress.

Study Limitations

Although significant main effects were found on a number of variables, it should be kept in mind that this study has a number of limitations. First off, the small overall number of participants in the study limits the number of complex statistical relationships that can be explored without risking Type 1 error. Adequate power was available to assess the main effects in this study but, as no interaction effects were found, power may be inadequate to reveal more complex interactions or mediating relationships.

Although a larger sample would be ideal, it should be considered that the population being sampled, adolescent children of cancer patients, is a small and hard to access population.

A typical person with cancer is either older or younger and, as such, does not have adolescent children. He or she usually either has no children or very young children or his/her children are grown adults at the time of his/her diagnosis.

One exception is the population of young breast cancer patients that comprises 75% of the sample in this study. Because breast cancer accounted for so much of the sample in this study, the results found here may apply more accurately to teenage children of breast cancer patients as opposed to adolescents whose parents have other types of cancer.

It should also be noted that our sample was made up of mostly younger adolescents ($M=13.96$ years old). Younger adolescents were more likely to agree to participate in the study than their older adolescent counterparts. The reasons older adolescents gave for not wanting to participate included having too many obligations and plans in the future that left no available time to participate in the study. These obligations included school events and college for the 17 and 18-year-old potential participants. As such, the results of this study may have limited generalizability to older adolescent populations. This participation variable of having less older, possibly more future-oriented adolescents willing to participate may also have influenced the primary temporal orientations shown in this study. It is possible that if more older adolescents had participated, the sample would have not have shown such a strong preference toward present temporal orientation.

Another possible limitation of the study is the high number of sibling pairs in this study. Of the 40 participants, 22 were part of sibling pairs. Although being part of a sibling pair did not prove to have a significant effect in our statistical analyses, it is possible that the limited power in this study is the reason these results were insignificant. This high sibling pair ratio in our study

may also limit the generalizability of this study to adolescent children of cancer patients who are not part of sibling pairs.

Implications and Directions for Clinical Applications

Results of this study suggest that expressive writing or a similar journaling task may be a possible intervention for adolescents whose parents have cancer. Such an intervention would have the advantages that it is easy to administer, its location of administration is flexible, and it could be inexpensive to administer. It also would not have to include individual or group therapy sessions which have the possible disadvantages of being seen as expensive, requiring too much of a time commitment (especially from busy teens), or being too invasive.

Written feedback provided by participants after the last writing session was quite positive across both groups. When asked how they felt about their writings, participants in the experimental group wrote things such as:

- “I feel changed.”
- “Today’s writing really pulled together my feelings that I’ve had in the past to the ones in the present. That feels good.”
- “Writing everything down helps make sense a little more about everything I have been feeling.”
- “I feel that this writing is helping. I think it has helped me understand who I am.”
- “I feel like I’ve actively taken this experience that was originally bad and turned it into a great thing.”
- “I actually (surprisingly) enjoyed it. It felt good to express all of my thoughts and emotions when I didn’t cry. Although I have told my parents how I feel, it still feels good.”

- “I think I wrote what I was feeling. It's hard for me to open up sometimes, but at the end I told things that I haven't told anyone. It's very truthful.”
- “I think that I can tell my feelings and still feel strong. It would be better for me than holding it all in because it feels good to get it off of my chest.”

Feedback from the control group was also positive. Although they did not write about their feelings in this group, they still seemed to enjoy participating in the study. Typical responses in the control group when asked about how they felt about their writings included:

- “I feel good.”
- “It gave me a chance to organize my thoughts which feels really good.”
- “I feel good knowing that I'm done and it's for a good cause.”
- “I feel fine”

When considering converting this experimental procedure into a clinical intervention we must consider factors such as the location of the intervention, the writing instructions given to adolescents, and the involvement of the intervention coordinator with the adolescents. In this study, most of the participants chose to participate in their own homes, a factor that Frattaroli (2006) found to be related to increased effects of expressive writing. If the intervention were moved to the adolescent's school or another location, it may change the effect of the expressive writing. This would need to be evaluated. Changes in writing instructions or any changes in the general protocol would need to be assessed to make sure the effects of the expressive writing are not being mitigated. Although some of the writing sessions were administered over the telephone (mainly the second and third writing sessions), the experimenter did interact quite a bit with the adolescents and their parents in this study. Again, this is a factor that has been shown to mediate positive results for expressive writing (Frattaroli, 2006). As such, a decreased presence

of the intervention provider in the administration of the writings or a switch to group-administered writing could alter the effects of the intervention.

With these possibilities in mind, the prospects for converting expressive writing protocols into practical and effective intervention for adolescent children of parent with cancer seem both doable and promising. Indeed, this is our sincere hope - a hope that many of the research participants echoed as one of their reasons for agreeing to take part in this research.

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Appendix A

Participant # _____

EXPRESSIVE WRITING INTERVENTION FOR TEENS WHOSE PARENTS HAVE CANCER INFORMED CONSENT FOR PARENT

Introduction

You and your child are being invited to participate in a research study investigating your child's experience of having a parent with cancer. This research study will be conducted at the University of Kansas Medical Center with Martha Barnard, Ph.D. as the principal investigator and Lesley A. Laub, M.A. as the co-investigator.

The Department of Pediatrics at the University of Kansas Medical Center supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you and your child wish to participate in the present study. You should be aware that even if you agree to participate, you are free to withdraw at any time without penalty or loss of services. You do not have to participate in this research study. It is important that before you make a decision to participate, you read the rest of this form. You should ask as many questions as needed to understand what will happen to you and your child if you participate in this study.

Background

We are interested in examining the issues that teens face when they have a chronically ill parent. When a family member is diagnosed with cancer, the whole family is affected. We want to find out how teens are dealing with their parent's cancer, and what helps them or hinders them in coping with this situation.

Purpose

The purpose of this study is to evaluate if writing about their lives will improve the psychological and physical health of teenagers whose parents have cancer.

Procedure

To determine what type of writing makes a difference, the teenagers will be assigned to 2 writing groups randomly (much like the toss of a coin). Teenagers will either write about how they manage time, or write about the experience of living with cancer for 20 minutes on three different occasions within a 3-week period. These writings will be kept confidential and only personnel associated with the study will be allowed access to them. Parents will not be allowed to read their child's writings. One exception is if the child reports abuse in the writings. In all interventions, the researchers are mandated by law to report suspected child abuse. The parent would be told of this concern and would be encouraged to report the incident to the Child Protection Agency with the researcher. Another exception is if the child threatens to harm himself/herself or threatens to harm another person in his/her writings. This information would be shared by the investigator and the child with the parent and the appropriate referral for immediate intervention would be made.

Parents and their children will also fill out a series of questionnaires about the parent's cancer, and the child's behaviors, mood, coping strategies, illness symptoms, sense of time, and goal setting. Your name and your child's name will not be associated in any way with the information collected about you or with the research findings from this study. The researchers will use a study number or a pseudonym instead of your name. If your child's answers on the questionnaires indicate that he or she is clinically depressed or anxious or if the child reports suicidal thoughts or abuse he/she will be seen in person by Dr. Barnard at the KU Behavioral Pediatric Clinic for free if you so choose. Dr. Barnard is available 24-hours/day by page to help families in crisis. For immediate care during evening/night hours, she also refers children to the KU Emergency Room.

There will be three sessions to the study. The first session will take approximately 1½ hours total, during which the parent and child will fill out questionnaires for an hour and the child will write for 20 minutes about the assigned topic (i.e., how they manage time, or their experience with cancer). During the second

session, the child will again fill out questionnaires for 10 minutes and will write again for 20 minutes on the same topic. During the third session, the child will fill out questionnaires for 10 minutes and write on the same topic for 20 minutes. These sessions will be scheduled at a time and place that is convenient for your family. Finally, you will be asked to keep track of the number of visits your child makes to the doctor for illness in the three months after the study. At the end of the three months, you and your child will be asked to fill out more questionnaires and send them back to the researcher along with your report of your child's doctors visits in a provided stamped and addressed envelope. If you decide to participate, your participation will last approximately 4 months total and will take approximately 3 hours of your time.

Risks

You and your child will not be exposed to any physical risk at any time during this study. However, you and your child may experience some emotional risk because you will have to think about the effects of cancer on your lives. If your child is, he/she will be referred for appropriate help.

Institutional Disclaimer Statement

“Although the University of Kansas Medical Center does not provide free medical treatment or other forms of compensation to persons injured as a result of participating in research, such compensation may be provided under the terms of the Kansas Tort Claims Act. If you believe you have been injured as a result of participating in research, you should contact the Office of Legal Counsel, University of Kansas Medical Center, Kansas City, KS 66160-7101. You will also be informed if any significant new findings develop during the course of the study that may affect your willingness to participate in this study.”

Benefits

Parents and their children participating in this study may benefit by having the opportunity to express their experiences and feeling related to the cancer. Also, if your child is experiencing emotional discomfort, it will be identified and options for counseling will be provided, if you so choose. Further, this study will benefit parents and their children by providing a better understanding of how adolescents are impacted by parental cancer. Additionally, this research will help in the development of effective writing interventions for teens experiencing distress because of their parent's cancer.

Alternatives

The other option to this study is not to participate.

Payment to Subjects

You and your child will be paid to participate in this study. You will be paid \$10 at the end of the first visit. You will be paid another \$10 at the end of the third visit. Finally, you will be paid another \$10 three months after the study when you fill out the last questionnaires given to you by the researcher and send them back to the researcher in the addressed stamped envelope provided. Your name, address, social security number, and the title of this study will be given to the KUMC Research Institute. This will be done so that the Research Institute can write a check for study payments. Payments are taxable income.

Costs

There are no costs to your participation.

Confidentiality and Privacy Authorization

The privacy of your health information is protected by a federal law known as the Health Insurance Portability and Accountability Act (HIPAA). If you choose to participate in this study, you will be asked to give permission for researchers to use and disclose your health information. To perform this study, researchers will collect information about you. This information will be collected from the study activities that are listed in the Procedures section of this consent form. Your name will not be associated in any way with the information collected about you or with the research findings from this study. The researchers will use a study number or a

pseudonym instead of your name. The information collected about you will be used by Dr. Barnard, Ms. Laub, members of their research team, the Department of Oncology, the Department of Surgery, the KU Cancer Center, KU Radiation Oncology, and KU Center for Research, officials at KU that oversee research, and government agencies that oversee research.

In addition, Dr. Barnard and her team may share the information gathered in this study, including your information, with representatives of Turning Point of Kansas City (the sponsor of the study) so that they may learn about the issues teens face when dealing with the illness of a parent. Again, your name would not be associated with the information disclosed to these individuals. Some persons or groups that receive your information may not be required to comply with the Health Insurance Portability and Accountability Act's privacy regulations, and your information may lose this federal protection if those persons or groups disclose it.

The researchers will not share information about you with anyone not specified above unless required by law or unless you give written permission. Permission granted on this date to use and disclose your information remains in effect indefinitely. By signing this form you give permission for the use and disclosure of your information for purposes of this study at any time in the future.

I understand that my and my child's participation are voluntary, and I can refuse to participate (or refuse my child to participate) at any time during the study without having the medical treatment we are receiving at the University of Kansas Medical Center affected. I also understand that all data on my child including their writings will be considered confidential and will only be released through written reports of this study without the use of my child's name. Any other release of this information outside personnel specifically involved in this study will require my written authorization.

Questions

You have read the information in this form. Dr. Barnard or her associates have answered your question(s) to your satisfaction. You know if you have any more questions after signing this you may contact Lesley A. Laub or Dr. Martha Barnard at (XXX) XXX-XXXX. Dr. Barnard may be contacted with questions 24 hours a day at (XXX) XXX-XXXX. If you have any questions about your rights as a research subject, you may call (XXX) XXX-XXXX or write the Human Subjects Committee, G006 Sudler, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160.

Subject Rights and Withdrawal from the Study

You understand that your participation in this study is voluntary. The choice not to participate or to quit at any time can be made without penalty or loss of benefits. You understand that not participating or quitting will have no effect upon the medical care or treatment you receive now or in the future at the University of Kansas Medical center. The study may be discontinued for any reason without your consent by the investigator conducting the study, by the sponsor of the study, or the FDA. Your participation can be discontinued by the investigator or by the sponsor if it is felt to be in your best interest or if you do not follow the study requirements.

You have a right to change your mind about allowing the research team to have access to your health information. To cancel your permission you must send a written request to Dr. Barnard at KU Medical Center, 3901 Rainbow Boulevard, Kansas City, KS 66160.

If you cancel permission to use your health information, you will be withdrawn from the study. The researchers and the sponsor may continue to use and share information that was gathered before your cancellation. They will stop collecting any additional information about you.

Consent

I hereby give my voluntary consent to participate in this study for my child and myself subject to the above restrictions. I understand that I will be provided with a copy of this signed consent form. I also understand that Dr. Barnard (XXX-XXX-XXXX) is available to answer any questions I might have during the duration of our participation in this study. I may call her or contact her at the following address: University of Kansas Medical Center, Department of Pediatrics, 3901 Rainbow Blvd., Kansas City, KS 66160-7330.

Child Participant's Name (Printed)

Date

Parent/Legal Guardian's Name (Printed)

Witness' Signature

Parent/Legal Guardian's Signature

Principal Investigator's Signature

“With my signature I affirm that I am at least 18 years of age and have received a copy of the consent form to keep.”

ASSENT STATEMENT (CHILD)

We are inviting you to take part in a study on what it is like to be a teenager with a parent who has cancer. Your parents have given us their permission for you to participate. As part of the project, you will answer some questions about yourself and your parents, and you will be asked to write about different topics in your life three different times for 20 minutes each time. You will either be asked to write about how you manage your time, or you will be asked to write about your experience with your parent's cancer. Your parent will also answer some questions and write down how many times you went to the doctor for illness in the three months after the study. Then you will answer some more questions on paper and send them back to the researcher in the mail.

If you don't want to take part in this study at all, that is okay. If you decide to participate and then want to stop, that is okay, too. Everything you say and do will be confidential (no one except you, your parents, the researchers, and your doctor will know what is going on). We hope this study will help make it easier for teenagers whose parents have cancer.

Do you have any questions?

Yes

No

Are you willing to be in the study?

Yes

No

Participant:_____

Date:_____

Witness:_____

Appendix B

Participant # _____

EXPRESSIVE WRITING INTERVENTION FOR TEENS WHOSE PARENTS HAVE CANCER INFORMED CONSENT FOR PARENT OF CHILD AGE 18

Introduction

You are being invited to participate in a research study investigating your child's experience of having a parent with cancer. This research study will be conducted at the University of Kansas Medical Center with Martha Barnard, Ph.D. as the principal investigator and Lesley A. Laub, M.A. as the co-investigator.

The Department of Pediatrics at the University of Kansas Medical Center supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the present study. You should be aware that even if you agree to participate, you are free to withdraw at any time without penalty or loss of services. You do not have to participate in this research study. It is important that before you make a decision to participate, you read the rest of this form. You should ask as many questions as needed to understand what will happen to you if you participate in this study.

Background

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Procedure

To determine what type of writing makes a difference, the teenagers will be assigned to 2 writing groups randomly (much like the toss of a coin). Teenagers will either write about how they manage time, or write about the experience of living with cancer for 20 minutes on three different occasions within a 3-week period. These writings will be kept confidential and only personnel associated with the study will be allowed access to them. Parents will not be allowed to read their child's writings.

Parents will also fill out a series of questionnaires about the parent's cancer, and the child's behaviors, mood, and illness symptoms. Your name will not be associated in any way with the information collected about you or with the research findings from this study. The researchers will use a study number or a pseudonym instead of your name. If your child's answers on the questionnaires indicate that he or she is clinically depressed or anxious or if the child reports suicidal thoughts or abuse he/she will be seen in person by Dr. Barnard at the KU Behavioral Pediatric Clinic for free if he/she so chooses. Dr. Barnard is available 24-hours/day by page to help families in crisis. For immediate care during evening/night hours, she also refers people to the KU Emergency Room.

There will be three sessions to the study. The first session will take approximately 1½ hours total, during which the parent and child will fill out questionnaires for an hour and the child will write for 20 minutes about the assigned topic (i.e., how they manage time, or their experience with cancer). During the second session, the child will again fill out questionnaires for 10 minutes and will write again for 20 minutes on the same topic. During the third session, the child will fill out questionnaires for 10 minutes and write on the same topic for 20 minutes. These sessions will be scheduled at a time and place that is convenient for your family.

Finally, you will be asked to keep track of the number of visits your child makes to the doctor for illness in the three months after the study. At the end of the three months, you and your child will be asked to fill out more questionnaires and send them back to the researcher along with your report of your child's doctors visits in a provided stamped and addressed envelope. If you decide to participate, your participation will last approximately 4 months total and will take approximately 3 hours of your time.

Risks

You will not be exposed to any physical risk at any time during this study. However, you may experience some emotional risk because you will have to think about the effects of cancer on your life.

Institutional Disclaimer Statement

“Although the University of Kansas Medical Center does not provide free medical treatment or other forms of compensation to persons injured as a result of participating in research, such compensation may be provided under the terms of the Kansas Tort Claims Act. If you believe you have been injured as a result of participating in research, you should contact the Office of Legal Counsel, University of Kansas Medical Center, Kansas City, KS 66160-7101. You will also be informed if any significant new findings develop during the course of the study that may affect your willingness to participate in this study.”

Benefits

Parents participating in this study may benefit by having the opportunity to express their experiences and feeling related to the cancer. Further, this study will benefit parents by providing a better understanding of how adolescents are impacted by parental cancer. Additionally, this research will help in the development of effective writing interventions for teens experiencing distress because of their parent's cancer.

Alternatives

The other option to this study is not to participate.

Payment to Subjects

Your child will be paid to participate in this study. Your child will be paid \$10 at the end of the first visit. He/she will be paid another \$10 at the end of the third visit. Finally, he/she will be paid another \$10 three months after the study when you fill out the last questionnaires given to you by the researcher and send them back to the researcher in the addressed stamped envelope provided. Your child's name, address, social security number, and the title of this study will be given to the KUMC Research Institute. This will be done so that the Research Institute can write a check for study payments. Payments are taxable income.

Costs

There are no costs to your participation.

Confidentiality and Privacy Authorization

The privacy of your health information is protected by a federal law known as the Health Insurance Portability and Accountability Act (HIPAA). If you choose to participate in this study, you will be asked to give permission for researchers to use and disclose your health information. To perform this study, researchers will collect information about you. This information will be collected from the study activities that are listed in the Procedures section of this consent form. Your name will not be associated in any way with the information collected about you or with the research findings from this study. The researchers will use a study number or a pseudonym instead of your name. The information collected about you will be used by Dr. Barnard, Ms. Laub, members of their research team, the Department of Oncology, the Department of Surgery, the KU Cancer Center, KU Radiation Oncology, and KU Center for Research, officials at KU that oversee research, and government agencies that oversee research.

In addition, Dr. Barnard and her team may share the information gathered in this study, including your information, with representatives of Turning Point of Kansas City (the sponsor of the study) so that they may learn about the issues teens face when dealing with the illness of a parent. Again, your name would not be associated with the information disclosed to these individuals. Some persons or groups that receive your information may not be required to comply with the Health Insurance Portability and Accountability Act's privacy regulations, and your information may lose this federal protection if those persons or groups disclose it.

The researchers will not share information about you with anyone not specified above unless required by law or unless you give written permission. Permission granted on this date to use and disclose your information remains in effect indefinitely. By signing this form you give permission for the use and disclosure of your information for purposes of this study at any time in the future.

I understand that my participation is voluntary, and I can refuse to participate at any time during the study without having the medical treatment I am receiving at the University of Kansas Medical Center affected. I also understand that all data on my child including their writings will be considered confidential and will only be released through written reports of this study without the use of my child's name. Any other release of this information outside personnel specifically involved in this study will require my written authorization.

Questions

You have read the information in this form. Dr. Barnard or her associates have answered your question(s) to your satisfaction. You know if you have any more questions after signing this you may contact Lesley A. Laub or Dr. Martha Barnard at (XXX) XXX-XXXX. Dr. Barnard may be contacted with questions 24 hours a day at (XXX) XXX-XXXX. If you have any questions about your rights as a research subject, you may call (XXX) XXX-XXXX or write the Human Subjects Committee, G006 Sudler, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160.

Subject Rights and Withdrawal from the Study

You understand that your participation in this study is voluntary. The choice not to participate or to quit at any time can be made without penalty or loss of benefits. You understand that not participating or quitting will have no effect upon the medical care or treatment you receive now or in the future at the University of Kansas Medical center. The study may be discontinued for any reason without your consent by the investigator conducting the study, by the sponsor of the study, or the FDA. Your participation can be discontinued by the investigator or by the sponsor if it is felt to be in your best interest or if you do not follow the study requirements.

You have a right to change your mind about allowing the research team to have access to your health information. To cancel your permission you must send a written request to Dr. Barnard at KU Medical Center, 3901 Rainbow Boulevard, Kansas City, KS 66160.

If you cancel permission to use your health information, you will be withdrawn from the study. The researchers and the sponsor may continue to use and share information that was gathered before your cancellation. They will stop collecting any additional information about you. \

Consent

I hereby give my voluntary consent to participate in this study for my child and myself subject to the above restrictions. I understand that I will be provided with a copy of this signed consent form. I also understand that Dr. Barnard (XXX-XXX-XXXX) is available to answer any questions I might have during the duration of our participation in this study. I may call her or contact her at the following address: University of Kansas Medical Center, Department of Pediatrics, 3901 Rainbow Blvd., Kansas City, KS 66160-7330.

Child Participant's Name (Printed)

Date

Parent/Legal Guardian's Name (Printed)

Witness' Signature

Parent/Legal Guardian's Signature

Principal Investigator's Signature

“With my signature I affirm that I am at least 18 years of age and have received a copy of the consent form to keep.”

Appendix C

Participant # _____

EXPRESSIVE WRITING INTERVENTION FOR TEENS WHOSE PARENTS HAVE CANCER INFORMED CONSENT FOR PARTICIPANTS AGE 18

Introduction

You and your parent(s) are being invited to participate in a research study investigating your family's experience of having a parent with cancer. This research study will be conducted at the University of Kansas Medical Center with Martha Barnard, Ph.D. as the principal investigator and Lesley A. Laub, M.A. as the co-investigator.

The Department of Pediatrics at the University of Kansas Medical Center supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the present study. You should be aware that even if you agree to participate, you are free to withdraw at any time without penalty or loss of services. You do not have to participate in this research study. It is important that before you make a decision to participate, you read the rest of this form. You should ask as many questions as needed to understand what will happen to you if you participate in this study.

Background

We are interested in examining the issues that teens face when they have a chronically ill parent. When a family member is diagnosed with cancer, the whole family is affected. We want to find out how teens are dealing with their parent's cancer, and what helps them or hinders them in coping with this situation.

Purpose

The purpose of this study is to evaluate if writing about their lives will improve the psychological and physical health of teenagers whose parents have cancer.

Procedure

To determine what type of writing makes a difference, teenagers will be assigned to 2 writing groups randomly (much like the toss of a coin). Teenagers will either write about how they manage time, or write about the experience of living with cancer. They will write for 20 minutes on three different occasions within a 3-week period. These writings will be kept confidential and only personnel associated with the study will be allowed access to them. Parents will not be allowed to read their child's writings. If the teenager threatens to harm himself/herself or threatens to harm another person in his/her writings, this information would be discussed by the investigator and the teenager and the appropriate referral for immediate intervention would be made.

Parents and their children will also fill out a series of questionnaires about the parent's cancer, and the child's behaviors, mood, coping strategies, illness symptoms, sense of time, and goal setting. Your name and your parent's name will not be associated in any way with the information collected about you or with the research findings from this study. The researchers will use a study number or a pseudonym instead of your name. If your answers on the questionnaires indicate that you are clinically depressed or anxious or if you report suicidal thoughts or abuse you will be seen in person by Dr. Barnard at the KU Behavioral Pediatric Clinic for free, if you so choose. Dr. Barnard is available 24-hours/day by page to help families in crisis. For immediate care during evening/night hours, she also refers people to the KU Emergency Room.

There will be three sessions to the study. The first session will take approximately 1½ hours total, during which the parent and child will fill out questionnaires for an hour and the child will write for 20 minutes about the assigned topic (i.e., how they manage time, or their experience with cancer). During the second

session, the child will again fill out questionnaires for 10 minutes and will write again for 20 minutes on the same topic. During the third session, the child will fill out questionnaires for 10 minutes and write on the same topic for 20 minutes. These sessions will be scheduled at a time and place that is convenient for your family. Finally, your parent will be asked to keep track of the number of visits you make to the doctor for illness in the three months after the study. At the end of the three months, you and your parent will be asked to fill out more questionnaires and send them back to the researcher along with your parent's report of your doctor visits in a provided stamped and addressed envelope. If you decide to participate, your participation will last approximately 4 months total and will take approximately 3 hours of your time.

Risks

You will not be exposed to any physical risk at any time during this study. However, you may experience some emotional risk because you will have to think about the effects of cancer on your life. If you do experience significant distress, you will be referred for appropriate help.

Institutional Disclaimer Statement

“Although the University of Kansas Medical Center does not provide free medical treatment or other forms of compensation to persons injured as a result of participating in research, such compensation may be provided under the terms of the Kansas Tort Claims Act. If you believe you have been injured as a result of participating in research, you should contact the Office of Legal Counsel, University of Kansas Medical Center, Kansas City, KS 66160-7101. You will also be informed if any significant new findings develop during the course of the study that may affect your willingness to participate in this study.”

Benefits

Cancer patients and their children participating in this study may benefit by having the opportunity to express their experiences and feeling related to the cancer. Also, if you are experiencing emotional discomfort, it will be identified and options for counseling will be provided, if you so choose. Further, this study will benefit cancer patients and their children by providing a better understanding of how adolescents are impacted by parental cancer. Additionally, this research will help in the development of effective writing interventions for teens experiencing distress because of their parent's cancer.

Alternatives

The other option to this study is not to participate.

Payment to Subjects

You will be paid to participate in this study. You will be paid \$10 at the end of the first visit. You will be paid another \$10 at the end of the third visit. Finally, you will be paid another \$10 three months after the study when you and your parent fill out the last questionnaires given to you by the researcher and send them back to the researcher in the addressed stamped envelope provided. Your name, address, social security number, and the title of this study will be given to the KUMC Research Institute. This will be done so that the Research Institute can write a check for study payments. Payments are taxable income.

Costs

There are no costs to your participation.

Confidentiality and Privacy Authorization

The privacy of your health information is protected by a federal law known as the Health Insurance Portability and Accountability Act (HIPAA). If you choose to participate in this study, you will be asked to give permission for researchers to use and disclose your health information. To perform this study, researchers will collect information about you. This information will be collected from the study activities that are listed in the Procedures section of this consent form. Your name will not be associated in any way with the information collected about you or with the research findings from this study. The researchers will use a study

number or a pseudonym instead of your name. The information collected about you will be used by Dr. Barnard, Ms. Laub, members of their research team, the Department of Oncology, the Department of Surgery, the KU Cancer Center, KU Radiation Oncology, and KU Center for Research officials at KU that oversee research, and government agencies that oversee research.

In addition, Dr. Barnard and her team may share the information gathered in this study, including your information, with representatives of Turning Point of Kansas City (the sponsor of the study) so that they may learn about the issues teens face when dealing with the illness of a parent. Again, your name would not be associated with the information disclosed to these individuals. Some persons or groups that receive your information may not be required to comply with the Health Insurance Portability and Accountability Act's privacy regulations, and your information may lose this federal protection if those persons or groups disclose it.

The researchers will not share information about you with anyone not specified above unless required by law or unless you give written permission. Permission granted on this date to use and disclose your information remains in effect indefinitely. By signing this form, you give permission for the use and disclosure of your information for purposes of this study at any time in the future.

I understand that my participation are voluntary, and I can refuse to participate at any time during the study without having the medical treatment I and/or my parent are receiving at the University of Kansas Medical Center affected. I also understand that all data on me including my writings will be considered confidential and will only be released through written reports of this study without the use of my name. Any other release of this information outside personnel specifically involved in this study will require my written authorization.

Questions

You have read the information in this form. Dr. Barnard or her associates have answered your question(s) to your satisfaction. You know if you have any more questions after signing this you may contact Lesley A. Laub or Dr. Martha Barnard at (XXX) XXX-XXXX. Dr. Barnard may be contacted with questions 24 hours a day at (XXX) XXX-XXXX. If you have any questions about your rights as a research subject, you may call (XXX) XXX-XXXX or write the Human Subjects Committee, G006 Sudler, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160.

Subject Rights and Withdrawal from the Study

You understand that your participation in this study is voluntary. The choice not to participate or to quit at any time can be made without penalty or loss of benefits. You understand that not participating or quitting will have no effect upon the medical care or treatment you or your parents receive now or in the future at the University of Kansas Medical center. The study may be discontinued for any reason without your consent by the investigator conducting the study, by the sponsor of the study, or the FDA. Your participation can be discontinued by the investigator or by the sponsor if it is felt to be in your best interest or if you do not follow the study requirements.

You have a right to change your mind about allowing the research team to have access to your health information. To cancel your permission you must send a written request to Dr. Barnard at KU Medical Center, 3901 Rainbow Boulevard, Kansas City, KS 66160.

If you cancel permission to use your health information, you will be withdrawn from the study. The researchers and the sponsor may continue to use and share information that was gathered before your cancellation. They will stop collecting any additional information about you.

Consent

I hereby give my voluntary consent to participate in this study for myself subject to the above restrictions. I understand that I will be provided with a copy of this signed consent form. I also understand that Dr. Barnard (XXX-XXX-XXXX) is available to answer any questions I might have during the duration of our participation in this study. I may call her or contact her at the following address: University of Kansas Medical Center, Department of Pediatrics, 3901 Rainbow Blvd., Kansas City, KS 66160-7330.

Participant's Name (Printed)

Date

Participant's Signature

Witness' Signature

Principal Investigator's Signature

“With my signature I affirm that I am at least 18 years of age and have received a copy of the consent form to keep.”

Appendix D

_____Participant #

EXPRESSIVE WRITING INTERVENTION FOR TEENS WHOSE PARENTS HAVE CANCER INFORMED CONSENT ASSENT STATEMENT (CHILD)

We are inviting you to take part in a study on what it is like to be a teenager with a parent who has cancer. Your parents have given us their permission for you to participate. As part of the project, you will answer some questions about yourself and your parents, and you will be asked to write about different topics in your life three different times for 20 minutes each time. You will either be asked to write about how you manage your time, or you will be asked to write about your experience with your parent's cancer. Your parent will also answer some questions and write down how many times you went to the doctor for illness in the three months after the study. Then you will answer some more questions on paper and send them back to the researcher in the mail.

If you don't want to take part in this study at all, that is okay. If you decide to participate and then want to stop, that is okay, too. Everything you say and do will be confidential (no one except you, your parents, the researchers, and your doctor will know what is going on). We hope this study will help make it easier for teenagers whose parents have cancer.

Do you have any questions?

Yes

No

Are you willing to be in the study?

Yes

No

Participant: _____

Date: _____

Witness: _____

Appendix F

Participant ID # _____

Experience with Cancer Questionnaire (For Parent) – Session 1

The following questions are about your cancer diagnosis, treatment, and long-term side effects. Please answer all of the questions to the best of your ability.

1. What type of cancer were you diagnosed with?

2. When were you diagnosed with cancer (Month/Year)? ____/____

3. How old were you when you were diagnosed with cancer? _____

4. What stage of cancer were you diagnosed with? _____

5. Which of the following treatments did you receive? (put a check mark next to each one)

1. Bone Marrow Transplant

2. Chemotherapy

3. Limb amputation

4. Radiation → To what part of the body did you receive radiation? _____

5. Stem cell transplant

6. Surgery

7. Other, please specify _____

6. How long did the treatment(s) last? _____

7. When did the treatment(s) end? (month/year) ____/____

8. Have you experienced a recurrence of cancer? (please circle answer)

Yes

No

→ If yes, when did the recurrence occur? _____

9. Have you experienced any long-term side effects from the treatment of your cancer (please circle answer)?

Yes

No

→ If yes, what side effects have you experienced?

10. Please rate how stressful your having cancer is or has been to you.

1

2

3

4

5

Not at all
Stressful

Somewhat
Stressful

Moderately
Stressful

Very
Stressful

Extremely
Stressful

11. Please rate how severe you believe your cancer is.

1

2

3

4

5

Not at all
Severe

Somewhat
Severe

Moderately
Severe

Very
Severe

Extremely
Severe

Appendix H

Participant ID # _____

The Goals Scale (Hope Scale)

Directions: Read each item carefully. Using the scale shown below, please select the number that best describes YOU and put that number in the blank provided.

1 = Definitely False 2 = Mostly False 3 = Somewhat False 4 = Slightly False 5 = Slightly True 6 = Somewhat True 7 = Mostly True 8 = Definitely True

- _____ 1. I can think of many ways to get out of a jam.
- _____ 2. I energetically pursue my goals.
- _____ 3. There are lots of ways around any problem.
- _____ 4. I can think of many ways to get the things in life that are most important to me.
- _____ 5. Even when others get discouraged, I know I can find a way to solve the problem.
- _____ 6. My past experiences have prepared me well for my future.
- _____ 7. I've been pretty successful in life.
- _____ 8. I meet the goals that I set for myself.

Appendix I

Participant ID # _____

Abbreviated Positive and Negative Affect Schedule (past few weeks)

Read each of the items below and then circle the number next to each item that best describes how you felt the past few weeks. For example, if you generally felt extremely angry, you would circle the 5 next to the word angry.

	Not at all	A little	Somewhat	Quite a bit	Extremely
Strong	1	2	3	4	5
Angry	1	2	3	4	5
Irritable	1	2	3	4	5
Nervous	1	2	3	4	5
Sad	1	2	3	4	5
Lonely	1	2	3	4	5
Afraid	1	2	3	4	5
Determined	1	2	3	4	5
Alert	1	2	3	4	5
Confident	1	2	3	4	5

Appendix J

Participant ID # _____

Coping Scale for Children and Youth

Listed below are some ways that people try to deal with their problems. Please tell us how you react to your parent's cancer. To do this, circle the number that best describes how often you would use each of these behaviors when dealing with your parent's cancer.

	Never	Sometimes	Often	Very Often
1. I would ask someone in my family for help.	1	2	3	4
2. I would try not to think about the problem.	1	2	3	4
3. I would go on with my usual activities as if nothing was wrong.	1	2	3	4
4. I would take time to figure out what I was really feeling.	1	2	3	4
5. I would think about the problem and try to figure out what I could do about it.	1	2	3	4
6. I would stay away from things that would remind me about the problem.	1	2	3	4
7. I would try not to feel anything inside me. I would want to feel numb.	1	2	3	4
8. I would pretend the problem wasn't very important to me.	1	2	3	4
9. I would think about or "get into" my feelings to understand them better.	1	2	3	4
10. I would know that I have lots of feelings about the problem, but I just wouldn't pay any attention to them.	1	2	3	4
11. I would take a chance and try a new way to solve the problem.	1	2	3	4
12. I would try to get away from the problem for a while by doing other things.	1	2	3	4
13. I would make a plan to solve the problem and then I would follow the plan.	1	2	3	4
14. I would think that my feelings are OK and that they are important.	1	2	3	4
15. I would pretend the problem had nothing to do with me.	1	2	3	4

CONTINUED ON NEXT PAGE →

Remember, circle the number that best describes how often you would use each of the following behaviors when dealing with when dealing with your parent's cancer.

	Never	Sometimes	Often	Very Often
16. I would go over in my head some of the things I could do about the problem.	1	2	3	4
17. I would think about the problem in a new way so that it wouldn't upset me as much.	1	2	3	4
18. I would go to sleep so that I wouldn't have to think about it.	1	2	3	4
19. I would be mean to someone even though they didn't deserve it.	1	2	3	4
20. I would know that it's OK to have the emotions that I do.	1	2	3	4
21. I would learn a new way of dealing with the problem.	1	2	3	4
22. I would try to pretend that the problem didn't happen.	1	2	3	4
23. I would let my feelings come out freely.	1	2	3	4
24. I would get advice from someone about what I should do.	1	2	3	4
25. I would hope that things would somehow work out and wouldn't do anything.	1	2	3	4
26. I would try to pretend that my problem wasn't real.	1	2	3	4
27. I would take time to express my emotions.	1	2	3	4
28. I would try not to be with anyone who would remind me of the problem.	1	2	3	4
29. I would share my feelings about the problem with another person.	1	2	3	4
30. I would allow myself to express my emotions.	1	2	3	4
31. I would try to figure out how I felt about the problem.	1	2	3	4
32. I would figure out what would have to be done and then I would do it.	1	2	3	4
33. I would keep my feelings to myself.	1	2	3	4
34. I would realize that there would be nothing I could do. I would just wait for it to be over with.	1	2	3	4
35. I would feel free to express my emotions.	1	2	3	4
36. I would decide to stay away from people and be by myself.	1	2	3	4
37. I would put the problem out of my mind.	1	2	3	4

Appendix K

Participant ID # _____

Post Traumatic Growth Inventory - Revised

Each statement below describes how a person may change after going through a difficult experience. Indicate the degree to which each statement describes how you have changed as a result of your experience with your parent's cancer. For example, you would put a 0 next to question number 1 if your experience with your parent's cancer did not change the things that are important to you in life.

- 0 = I did not experience this change as a result of my experience.
 1 = I experienced this change to a very small degree as a result of my experience
 2 = I experienced this change to a small degree as a result of my experience
 3 = I experienced this change to a moderate degree as a result of my experience
 4 = I experience this change to a great degree as a result of my experience
 5 = I experience this change to a very great degree as a result of my experience

1. _____ The things that are important to me in life.
2. _____ An appreciation for the value of my own life.
3. _____ I developed new interests.
4. _____ Knowing that I can do things on my own.
5. _____ I better understand spiritual/religious things.
6. _____ Knowing that I can count on people in times of trouble
7. _____ I established a new path for my life.
8. _____ A sense of closeness with others.
9. _____ A willingness to express my emotions.
10. _____ Knowing that I can handle difficulties.
11. _____ I'm able to do better things with my life.
12. _____ Being able to accept the way things work out.
13. _____ I appreciate each day.
14. _____ I have new opportunities that I didn't have before.
15. _____ Caring about other people.
16. _____ I put effort into my relationships.
17. _____ I'm more likely to try to change things that need changing.
18. _____ I have a stronger religious faith.
19. _____ I discovered that I'm stronger than I thought I was.
20. _____ I learned a great deal about how wonderful people are.
21. _____ I accept needing others.

Appendix L

Participant ID # _____

Temporal Orientation Scale

Please read each statement, and as honestly as you can, answer the question, "How true is this statement of me?" Indicate the number that corresponds with your number in the space provided. There are no right or wrong answers. This questionnaire is only interested in your attitudes about several statements. Use the scale that has been provided below.

Not True			Somewhat True			Very True
1	2	3	4	5	6	7

- _____ 1. I think about the past a lot.
- _____ 2. When I want to get something done, I make step by step plans and think about how to complete each step.
- _____ 3. I believe what is done is done so it is better to move on than dwell on the past.
- _____ 4. Generally, I am more focused on what is going on now than on what will happen in the future.
- _____ 5. I think a lot about what life was like when I was younger.
- _____ 6. I often think of all the things I wish I had done differently in my past.
- _____ 7. I take care of what needs done before having fun.
- _____ 8. The joy in my life comes from what I am doing now, not from what I will be doing later.
- _____ 9. I often wish I could return to things as they used to be.
- _____ 10. I am able to resist temptations when there is work to be done.
- _____ 11. I try to live one day at a time.
- _____ 12. I know what kind of job or further schooling I will be doing in the future.
- _____ 13. When daydreaming I relive past experiences.
- _____ 14. When I get into a tight spot, I usually find a creative way to get out.
- _____ 15. I try to follow through on doing things if I think doing them will get me to where I want to be.
- _____ 16. I find it impossible to do anything without thinking about things I have already done.
- _____ 17. I keep working at a difficult, boring task if it will help me to get ahead.
- _____ 18. It is very important to remember the past to know how to live in the present.
- _____ 19. I get things done on time, including meeting obligations to friends and authorities on time.
- _____ 20. Thinking about the past makes me very emotional.
- _____ 21. I like to enjoy what I am doing now rather than think about what I need to do so I could have fun tomorrow.
- _____ 22. Many of the things I do now are because of my past experiences.
- _____ 23. I get things done by working at a steady pace.
- _____ 24. I often think about things I used to do.
- _____ 25. I try to do things that will help me get what I want in the future.
- _____ 26. If I take care of the present, the future will take care of itself.
- _____ 27. I often think about what life was like for my parents and grandparents.

Appendix M

Participant ID # _____

Physical Symptoms Measure

Think back over the past 30 days. On how many of these days have you experienced each of the physical symptoms below? For example, if you had a headache on about 20 out of the last 30 days, put a 20 in the space beside that item. If you are not sure about the number of days you have experienced each symptom, please give your best estimate.

Do not report the days you experienced a symptom as a result of intentional physical exercise.

- _____ headache
- _____ chest pain
- _____ coughing/sore throat
- _____ out of breath
- _____ stiff/sore muscles
- _____ stomach ache/pain
- _____ runny/congested nose
- _____ faintness/dizziness
- _____ acne/pimples

How many times have you been to the doctor because you were sick in the past 3 months?

_____ times total

Appendix N

Participant ID # _____

Impact of Events Scale -Revised

Below is a list of comments made by people after stressful life events. Please check each item, indicating how frequently these comments were true for you DURING THE PAST SEVEN DAYS regarding your experience of you parent's cancer. If they did not occur during that time, please mark the "not at all" column.

	FREQUENCY			
	Not at all	Rarely	Sometimes	Often
1. I thought about it when I didn't mean to.				
2. I avoided letting myself get upset when I thought about it or was reminded about it.				
3. I tried to remove it from my memory.				
4. I had trouble falling asleep or staying asleep because of pictures or thoughts about it that came into my mind.				
5. I had waves of strong feelings about it.				
6. I had dreams about it.				
7. I stayed away from reminders of it.				
8. I felt as if it hadn't happened or it wasn't real.				
9. I tried not to talk about it.				
10. Pictures about it popped into my mind.				
11. Other things kept making me think about it.				
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.				
13. I tried not to think about it.				
14. Any reminder brought back feelings about it.				
15. My feelings about it were kind of numb.				

Appendix O

Writing Instructions

Prior to first writing:

This study is an extremely important project looking at writing. Over the next three sessions, you will be asked to write about one of several topics for 20 minutes each day. First, I will talk with you and give you your instructions for the day. You will then be left alone to write. I will tell you when to begin writing. At the end of the 20 minutes, I will come back and to let you know that the 20 minutes are up. You will then be given some brief questionnaires to complete, after which you will talk with me for a couple of minutes.

The only rule we have about your writing is that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don't worry about grammar, spelling, or sentence structure. Just write. Different people will be asked to write about different topics. Because of this, I ask that you not talk with anyone about the experiment. Because we are trying to make this a tight experiment, I can't tell you what other people are writing about or anything about the nature or predictions of the study. Once the study is complete, however, we will tell you everything. Right now, we expect the study to be complete in about one year. Another thing is that sometimes people feel a little sad or depressed after writing. If that happens, it is completely normal. Most people say that these feelings go away in an hour or so. If at any time over the course of the experiment you feel upset or distressed, please contact me or any of the other experimenters immediately.

Another thing: your writing is completely anonymous and confidential. We ask you to put your subject number on your writing samples when you turn them in. I promise that none of the experimenters, including me, will link your writing to you. The one exception is that if your writing indicates that you intend to harm yourself or others, we are legally bound to match your ID with your name. Above all, we respect your privacy. Do you have any questions to this point? Do you still wish to participate?

Experimental Condition Instructions:

Session 1:

What I would like to have you write about for the next three sessions is your experience of your parent's cancer. In your writing, I want you to really let go and explore your very deepest emotions and thoughts. You can write about the same experience on all three days or about different experiences each day. Whatever you choose to write, it is critical that you really delve into your deepest emotions and thoughts. Ideally, we would also like you to write about significant experiences or conflicts that you have not discussed in great detail with others. Remember that you have three sessions to write. You might tie your personal experiences with your parent's cancer to other parts of your life. How is it related to your childhood, your family, people you love, who you are, or who you want to be. Again, in your writing, examine your deepest emotions and thoughts regarding your parent's cancer.

Session 2:

How did yesterday's writing go? Today, I want you to continue writing about your experience of your parent's cancer. It could be the same topic that you wrote about yesterday or it could be something different. But today, I really want you to explore your very deepest emotions and thoughts...

Session 3:

You have survived the first two sessions, and today is the last one. In your writing today, I again want you to explore your deepest thoughts and feelings about your parent's cancer. Remember that this is the last day and so you might want to wrap everything up. For example, how is this experience related to your current life and your future? But feel free to go in any direction you feel most comfortable with and delve into your deepest emotions and thoughts...

Control Condition Instructions

Session 1:

What I would like you to write about over the next four days is how you use your time. Many teenagers' schedules are greatly disrupted by their parent's cancer. We are interested in how you plan to manage your time. Each day, I will give you different writing assignments on the way you spend your time. In your writing, I want you to be as objective as possible. I am not interested in your emotions or opinions. Rather I want you to try to be completely objective. Feel free to be as detailed as possible. In today's writing, I want you to describe what you did yesterday from the time you got up until the time you went to bed. For example, you might start when your alarm went off and you got out of bed. You could include the things you ate, where you went, which buildings or objects you passed by as you walked from place to place. The most important thing in your writing, however, is for you to describe your days as accurately and as objectively as possible.

Session 2:

Today, I want you to describe in detail what you will do as soon as the experiment is over until you go to bed tonight. For example, you might start by noting that you will walk down the hallway, go to your room, finish your homework, etc.

Session 3:

This is the last day of the experiment. In your writing today, I would like you to describe what you will be doing over the next week...

Appendix P

Participant ID # _____

Abbreviated Positive and Negative Affect Schedule (present moment)

Read each of the items below and then circle the number next to each item that best describes how you would feel at this moment. For example, if you feel extremely angry, you would circle the 5 next to the word angry.

	Not at all	A little	Somewhat	Quite a bit	Extremely
Strong	1	2	3	4	5
Angry	1	2	3	4	5
Irritable	1	2	3	4	5
Nervous	1	2	3	4	5
Sad	1	2	3	4	5
Lonely	1	2	3	4	5
Afraid	1	2	3	4	5
Determined	1	2	3	4	5
Alert	1	2	3	4	5
Confident	1	2	3	4	5

Appendix Q

Participant ID # _____

Perceived Physiological Arousal Measure

RIGHT NOW, to what degree are you currently experiencing each of the following, on a scale from 1 = NOT AT ALL, to 7 = A GREAT DEAL.

___ 1. racing heart ___ 5. shortness of breath

___ 2. upset stomach ___ 6. cold hands

___ 3. headache ___ 7. sweaty hands

___ 4. dizziness ___ 8. pounding heart

Appendix R

Participant ID # _____

Post-Essay Questionnaire – Session 1

Please rate the following, on a scale from 1 = not at all, to 7 = a great deal.

- _____ 1. How personal was the essay you wrote today?
- _____ 2. How much have you told other people about what you wrote about today?
- _____ 3. How much did you reveal your emotions in what you wrote about today?
- _____ 4. How much have you wanted to tell another person about what you wrote about today?
- _____ 5. How much have you actively held back from telling others about what you wrote about today?

If you have actively held back, what are your reasons for doing so? (Please list blow.)

- _____ 6. How much did you gain a greater understanding of your experience from what you wrote today?

Please describe briefly how you feel about what you wrote today.

Appendix S

Participant ID # _____

Post-Essay Questionnaire – Session 2

Please rate the following, on a scale from 1 = not at all, to 7 = a great deal.

- _____ 1. How personal was the essay you wrote today?
- _____ 2. How much have you told other people about what you wrote about today?
- _____ 3. How much did you reveal your emotions in what you wrote about today?
- _____ 4. How much have you wanted to tell another person about what you wrote about today?
- _____ 5. How much have you actively held back from telling others about what you wrote about today?

If you have actively held back, what are your reasons for doing so? (Please list blow.)

- _____ 6. How much did you gain a greater understanding of your experience from what you wrote today?

Please describe briefly how you feel about what you wrote today.

Appendix T

Participant ID # _____

Post-Essay Questionnaire – Session 3

Please rate the following, on a scale from 1 = not at all, to 7 = a great deal.

- _____ 1. How personal was the essay you wrote today?
- _____ 2. How much have you told other people about what you wrote about today?
- _____ 3. How much did you reveal your emotions in what you wrote about today?
- _____ 4. How much have you wanted to tell another person about what you wrote about today?
- _____ 5. How much have you actively held back from telling others about what you wrote about today?

If you have actively held back, what are your reasons for doing so? (Please list blow.)

- _____ 6. How much did you gain a greater understanding of your experience from what you wrote today?

Please describe briefly how you feel about what you wrote today.

On a scale from 1 = not at all, to 7 = a great deal, during your participation in this research project:

- _____ 1. During your normal day, to what extent have you thought about this project since it began?
- _____ 2. During the hours that you were not involved in the project, to what extent have you thought about the topics you wrote about?
- _____ 3. During the project, how much have you talked to other people about what you wrote?
- _____ 4. Before the project began, to what extent did you think about the topics you wrote about?
- _____ 5. Before the project began, to what extent did you talk to others about the topics you wrote about?

On a scale from 1 = not at all, to 7 = extremely, during your participation in this research project:

- _____ 1. Overall, how difficult has it been for you to write during the research project?
- _____ 2. How sad or depressed have you felt during the times that you were not in the project.
- _____ 3. How happy have you felt during the times that you were not in the project?
- _____ 4. To what extent has this project been valuable or meaningful to you?
- _____ 5. To what extent has this project been interesting to you?

