**Posttraumatic Growth in Parents following their Child’s Death in a Pediatric Intensive Care Unit**

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**Short running title**: Posttraumatic Growth in Bereaved Parents

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**ABSTRACT**

**Background:** Although bereaved parents suffer greatly, some may experience positive change referred to as posttraumatic growth.

**Objective:** Examine the extent to which parents perceive posttraumatic growth after their child’s death in a pediatric intensive care unit (PICU), and associated factors.

**Design:** Longitudinal parent survey conducted 6 and 13 months after a child’s death. Surveys included the Posttraumatic Growth Inventory Short Form (PTGI-SF), a 10-item measure with range of 0-50 where higher scores indicate more posttraumatic growth. Surveys also included the Inventory of Complicated Grief (ICG), the Patient Health Questionnaire (PHQ-8) for depression, the Short Post-Traumatic Stress Disorder Rating Interview (SPRINT), a single item on perceived overall health, and sociodemographics.

**Setting/Subjects:** 157 parents of 104 children who died in one of eight PICUs affiliated with the U.S. Collaborative Pediatric Critical Care Research Network.

**Results:** Participants were 62.4% female, 71.6% White, and 82.7% married. Mean PTGI-SF scores were 27.5 ± 12.52 at 6 months and 28.6 + 11.52 at 13 months (p = 0.181). On multivariate modeling, higher education (compared to those not completing high school), having one surviving child in the family (compared to none), shorter PICU stay, and higher 6-month PHQ-8 scores (reflecting more depression symptoms) were associated with lower 13-month PTGI-SF scores (p=0.011, 0.004, 0.037, and 0.001, respectively).

**Conclusion:** Parents bereaved in PICUs perceive a moderate degree of posttraumatic growth in the first 13-months after their child’s death however variability is wide. Education level, family structure, PICU course, and depression symptoms may influence parents’ perception of posttraumatic growth.

**INTRODUCTION**

The death of a child is devastating and often leads to intense grief for parents. Bereaved parents are at high risk for adverse mental health including anxiety, depression, posttraumatic stress, and complicated grief. 1-3 Complicated grief is a maladaptive form of grief that is characterized by strong yearning for and preoccupation with the deceased, as well as difficulty accepting the reality of the death.4,5 Despite these risks, many bereaved parents find positive ways in which their lives have changed following their child’s death. Such positive changes have been referred to as stress-related growth, benefit finding, or posttraumatic growth.6-8

Posttraumatic growth is defined as positive change that occurs as a result of one’s struggle with highly challenging life events. As posited by Tedeschi and Calhoun,8 when an individual experiences a traumatic event severe enough to challenge their assumptive world, the resulting distress stimulates cognitive and emotional processing, which in turn may contribute to making sense of the event, finding meaning, and posttraumatic growth. Posttraumatic growth is manifested by enhanced relationships, changed priorities, personal strength, spiritual or existential change, and increased appreciation of life.8-9 Posttraumatic growth has been identified in adults with a variety of traumatic experiences such as refugees,10 war veterans,11 and bereaved individuals,12-13 including bereaved parents.7, 14-15

We have previously demonstrated that parents whose children die in pediatric intensive care units (PICU) have high rates of adverse mental health symptoms during bereavement.16 The extent to which parents bereaved in PICUs experience posttraumatic growth and the associated factors have not been well described. In parents whose children survived a PICU stay, Colville et al found posttraumatic growth to be more strongly associated with moderate levels of posttraumatic stress than high or low levels,17 while Rodriguez-Ray et al found higher levels of posttraumatic growth were associated with higher levels of posttraumatic stress, anxiety and depression.18 We aimed to examine the extent to which parents perceive posttraumatic growth after their child’s death in a PICU. We hypothesized that the extent of posttraumatic growth reported by parents is associated with parent characteristics, including mental health, child characteristics, and characteristics of the child’s clinical course. Greater understanding of posttraumatic growth among parents bereaved in PICUs may help guide supportive care.

**METHODS**

**Design and setting**

This study was a longitudinal survey conducted between September 2016 and March 2019 across eight children’s hospitals affiliated with the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network (CPCCRN).16Participants were asked to complete surveys 6 and 13 months after their child’s death in a PICU. The study was approved by the University of Utah Institutional Review Board (IRB), which serves as the central IRB for the CPCCRN. The need for written consent was waived.

**Participants**

Parents (i.e., biological and/or legal guardians) were eligible if their child died in a PICU, they were English or Spanish speaking, and were at least 18 years old. One or more parents of each deceased child were eligible. The children’s medical records were reviewed to obtain parents’ contact information and primary language for purpose of recruitment.

**Study Procedures**

Eligible parents were mailed surveys in English or Spanish at 6 and 13 months after their child’s death. If completed surveys were not returned within one month, telephone contact was attempted to offer parents the option of completing the survey by telephone. If the household was successfully contacted by telephone but the survey was not completed, parents were categorized as refusing to participate. If the household could not be contacted by telephone after 3 or more attempts, the parents were categorized as unable to contact. Survey packets included a study information sheet offering parents the assistance of the local PICU social worker or psychologist for bereavement support or mental health referrals. Social worker or psychologist assistance was available regardless of parental participation in this study.

Surveys administered at 6 and 13 months asked parents to complete the following measures: the Posttraumatic Growth Inventory – Short Form (PTGI-SF),19 the Inventory of Complicated Grief (ICG),20,21 the Patient Health Questionnaire-8 (PHQ-8),22,23 the Short Post-Traumatic Stress Disorder Rating Interview (SPRINT),24 and a single item on perceived overall health.25 Surveys administered at 6 months also requested parents to provide sociodemographic data. For parents who completed surveys, their deceased child’s medical records underwent further review to collect characteristics of the child and their clinical course.

**Outcome**

The primary outcome for this study was the extent of posttraumatic growth perceived by parents 13 months after their child’s death as assessed by the PTGI-SF.19 The PTGI-SF is a 10-item measure of the extent of positive change resulting from adversity. Posttraumatic growth is assessed across 5 domains including (1) relating to others, (2) new possibilities, (3) personal strength, (4) spiritual change, and (5) appreciation of life. Each domain has two items. Responses are rated from 0 (no change) - 5 (very great degree of change) and summed to obtain domain scores ranging from 0-10 and total scores from 0-50. Higher scores indicate more positive change. Cronbach’s α is >0.8 for various samples.19

**Independent variables**

Independent variables included parent 6-month responses to the ICG, PHQ-8, SPRINT, and overall health item; parent sociodemographics; and characteristics of the child and their clinical course.

The ICG is a 19-item measure that assesses the frequency of complicated grief symptoms.20 Responses are rated from 0-4 and summed to obtain total scores ranging from 0-76. Higher scores indicate more grief symptoms. Scores >30 at least 6 months after a death have been used as a positive screen for complicated grief.21 Cronbach’s α has been reported as 0.94.20

The PHQ-8 is an 8-item measure that assesses the frequency of depression symptoms.22,23 Responses are rated from 0-3 and summed to obtain total scores ranging from 0-24. Scores of 5, 10, 15 and 20 have been used as positive screens for mild, moderate, moderately severe, and severe depression, respectively.23 Cronbach’s α has been reported to range from 0.82-0.88.26,27

The SPRINT is an 8-item measure that assesses the frequency of posttraumatic stress symptoms.24 Responses are rated from 0-4 and summed to obtain total scores ranging from 0-32. Scores ≥14 have been used as a positive screen for posttraumatic stress disorder (PTSD).24 Cronbach’s α has been reported to range from 0.77-0.87.24

Perceived overall health was assessed by one item:25 “In general, would you say your overall health is (1) excellent, (2) very good, (3) good, (4) fair, (5) poor.”

Parent sociodemographics included gender, age, race, ethnicity, marital status, education, relationship to the deceased child, and number of surviving children.Relationship to the deceased child was categorized as biological parent or other legal guardian. Child characteristics included gender, age at time of death, cause of death, trajectory of death, mode of death, and PICU and hospital lengths of stay. Trajectory of death was categorized as sudden unexpected death, death from a potentially curable disease, death from a lethal congenital anomaly in the first few weeks of life, or death from a progressive condition with intermittent crises.28 Mode of death was categorized as limitation or withdrawal of life support, brain death, or unsuccessful cardiopulmonary resuscitation.

**Statistical analysis**

Scores for each measure were calculated based on available data if at least 80% of the items in the measure were completed. Missing item responses were replaced by the mean of the completed items. If less than 80% of the items were completed for any measure, the score was considered missing. Only parents who responded to the 13-month survey with at least 80% of the PTGI-SF items completed were included in the current analysis.

Parent and child characteristics are summarized using frequencies and percentages for categorical variables, and means and standard deviations for continuous variables. Parents that responded to the 13-month survey with at least 80% completion of PTGI-SF items were compared to those that did not respond using t-tests for continuous variables, Fisher’s exact tests for categorical variables and Cochran-Armitage trend test for discrete ordinal variables. For the outcome of interest, posttraumatic growth, linear mixed models taking into account the correlation between parents of the same child were considered appropriate after examination of distribution plots. Posttraumatic growth was first analyzed by measuring the change in total PTGI-SF score and the 5 domains from 6 to 13 months, and assessing the significance of those changes using linear mixed models. Next, each parent and child characteristic was assessed as an independent predictor of 13-month PTGI-SF score. Variables with p-value <0.2 in those univariable mixed models were then considered for the multivariate model. Multicollinearity was assessed for all candidate predictors; where two predictors had high correlation (>0.7), the most clinically relevant variable was included in the full model. The final multivariate model was constructed through manual backward selection, until all remaining predictors had a p-value <0.1.

**RESULTS**

Parents of 710 deceased children were eligible for the study. Of these, 235 parents of 158 children responded to the 6-month survey (22% of eligible families). One hundred and fifty-seven parents of 104 children responded to the 13-month survey with completion of at least 80% of the PTGI-SF items (65.8% of families responding at 6 months and 14.6% of all eligible families). Parents responding to 13-month surveys were more likely to be married and to report less complicated grief symptoms and better overall health at 6 months than those who did not respond (Table 1). Child characteristics were similar between parents responding to 13-month surveys and those who did not (Table 2).

Of 157 participating parents, 98 (62.4%) were female, 111 (71.6%) were White, 134 (86.5%) were non-Hispanic, 129 (82.7%) were married, and 139 (89.7%) had at least a high school education (Table 1). One-hundred and forty-three (91.1%) were biological parents and 26 (16.6%) had lost their only child. Six-month ICG score was 33.8 + 15.35 with 86 (57.7%) parents having scores ≥30; PHQ-8 score was 9.0 ± 6.36 with 66 (43.7%) having scores ≥10; and SPRINT score 14.0 ± 8.31 with 78 (51.70%) having scores ≥14. Six-month overall health was rated as fair or poor by 33 (22.1%) parents.

Of 104 deceased children, 58 (55.8%) were male and mean age at time of death was 8.3 ± 8.19 years (Table 2). Trajectory of death was sudden unexpected for 26 (25.0%), and mode of death was limitation or withdrawal of life support for 81 (77.9%). Mean PICU and hospital length of stay was 23.1 ± 38.4 days, and 28.3 + 42.8 days, respectively.

Parent PTGI-SF score was 27.5 ± 12.52 at 6 months and 28.6 + 11.52 at 13 months (p=0.181) (Table 3). Domain scores were not significantly different between 6 and 13 months.

In univariable analyses, the following variables were identified as candidate predictors of parental 13-month PTGI-SF score (Table 4): 6-month ICG, PHQ-8, SPRINT and overall health scores, race, ethnicity, education level, marital status, number of surviving children, PICU length of stay, and hospital length of stay. Sets of variables with high correlation included PHQ-8 and SPRINT scores, as well as hospital and PICU length of stay. As both sets of variables were identified as candidate predictors for multivariable modeling, PHQ-8 and PICU length of stay were chosen for the full model.

The final multivariate model is shown in Table 5. While adjusting for other variables in the model, higher education (compared to some high school or less), one surviving child in the family (compared to no surviving children), shorter PICU length of stay, and higher 6-month PHQ-8 score were associated with lower 13-month PTGI-SF score (p=0.011, 0.004, 0.037, and 0.001, respectively).

**DISCUSSION**

Our study evaluates posttraumatic growth in bereaved parents after the death of their child in the PICU, and explores parent and child characteristics associated with posttraumatic growth. Bereaved parents in our study reported a moderate amount of posttraumatic growth, although variability was wide. Average PTGI-SF scores were 28.8 + 11.5 at 13 months after their child’s death. Factors associated with less posttraumatic growth were greater parental depression symptoms, higher parental education levels, single surviving child, and a shorter PICU stay.

Parents whose children die in a PICU may represent a unique population of bereaved individuals. PICUs are characterized by technologically advanced care typically aimed at restoring a child’s health.29 Death is often not expected by parents at the time of their child’s admission to a PICU. In a recent study by Albuquerque and colleagues,7 parents whose children died from a variety of circumstances including fetal loss (27%) reported PTGI-SF scores of 40.4 ± 12.5 representing a greater degree of growth than observed in our parent cohort. Besides different circumstances and setting of death, time since death was also longer in Albuquerque et al’s study, ranging from six months to 10 years with an average of 2.8 ± 2.3 years. One might expect that longer time from a child’s death would allow for more growth; however, time since death was not a significant predictor of posttraumatic growth in Albuquerque et al’s study.

The notion that personal growth can emerge as a result of the distress associated with losing a loved one has been suggested by bereavement researchers for decades.30 Yet, studies on the relationship between bereavement-related distress and posttraumatic growth have had heterogeneous results. When investigating grief symptoms and posttraumatic growth, some studies have shown a negative association,30 some a positive association,31 and others have shown that these outcomes are independent of each other.15 A curvilinear relationship has also been described in which bereaved individuals with moderate symptoms of grief, depression, anxiety, and posttraumatic stress have greater posttraumatic growth than those with low or high symptom levels.13,32,33

Findings from our study suggest an negative association between bereavement-related distress and growth. Greater symptoms of complicated grief, depression and posttraumatic stress were associated with less posttraumatic growth on univariate analyses in our parent cohort. Of these, depression remained a significant predictor of less growth when adjusted for other variables. Notably, more than half of our bereaved parents had mental health symptoms of sufficient severity to screen positive for complicated grief, depression and/or PTSD at 13 months after their child’s death. Complicated grief is characterized by intense longing for the deceased and inability to accept the reality of the death, depression by feelings of worthlessness and self-loathing, and PTSD by anxiety and fear.4,5,34 Posttraumatic growth is posited to occur as bereaved individuals attempt to make meaning from their loss and reconstruct their world in the absence of their loved one.12,15 Perhaps high levels of adverse mental health symptoms experienced by some bereaved parents prohibit the process of meaning reconstruction, and thereby delay or prohibit the attainment of growth after their child’s death.

In our study, bereaved parents with some college/vocational school or higher education had less posttraumatic growth when compared to parents not completing high school. This result is surprising and difficult to explain. Parents with higher education likely possess greater health literacy, and therefore we expected them to more readily make sense of their child’s death, at least in the medical realm, leading to greater posttraumatic growth. Additionally, we were surprised that parents with one surviving child had less posttraumatic growth than parents who lost their only child. Prior studies suggested that caring for surviving children during bereavement can be burdensome to parents resulting in less time and energy to process their grief.35 However, parents in our study with multiple surviving children did not have the least amount of growth. Perhaps bereaved parents with a single surviving child become increasingly focused on that child’s health and protection, utilizing energy that may have otherwise been spent processing their loss and attaining more growth. Parents with no surviving children may also be forced to undertake a more profound meaning reconstruction due to their lost role as parent, ultimately resulting in greater growth potential and eventual growth.

Shorter PICU length of stay was also associated with less posttraumatic growth although the magnitude of the effect was small (one day decrease in PICU stay was associated with 0.05 point decrease in PTGI-SF score). Longer PICU stays may allow more trusting relationships to develop with PICU staff, thereby reducing anger and blame and promoting personal growth.

Strengths of this study include the longitudinal design which suggests a sequence of events in which adverse mental health symptoms interfere with the development of posttraumatic growth in bereaved parents. Strengths also include the racial, ethnic and geographic diversity of participants. Limitations include our low overall response rate which may be related to the distress of bereavement and added burden of research participation. Responders to 13-month surveys reported less complicated grief symptoms and better overall health at 6 months post-death than non-responders. This difference may have biased our results towards healthier parents causing overestimation of the level of posttraumatic growth at 13 months. The PTGI-SF is a shortened version of the full 21-item Posttraumatic Growth Inventory.19 Although research comparing the PTGI-SF to the full version suggests the PTGI-SF is psychometrically sound and that it can be substituted for the full version to reduce respondent burden, in-depth exploration of the five domains of posttraumatic growth was not possible with the PTGI-SF due to the reduced number of items. The mental health surveys used in this study assess frequency of symptoms and are screening tools rather than diagnostic instruments. Several variables potentially associated with posttraumatic growth were not evaluated in our study such as parent resiliency, social support, and the nature and extent of parents’ continuing bonds with their deceased child.7,14 Parents included in our study experienced their child’s death in a PICU, a setting where death is often unexpected. Our findings may not apply to parents whose children die in other environments.

**CONCLUSIONS**

Parents bereaved in PICUs perceive a moderate degree of posttraumatic growth in the first 13-months after their child’s death, although variability is wide. Adverse mental health symptoms may hinder development of posttraumatic growth. Higher levels of parental education and the presence of surviving children in the family may not be protective for bereaved parents and hence these resources should not dissuade clinicians from offering supportive interventions.

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