

Parental Posttraumatic Growth Following Pediatric Hematopoietic Stem Cell Transplant

By

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DEDICATION

To the parents of children with life-threatening and life-limiting diseases and the health professionals who care for them,
I am in awe of your courage, passion, and dedication.

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Chapter 1

Introduction

Statement of the Problem

Hematopoietic stem cell transplant (HSCT) improves long-term survival from otherwise incurable diseases. However, the preparative chemotherapy, prolonged and isolating hospitalization, and adverse late effects from the transplant introduce a myriad of potential complications, including death (Barrera, Boyd-Pringle, Sumbler, & Saunders, 2000; Buchsel, 2009). After the preparative conditioning and infusion of stem cells, children endure severe immune suppression, frequent blood and platelet transfusions, mucositis, nausea, vomiting, appetite suppression, mood changes, and ongoing risk for graft versus host disease (Bevans, Mitchell, & Marden, 2008). For up to 60 days following transplant, children describe a sense of “torture,” isolation, and slow passage of time (Breitwieser & Vaughn, 2014). Children report that familial support is crucial to comfort, distract, and normalize life following HSCT (Breitwieser & Vaughn, 2014).

Parents fill an essential role through each stage of the HSCT trajectory including preparation, recovery, and survivorship. In addition to routine childcare responsibilities, these parents make significant healthcare decisions and provide complex care regimens for their children. Parents carefully monitor children’s health, administer both intravenous and enteral medications, attend frequent medical appointments, and provide ongoing support specific to the children’s physical, emotional, and cognitive needs for years after HSCT. Many parents face additional stressors including relocation for HSCT, financial burden related to lost income and

medical costs, and separation from family and social supports (Bona et al., 2015; Majhail, Rizzo, et al., 2013).

Hematopoietic Stem Cell Transplant. HSCT has curative ability for congenital and acquired childhood diseases. This includes approximately 8 blood malignancies and 20 nonmalignant diseases, which are divided further into five groups including hemoglobinopathies, metabolic storage disease, bone marrow failure, immune deficiency, and unique rare diseases (Pulsipher et al., 2010). HSCT involves infusion of healthy hematopoietic stem cells from a matched donor following a preparative regimen of aggressive chemotherapy, and in some instances, radiotherapy (Bevans et al., 2008). Care and support provided by parents of children undergoing HSCT includes seven to ten days of preparative conditioning chemotherapy prior to infusion of stem cells, and two to four additional weeks of inpatient monitoring while awaiting white blood cell count recovery (Bevans et al., 2008). Once discharged, parents reside with their children near the hospital for at least the first 100 days after HSCT when life-threatening complications are most common (Bevans et al., 2008; Majhail et al., 2010).

Distress. Parental distress typically increases immediately prior to transplant, peaks three weeks post-HSCT when physical effects of chemotherapy are most prominent, and again increases at the time of hospital discharge (Phipps, Dunavant, Lensing, & Rai, 2005). Not surprisingly, these peaks coincide with times when caregiving responsibilities are highest. Distress caused by the child's HSCT results in negative consequences for some parents, such as post-traumatic stress syndrome (Riva et al., 2014). Cumulative distress from children's HSCT and recovery challenges parent adaptation to the caregiver role.

Posttraumatic Growth. Distress is also associated with positive personal growth for some parents (Best, Streisand, Catania, & Kazak, 2001; Lindwall et al., 2014; McDowell,

Titman, & Davidson, 2010; Rini et al., 2004; Riva et al., 2014; Yonemoto, Kamibeppu, Ishii, Iwata, & Tatezaki, 2012). These positive changes have been described as posttraumatic growth (PTG) and include increased appreciation for life, enhanced relationships and connectedness to others, increased personal strength, and deepened spirituality (Tedeschi, Park, & Calhoun, 1998). Caregivers that developed routine and structure after HSCT, maintained optimism, and envisioned a future beyond HSCT have developed more hope and meaning from the experience (Wilson, Eilers, Heermann, & Million, 2009). This suggests that caregiver PTG may enhance adaptation to the caregiver role. The effect of PTG on the caregiving experience needs to be studied to provide further support for caregiver PTG as a means for minimizing psychological morbidity, improving health outcomes, and enhancing quality of life for both parent caregivers and children after HSCT.

Theoretical Framework

Tedeschi and Calhoun's functional-descriptive model of PTG guided the study's aims (Figure 1). The theory describes which life experiences precipitate PTG, identifies a framework for characteristics that moderate PTG, and provides a robust definition of PTG. PTG is defined as a positive change after trauma and is characterized by new personal strength, priorities, appreciation for life, and enhanced relationships and spirituality (Tedeschi & Calhoun, 2004). Traumatic events, those more distressing and threatening than everyday life, are necessary antecedents for PTG. Cognitive processes in addition to environmental and personal factors contribute to the positive reinterpretation of the trauma.

According to Tedeschi and Calhoun (1998), an experienced trauma increases distress and destroys one's previously held worldviews. The distress leads to unconscious rumination about

the trauma (Tedeschi et al., 1998). As the individual copes with the distress of the trauma, rumination becomes more deliberate and focuses on positive reappraisal of the trauma (Tedeschi et al., 1998). Positive reappraisal can lead to PTG in the areas of enhanced relationships with others, new life possibilities, increased personal strength, deepened spirituality, and increased appreciation for life (Tedeschi et al., 1998).

Tedeschi and Calhoun have a robust definition of PTG, which describes an exposure to a trauma and the mediating effects of distress, coping, and a cognitive process, rumination. Despite these strengths, Tedeschi and Calhoun's theory needs continued refinement of identification of the most influential moderating variables that shape PTG. Continued research is needed to inform a more complete theoretical model. This work is needed to clarify personal intrinsic and extrinsic characteristics that serve as influential moderators and mediators for PTG. Tedeschi and Calhoun describe PTG as a process and an outcome, which poses a challenge to understanding when PTG develops and when to measure PTG. Furthermore, this discrepancy between PTG as an outcome or a process leads to difficulty understanding distal benefits to PTG, particularly how PTG fosters adaptation following trauma. Further research is needed to conceptualize the distal benefits of PTG on the individual and substantiate its significance.

Concepts within the functional descriptive model of PTG (Figure 1) guided development of this study's conceptual framework (Figure 2). The relationship between parental PTG and caregiving was not addressed within the functional descriptive model of PTG. Thus, the PI added caregiving to the conceptual framework based on synthesis of caregiving literature. Parental caregiving experiences are central to the PTG narrative development. The PI proposed a bidirectional relationship between the primary study outcome, PTG, and the secondary study outcome, caregiving. For definitions of the concepts see pages 34 and 35.

Critical Analysis of Relevant Literature

The PTG literature among populations of parents of children undergoing HSCT or with life-threatening disease, including childhood cancer, was reviewed. Due to the limited number of results, the search was broadened to include measurement of PTG among caregivers of adult HSCT recipients or cancer survivors. While it is recognized that the role of a partner or spouse is different than the role of a parent, the responsibilities of the caregiver in the setting of cancer or HSCT are similar to that of a parent providing care to the child.

This search resulted in a total of 25 studies that underwent further review and analysis. The studies collectively represent 21 pediatric studies, including 14 studies of parents with children undergoing cancer treatment (Barakat, Alderfer, & Kazak, 2006; Best et al., 2001; Hullmann, Fedele, Molzon, Mayes, & Mullins, 2014; Hungerbuehler, Vollrath, & Landolt, 2011; Kim, 2017; Michel, Taylor, Absolom, & Eiser, 2010; Phipps et al., 2015; Quin, 2004; Rosenberg, Starks, & Jones, 2014; Schepers, Okado, Russell, Long, & Phipps, 2018; Tillery, Howard Sharp, Okado, Long, & Phipps, 2016; Turner-Sack, Menna, Setchell, Maan, & Cataudella, 2016; Yaskowich, 2002; Yonemoto et al., 2012), one study of pediatric HSCT and cancer survivors (Nakayama et al., 2017), four studies of parents with children undergoing HSCT (Lindwall et al., 2014; McDowell et al., 2010; Rini et al., 2004; Riva et al., 2014), and two studies of parents with children facing life-threatening illness (Li, Cao, Cao, Wang, & Cui, 2012; Schneider, Steele, Cadell, & Hemsworth, 2011). From the adult caregiver literature, four additional studies were included in the analysis. This included three studies of caregivers of adults with cancer (Cormio et al., 2014; Kohle et al., 2015; Zwahlen, Hagenbuch, Carley, Jenewein, & Buchi, 2010) and 1 study of spousal couples following HSCT (Bishop et al., 2007).

Design. Of the 20 studies with a cross sectional design, nine described PTG and factors correlated with PTG (Hullmann et al., 2014; Kim, 2017; Li et al., 2012; McDowell et al., 2010; Michel et al., 2010; Nakayama et al., 2017; Quin, 2004; Riva et al., 2014; Yonemoto et al., 2012). Eleven studies compared PTG and factors associated with PTG among different groups of participants (Barakat et al., 2006; Bishop et al., 2007; Cormio et al., 2014; Phipps et al., 2015; Rosenberg et al., 2014; Schepers et al., 2018; Schneider et al., 2011; Tillery et al., 2016; Turner-Sack et al., 2016; Yaskowich, 2002; Zwahlen et al., 2010). The remaining five used longitudinal designs, including one that focused on factors that promote PTG (Best et al., 2001) and four that compared PTG over time and between participant groups (Hungerbuehler et al., 2011; Kohle et al., 2015; Lindwall et al., 2014; Rini et al., 2004). Though there was a predominance of descriptive and comparative studies, two intervention studies designed to influence caregiver PTG were also reviewed (Kohle et al., 2015; Lindwall et al., 2014). Importantly, however, the study by Kohle et al. (2015) describes only an intervention protocol for a future study and does not provide any data.

Sampling. All studies sampled a convenience population except for the work of Quin (2004) and Kohle (2015). The majority (61%) of caregivers were female in 14 of the 23 studies with convenience samples (Barakat et al., 2006; Hullmann et al., 2014; Kim, 2017; Li et al., 2012; Lindwall et al., 2014; Michel et al., 2010; Phipps et al., 2015; Rini et al., 2004; Riva et al., 2014; Rosenberg et al., 2014; Schepers et al., 2018; Schneider et al., 2011; Tillery et al., 2016; Turner-Sack et al., 2016). Caregivers were primarily white, had completed at least some college education, and were of middle socioeconomic status. The majority of care recipients had leukemia in 11 of the 24 studies (Best et al., 2001; Bishop et al., 2007; Hullmann et al., 2014;

Kim, 2017; Lindwall et al., 2014; Michel et al., 2010; Nakayama et al., 2017; Phipps et al., 2015; Rini et al., 2004; Riva et al., 2014; Turner-Sack et al., 2016).

There was a wide range of time between identified traumatic event and measure of PTG across the studies. Five studies required PTG measures to be completed at a specific time period following the traumatic event (Hungerbuehler et al., 2011; Li et al., 2012; Lindwall et al., 2014; McDowell et al., 2010; Rini et al., 2004). Among these studies, PTG was measured between one month and three years ($M = 1$ year) post-trauma. Across studies, however, there was wide variability from the time of the identified traumatic event to the PTG measurement, as little as one month to a maximum of 20 years post trauma (Tillery et al., 2016; Yonemoto et al., 2012; Zwahlen et al., 2010).

Reasons for declining participation in the study were not readily described across studies. Reasons caregivers offered for declining study participation included feeling overwhelmed (Hungerbuehler et al., 2011; Rini et al., 2004), lack of interest (Cormio et al., 2014; Kim, 2017; Rini et al., 2004), lack of time (Cormio et al., 2014; Kim, 2017; Rini et al., 2004), and worry for increased distress or painful memories (Best et al., 2001; Zwahlen et al., 2010). Caregivers with such an interest in the topic of PTG or a natural openness to sharing information may have been more likely to report PTG compared to caregivers who declined participation.

Methodology. Twenty-two studies used quantitative approaches to measure PTG (Barakat et al., 2006; Best et al., 2001; Bishop et al., 2007; Cormio et al., 2014; Hullmann et al., 2014; Hungerbuehler et al., 2011; Kim, 2017; Li et al., 2012; Lindwall et al., 2014; Michel et al., 2010; Nakayama et al., 2017; Phipps et al., 2015; Rini et al., 2004; Riva et al., 2014; Schepers et al., 2018; Schneider et al., 2011; Tillery et al., 2016; Turner-Sack et al., 2016; Yaskowich, 2002; Yonemoto et al., 2012; Zwahlen et al., 2010). One study used a qualitative approach (McDowell

et al., 2010), and two studies used a mixed methods approach (Quin, 2004; Rosenberg et al., 2014). The quantitative approach enabled comparison of PTG between different caregivers and association of variables with PTG both within and across studies. However, the qualitative data provided contextual background and depth to the PTG findings not captured through the quantitative approach.

Measurement.

Quantitative measurement. The most frequently used quantitative measure of PTG among caregivers of HSCT recipients, applied in 18 studies, was the Posttraumatic Growth Inventory (PTGI) (Best et al., 2001; Bishop et al., 2007; Cormio et al., 2014; Hullmann et al., 2014; Hungerbuehler et al., 2011; Kim, 2017; Kohle et al., 2015; Li et al., 2012; Michel et al., 2010; Nakayama et al., 2017; Riva et al., 2014; Rosenberg et al., 2014; Schepers et al., 2018; Schneider et al., 2011; Turner-Sack et al., 2016; Yonemoto et al., 2012; Zwahlen et al., 2010). The Post-Traumatic Growth Inventory (PTGI) is a 21-item, 6-point Likert response scale, with an overall Cronbach's alpha of .90 and individual subscale Cronbach's alpha ranging from .79-.83 based on factors of relating to others, new possibilities, spiritual change, personal strength, and appreciation of life (Tedeschi & Calhoun, 1996). Similar Cronbach's alpha values were calculated in numerous reviewed studies (Barakat et al., 2006; Best et al., 2001; Hullmann et al., 2014; Hungerbuehler et al., 2011; Kim, 2017; Michel et al., 2010; Nakayama et al., 2017; Phipps et al., 2015; Riva et al., 2014; Rosenberg et al., 2014; Schepers et al., 2018; Turner-Sack et al., 2016; Yaskowich, 2002). Each item describes an area of potential growth and change then asks the respondent to rate their level of change from the crisis from "no change" to "very great degree of change." The measure was originally validated among undergraduate students identified as having experienced a negative life event in the preceding 5 years (Tedeschi &

Calhoun, 1996). Validity was established by showing that PTG was higher among individuals following trauma than individuals who had not experienced trauma (Tedeschi & Calhoun, 1996).

The overall strengths of the PTGI are the wide usage in existing literature and good reliability and validity. Additionally, the PTGI was created to operationalize the conceptual definition of PTG provided by Tedeschi and Calhoun (2004) and therefore all aspects of the conceptual definition are present in the questionnaire. A challenge to interpreting the PTGI is that the score suggests a degree of PTG but there is no cut score to distinguish those with PTG and those without PTG.

The benefit finding scale (BFS) measured PTG in two studies (Lindwall et al., 2014; Tillery et al., 2016). The benefit finding scale is a 17-item survey assessing positive effects of a challenging experience. Participants respond on a five-point Likert scale ranging from “not at all” to “very much” to statements inquiring the degree to which they experienced change as a result of cancer. Previous reliability testing has demonstrated strong internal consistency among women with breast cancer (Cronbach’s alpha .95) with and among parents of children with cancer (Cronbach’s alpha .92) (Antoni et al., 2001; Tillery et al., 2016). In addition to its infrequent use among parent caregivers, a limitation of the BFS is that the items do not correspond to each of the five dimensions of PTG. Additionally, the BFS inadequately measures the transformative nature of PTG in changing the individual’s life trajectory and decision-making.

Qualitative measurement. Qualitative measure of PTG occurred through semi-structured interview in three of the reviewed studies (McDowell et al., 2010; Quin, 2004; Rosenberg et al., 2014). None of the qualitative interview questions were developed with the specific aim to measure PTG. The interview conducted by Rosenberg et al. (2014) included a single question

about how the child's cancer affected the parent caregiver. If responses reflected new meaning or forward movement from the experience, the parent was assigned as "resilient" or, if these criteria were not met, "not resilient," (Rosenberg et al., 2014). The interview questions within the study by McDowell, Titman, and Davidson (2010) aimed at understanding broadly the HSCT experience, including parent perceived benefit from HSCT. This indirect approach of measuring PTG is similar to Quin's inquiry about how children's health influences other experiences in parents' lives (Quin, 2004).

Development of PTG. The PTG literature suggests that the trauma associated with a cancer diagnosis, cancer treatment, life threatening illness, and HSCT do contribute to positive changes for many caregivers. As previously discussed, there is no quantitative measure that differentiates those that experience PTG from those that do not experience PTG. Evidence that parents develop PTG in response to these circumstances can be drawn from several studies that compare PTG between parents and other groups of individuals. The following is a description of qualitative findings and quantitative findings comparing PTG over time or between difference groups.

The qualitative interviews showed evidence of parental PTG within each of the five dimensions (e.g. relating to others, new possibilities, personal strength, spiritual change, and appreciation of life) of PTG (McDowell et al., 2010; Quin, 2004; Rosenberg et al., 2014). Caregivers experienced enhanced relationships with family members and stronger relationships with their spouses (McDowell et al., 2010; Quin, 2004). Parent caregivers reported a shift in life priorities along with a desire to find a new purpose in life and help others (McDowell et al., 2010; Quin, 2004; Rosenberg et al., 2014). While both mothers and fathers experienced enhanced personal strength following children's HSCT, mothers were more likely than fathers to

describe that their child's cancer led to increased self-confidence and independence (McDowell et al., 2010; Quin, 2004). Parents of children who completed cancer treatment described a sense of deepened faith and religious strength, enhanced appreciation for life, and a commitment to treasuring daily life experiences (Quin, 2004; Rosenberg et al., 2014).

The quantitative measure of PTG showed parents of children with cancer experienced higher levels of PTG compared to parents of healthy children reflecting on a previous distressing event (Phipps et al., 2015; Schepers et al., 2018; Yonemoto et al., 2012). Parents of children with cancer also reported higher levels of PTG compared to parents of children with diabetes (Hungerbuehler et al., 2011). Longitudinal PTG measurements before and six months after the child's HSCT showed increased PTG as time passes after HSCT (Lindwall et al., 2014; Rini et al., 2004).

Previous work suggested that mothers experience higher levels of growth than fathers (Hungerbuehler et al., 2011; Nakayama et al., 2017; Riva et al., 2014; Schneider et al., 2011; Yonemoto et al., 2012) Among mothers of children with cancer, 90% observed two positive changes that occurred to them as a result of their children's cancer, and nearly 50% identified four or more positive changes (Barakat et al., 2006). The tendency for females to experience higher PTG than males expands into literature on caregivers of spouses with cancer. Female caregivers and their spouses with cancer had similar levels of PTG but this was not true for male caregivers of spouses with cancer (Zwahlen et al., 2010).

Several other studies also showed the dynamic relationship between caregiver PTG and care recipient PTG. Childhood cancer survivors and their parents described similar levels of PTG after cancer treatment (Turner-Sack et al., 2016). Not surprisingly, parental PTG is higher among parents of children who survive cancer treatment compared to bereaved parents (Rosenberg et

al., 2014). Adults with cancer admitted for treatment report lower PTG than their caregivers (Cormio et al., 2014). However, this finding was not reproduced in a study of adult survivors of HSCT. Though adult HSCT recipients demonstrated higher levels of growth compared to a control sample of healthy adults, their caregiving spouses did not (Bishop et al., 2007). Additionally, parents of young adults with osteosarcoma report higher PTG than a control population, osteosarcoma survivors had higher PTG than the parent caregiver (Yonemoto et al., 2012). These inconsistencies may be attributed to the different types of relationships and levels of dependence between spouses and parents of children of various stages of development.

The timing of PTG measurement could offer an alternate explanation for variation in PTG among caregivers. Though Cormio et al. (2014) reported higher PTG among caregivers than adult care recipients, PTG was measured near the time of diagnosis and prior to the start of cancer treatment. Conversely, Bishop et al., (2007) measured PTG among adult cancer survivors and their caregivers up to 19 years into survivorship and, as a result, increases likelihood that a multitude of other factors in addition to recall affected the study's findings. Research that measures PTG longitudinally at consistent time points increases reliability and better assesses changes to PTG over time.

Parental PTG following pediatric HSCT. To date only five studies describe PTG specifically among parents of children undergoing HSCT (Lindwall et al., 2014; McDowell et al., 2010; Nakayama et al., 2017; Rini et al., 2004; Riva et al., 2014). However, only four studies measured PTG among a sample limited to only parents of children surviving HSCT (Lindwall et al., 2014; McDowell et al., 2010; Rini et al., 2004; Riva et al., 2014). None of these four studies' primary aims were to explore parental PTG after HSCT but measured PTG either directly or indirectly as part of a different aim. A cross-sectional approach was used in 3 studies (McDowell

et al., 2010; Nakayama et al., 2017; Riva et al., 2014) and a longitudinal approach was used in the two others (Lindwall et al., 2014; Rini et al., 2004). PTG was explored qualitatively in one study (McDowell et al., 2010) and quantitatively among the other four (Lindwall et al., 2014; Nakayama et al., 2017; Rini et al., 2004; Riva et al., 2014). Only two of studies measured PTG with the most widely used measure of PTG, the posttraumatic growth inventory (PTGI) (Nakayama et al., 2017; Riva et al., 2014). This variation is partially explained by the approach of two studies to measure benefit finding rather than PTG (Lindwall et al., 2014; Rini et al., 2004). Benefit-finding is an overlapping but not as comprehensive and transformational concept as PTG, defined as discovering the “silver lining” from a traumatic experience (Davis, Nolen-Hoeksema, & Larson, 1998).

Previous studies demonstrate the multifactorial nature PTG. While both longitudinal studies demonstrate evidence of parental PTG from baseline to six months after HSCT (Lindwall et al., 2014; Rini et al., 2004), the mediators and moderators of PTG are unclear. Symptoms of anxiety and depression, burnout, and posttraumatic stress are all described among parents after a child’s HSCT; yet these negative symptoms were also associated with PTG (Riva et al., 2014). High levels of distress and perceived medical risk were also an important factor in development of parental PTG (Rini et al., 2004; Riva et al., 2014). This may be attributed to in part by the complex care provided by parents. The year after a child’s HSCT has been described as “abnormal normalcy” and characterized by intense medical care regimens, parental sense of isolation, and ongoing uncertainty regarding the child’s long-term survival (McDowell et al., 2010).

Social support after a child’s HSCT is important to PTG. Parents who report higher partner satisfaction and identify stronger spousal relationships as a result of enduring HSCT-

related conflict describe having stronger marital relationships, a dimension of PTG (Kim, 2017; McDowell et al., 2010; Riva et al., 2014). Similarly, healthcare providers are integral in parent PTG, delivering reassurance and support when other social supports may not fully understand or relate to the tumultuous HSCT journey (McDowell et al., 2010). Beyond an incomplete understanding of how parent PTG develops after a child's HSCT, interventions that promote PTG are also unknown. The only parent intervention to date showed that parent PTG does increase over time after the child's HSCT, but a parent-focused relaxation program had no effect on parent PTG compared to a control (Lindwall et al., 2014).

Gender comparison for parent PTG after HSCT is not well documented. Previous studies describe parental PTG predominately among mothers. While this is a limitation of the literature, PTG is often measured among the parent who identifies as the child's primary caregiver. Mothers traditionally provide more childrearing responsibilities than fathers and may be more likely to be the primary caregiver after HSCT. As such, it is not possible to differentiate the influence between caregiving responsibilities and parent gender on PTG.

Another important consideration for interpreting parental PTG after HSCT is the child's disease process. Overall, previous work is generalizable primarily to parents of children who underwent HSCT for malignancy. As previously discussed, HSCT is an increasingly innovative treatment for children with non-malignant hematologic, immunologic, and metabolic disease. The experience of these parents prior to HSCT may range from caring for a child with a life-long, slowly progressing disease or conversely, a sudden diagnoses requiring immediate HSCT. These aspects may alter the traumatic impact of HSCT and subsequent PTG development.

The most limiting component of interpretation for existing PTG literature is the lack of clarity about when PTG develops after trauma and how PTG changes over time. While previous

longitudinal work described parental PTG increases over the six months after children's HSCT (Lindwall et al., 2014; Rini et al., 2004), there were shortcomings both in describing PTG during the immediate HSCT recovery as well as beyond six months post HSCT. The two quantitative, cross sectional studies measuring parental PTG had wide variation from time of HSCT, ranging from months to many years. Subsequent trauma, changes in factors that shape PTG (i.e. distress), and changes to levels of PTG over time all threaten the validity of PTG findings. Knowledge about how and when PTG develops after HSCT is central to better identification of factors that mold PTG and necessary to guide any parent PTG interventions.

PTG Correlates. To better understand factors that shape PTG, the frequency of each previously measured factor was categorized and summarized based on effect size. Identification of these effect sizes are important to guide further theory development, hypothesize variables predictive of PTG, and inform interventions to promote PTG. To synthesize PTG correlates, previously measured variables were organized within the following categories: psychological, environmental, parent & caregiving characteristics, and child & disease characteristics. These correlates are described further below.

Caregiver psychological correlates. Among the previously investigated psychological variables measured in caregiver PTG research, distress, post-traumatic stress, depression, and optimism all were measured in multiple studies. The effect sizes for unadjusted and adjusted distress ranged from .08 to .48 (Barakat et al., 2006; Hungerbuehler et al., 2011; Riva et al., 2014; Schepers et al., 2018; Yonemoto et al., 2012). Post-traumatic stress adjusted and unadjusted effect sizes ranged from .13 to .25 (Li et al., 2012; Michel et al., 2010; Riva et al., 2014). With the exception of one study (Schepers et al., 2018), correlations demonstrated that as post-traumatic stress or distress increased, PTG also increased. This finding is consistent with

PTG theory, which identified stress and distress as key concepts in development of PTG. Depression was measured in two studies and showed equivocal effect sizes for PTG, ranging from -.07 to .04 (Riva et al., 2014; Schneider et al., 2011). The effect size for optimism and PTG in a study of parents of children with life threatening illness was .10 to .18 (Schneider et al., 2011) but much higher among mothers after a child's HSCT, adjusted effect size $r = .31$ (Rini et al., 2004). This may suggest that optimistic mothers experience more PTG than fathers or could also suggest that the curative nature of HSCT increased optimism more than caregivers of children with ongoing, life-limiting illness.

All other psychological factors were only assessed in single studies and cannot be compared across the studies. Rumination, another key concept in PTG theory, was measured in a single study and demonstrated an expected strong effect size of .50 (Kim, 2017). Factors with the highest effect sizes include emotional intelligence ($r = .44$) (Li et al., 2012), hope ($r = .38$) (Hullmann et al., 2014), and self-esteem for women ($r = .25$) (Schneider et al., 2011). All remaining variables including unadjusted anxiety (Riva et al., 2014), and adjusted psychological adaptation (Rini et al., 2004), self-efficacy (Li et al., 2012), and resilience (Li et al., 2012) had effect sizes less than .2.

Environmental correlates. Environmental factors that shape caregiver PTG focused on the influences of social, work, and home life. Parent perceived social support from friends and family showed effect sizes ranging overall from .07 to .26 (Kim, 2017; Li et al., 2012; Riva et al., 2014), but as high as .43 for support from a significant other (Kim, 2017). This suggests among all forms of social support, the support from the co-parent has the strongest relationship with PTG. Interestingly, when either the parent or the child reported the child's sense of social support, both had an inverse relationship with parent PTG ($r = .10-.24$) (Yaskowich, 2002).

The number of children in the home and PTG had small effect sizes of .13 to .22 in a sample of parent caregivers after HSCT (Rini et al., 2004) and only .03 among Chinese parents of children with congenital disease (Li et al., 2012). PTG increased as the number of children in the home increased. The small effect size among Chinese parents may reflect cultural and societal influences that support having few children. Related to the number of children in the home, the relationship between PTG and family function had an effect size of .20 (Hungerbuehler et al., 2011). These studies suggest that family environment has a pertinent but limited role in parent PTG after a child's HSCT.

Only a single study examined the relationship of parental job stress on PTG ($r = .14$) (Riva et al., 2014). Employment following a child's HSCT is difficult to maintain due to hospitalization, frequent appointments, and need for parental care at home for months after HSCT. This may explain the infrequency of work-related variables described in previous research.

Demographic correlates. Demographic information was well described in the reviewed studies but relationships of these characteristics with parent PTG was not readily examined. The age of the parent caregiver had a negligible effect size of .10 to .16 (Li et al., 2012; Riva et al., 2014), similar with the effect size of the child's age regardless of time of measurement. The effect sizes for the child's age at the time of diagnosis were .19 and .1 at time of study (Michel et al., 2010). Across the studies females experienced higher PTG than males; effect sizes ranged from .13 to .36 (Hungerbuehler et al., 2011; Li et al., 2012; Nakayama et al., 2017; Schneider et al., 2011; Yonemoto et al., 2012; Zwahlen et al., 2010). The effect size for socioeconomic status (SES) and PTG ranged from .02 to .15 (Li et al., 2012; Michel et al., 2010; Schepers et al., 2018), and except for the study by Schepers et al. (2018) there was a positive correlation between

PTG and income. Similarly small effect sizes were described for education ($r=.10-.25$) (Li et al., 2012; Rini et al., 2004).

Disease correlates. Numerous aspects of the child's disease and treatment were studied in relation to caregiver PTG. The effect sizes for time since the identified traumatic event, whether it be time from HSCT (Lindwall et al., 2014; Rini et al., 2004; Riva et al., 2014), diagnosis of cancer (Phipps et al., 2015), or end of cancer treatment (Michel et al., 2010; Yonemoto et al., 2012), resulted in effect sizes ranging from .05 to .67. Effect sizes were largest among studies measuring PTG less than 5 years after the event. While there were positive correlations between passage of time and PTG, days of hospitalization had an inverse relationship with parent PTG ($r=.27$) (Hungerbuehler et al., 2011).

Several different variables attempted to measure parent perception of disease and treatment severity. Compared to parents of children newly diagnosed with diabetes, parents of children with cancer had higher PTG ($r=.31$) (Hungerbuehler et al., 2011). The effect size of the impact of the child's illness on the caregiver ranged from .08 to .41 (Michel et al., 2010). Disease recurrence had a stronger effect size than diagnosis risk for poor prognosis ($r=.46$ versus .14) (Nakayama et al., 2017; Rini et al., 2004). The effect size for cancer treatment did not differ between those currently on cancer treatment and those off cancer treatment ($r=.28$ versus .30) (Phipps et al., 2015). Measured treatment severity included regimen related toxicity ($r=.14-.15$) (Rini et al., 2004), late treatment effects ($r=.66$) (Nakayama et al., 2017), and treatment components including surgery, radiation, and HSCT ($r=.21-.24$) (Nakayama et al., 2017). These effect sizes demonstrate that higher disease and treatment severity likely contribute to parent PTG.

Care recipient psychological correlates. Beyond attributes of the disease and treatment, several studies also measured psychological aspects of the child or adult care recipient. The most common variable of interest was the relationship between the caregiver's PTG and the care recipients PTG ($r = .06-.55$) (Bishop et al., 2007; Michel et al., 2010; Tillery et al., 2016; Turner-Sack et al., 2016; Yaskowich, 2002). All studies measuring parent and child PTG showed a positive relationship, but a negative correlation was found between PTG of caregivers and the adult HSCT recipients (Bishop et al., 2007). Only one study to date measured the connection between parent PTG and the parent-child relationship (Schepers et al., 2018). Reports of the relationship from both the perspective of the child and the parent showed equivocal effect sizes (.01-.04) (Schepers et al., 2018). Lastly, individual characteristics of the child showed self-efficacy ($r = .35$) to have a stronger effect size than general adjustment ($r = .01-.03$) (Schepers et al., 2018; Yaskowich, 2002). Interestingly, PTG was inversely correlated with parent's report of the child's self efficacy, suggesting that parents experienced lower levels of PTG when children are more independent and have less caregiving needs.

Caregiving correlates. A review of caregiving attributes and parent PTG revealed that few variables have been previously explored in the literature. Of the five variables explored, no single variable was measured in more than one study. Meaning in caregiving had the strongest effect size, .68 for men and .66 for women, followed closely by spirituality ($r = .42$ for women and $r = .48$ for men) (Schneider et al., 2011). These strong effect sizes may reflect overlap with the conceptual definition of PTG. Both caregiver burnout and caregiver burden had very small effect sizes, .05 for burnout and .02-.11 for burden (Riva et al., 2014; Schneider et al., 2011). The importance of additional exploration in the relationship between PTG and caregiver quality of

life was evident in the effect sizes of .26 for mental quality of life and .30 for the physical quality of life (Michel et al., 2010).

Discussion. This synthesis of effect sizes clearly communicates the complexity and multifactorial nature of caregiver PTG in the setting of cancer and HSCT. The relatively inconsistent small effect sizes for variables across the studies suggest that there are likely a multitude of intrinsic and extrinsic factors that shape caregiver PTG after a child's HSCT. While factors such as caregiver stress and distress, disease severity and treatment characteristics, and caregiver gender have been explored in multiple studies, many variables have only been measured in a single study. More research is needed, especially given the lack of studies on caregiver PTG after the child's HSCT to explore which parent and child intrinsic and extrinsic variables are most salient to caregiver PTG after a child's HSCT. A broader exploration of the HSCT journey and caregiving experience may help better delineate variables that have the strongest relationship with parent PTG after pediatric HSCT.

Limitations

Sampling. Additional research is needed to describe PTG among parents of children undergoing HSCT for metabolic, hematological, and solid tumor diseases. Diverse samples that include both the mothers and the fathers of children undergoing HSCT will better identify the relationship of PTG between both of the parents and the child. Research should seek to recruit patients with diverse SES and ethnic backgrounds to enhance the generalizability of the research. Sampling bias may have occurred in previous studies due to differences between participants and those who declined participation. Since reasons for non-participation were not readily described,

it is possible that participants were more attracted to or interested in the topic of PTG and thereby more likely to experience PTG.

Design. There are numerous cross-sectional studies on caregiver PTG yet the bulk of this work included samples of caregivers often years beyond the traumatic event of cancer treatment or HSCT. This variation increases potential that additional traumas, individual maturation, and poor recall influenced PTG findings and limited identification of factors that foster PTG. Cross-sectional studies that measure parental PTG consistently at the same time period after HSCT will better identify factors that are associated with PTG. This information can be used to inform longitudinal work to better understand if a predictive relationship exists between identified PTG factors and parental PTG.

Though longitudinal research is necessary to understand which factors predict PTG, design of these studies will be less burdensome if the timing of when caregiver PTG develops after HSCT is clarified. Previous literature does not measure PTG sooner than six months after HSCT. No previous work examined parent PTG during the critical first 100 days after a child's HSCT when caregiving needs and potential for complications are highest. Understanding the timing of PTG development is important in better identification of the factors associated with PTG and ultimately for development of an intervention to support parental PTG.

Methodology. Majority of existing research measures PTG and factors associated with PTG quantitatively. This synthesis of effect sizes identified that parental PTG is associated with psychological, personal, environmental, and disease characteristics of both the parent and the child. Few characteristics were measured in more than one study, which makes development of a strong body of knowledge for PTG difficult. More research is needed to identify what caregiving

factors support PTG or if PTG also contributes to benefits in the caregiving experience, satisfaction with caregiver, or caregiver quality of life.

Previous qualitative research explored the general long-term effects and experiences of caring for a child after HSCT or cancer treatment. While parents did describe positive change characteristic of PTG, the specific aims of these studies did not concentrate on the primary dimensions of PTG. To truly develop a deeper understanding of parental PTG, qualitative work should be designed with the intention of creating conversation surrounding the five PTG dimensions.

Measurement. Though the PTGI has been used extensively in the literature, it is difficult to compare results across studies due to revisions, translations, and variations in reporting PTGI scores. Additionally, as previously stated, the PTGI does not have established cutoffs to define who has achieved PTG and who has not. Furthermore, it is unclear how to interpret the PTGI scores for individual dimensions of PTG (i.e. personal strength). Of the primary PTG concepts within Tedeschi and Calhoun's functional-descriptive model of PTG, only distress has been studied extensively. The other core concepts of PTG theory, coping and rumination, have not been well measured among parents of children after HSCT.

Gaps in the Literature

There is limited literature that describes parental PTG after a child's HSCT, and a majority of the knowledge of factors that are associated with parental PTG is provided from the perspective of parents with children who survived cancer. There is currently no literature describing PTG during or immediately following the intense recovery period following pediatric HSCT. No longitudinal studies exist to measure PTG prior to the child's HSCT through six

months post-HSCT to understand how PTG changes over time. No prior work studied the elements of the caregiving experience that play a role in PTG. Lastly, there is no longitudinal research to investigate the role of PTG in health outcomes or adaptation for the child or the parent.

According to Tedeschi and Calhoun (2004), the narrative of one's trauma and experiences following the trauma are important to understanding the active process of PTG development. The degree to which an individual experiences growth is shaped by how the individual manages distress from the trauma and is able to shift focus to what is gained from the experience. This transformative process changes the individual's worldview and life experiences. What is not clearly documented in the literature is how this evolution occurs among parents after a child's HSCT, particularly because the trauma of a child's HSCT is not isolated to the actual delivery of the transplant but throughout the child's unpredictable and risky recovery period. The day-to-day experience of providing care and attending to the child's needs may be central to parental PTG. A broad examination of these parental HSCT narratives is needed to better understand caregiving as an important contributor to parental PTG.

Beyond the general collection of caregiving narratives, there is a need to explore PTG among parents of children undergoing HSCT for a greater diversity of conditions including metabolic, hematological, and oncologic diseases. For some parents, the underlying disease process treated by HSCT was congenital or chronic in nature, while for others the need for HSCT sudden and unexpected. These circumstances alone may alter parental PTG. Parent narratives should be collected in the early recovery period after HSCT, when parental recall is most accurate and parents may be still actively developing PTG. This time period of early HSCT recovery may be well suited for an intervention to foster PTG, particularly because parents have

a high degree of interaction with the healthcare team. For this reason, there is a need to explore the impact of nurses on parental PTG, particularly how nurses shape parent experience after HSCT.

Purpose of the Study

The purpose of the dissertation was to explore parental PTG in the first 100 days after their child's HSCT. This time period was selected based on previous research suggesting that adaptation to trauma is most malleable four to six weeks after the trauma (Caplan, 1964). The first 100 days after HSCT are filled with high caregiver distress and caregiving responsibilities. This study delivers a deeper understanding of parental PTG in the first 100 days after the child's HSCT, the factors that shape PTG, and how the experience of caring for children contributes to PTG. Specific aims and hypotheses as well as definitions for key terms used to guide this study's design and methodology are described below.

Specific Aims/Hypotheses

The primary aims and hypotheses of this study included:

Aim 1: Describe and assess the associations of parent personal (e.g. child age and gender, parent age and gender, ethnicity, parent education and marital status), environmental (e.g. number of children in home, need to relocate for HSCT, socioeconomic status), and event-related factors (e.g. child's diagnosis, time since diagnosis, number of days hospitalized for initial HSCT stay, number of hospital readmissions, presence of child graft versus host disease, nursing care during hospitalization) with parental PTG.

Hypothesis 1.1: Level of parental PTG will be positively associated with parent age, child

age, parent education, number of children in the home, parent education, time since the child's diagnosis, number of days hospitalized for initial HSCT stay, and number of hospital readmissions.

Hypothesis 1.2: Level of parental PTG will be higher among parents with the following characteristics: married, female gender, Hispanic ethnicity, female child HSCT recipient, need to relocate for HSCT, and child HSCT recipient with graft versus host disease.

Hypothesis 1.3: Level of parental PTG will be inversely associated with parent socioeconomic status.

Aim 2: Assess the association of concepts within the functional-descriptive model of PTG (e.g. distress, rumination, and coping) with parental PTG.

Hypothesis 2.1: Level of parental PTG will be positively associated with distress and rumination.

Hypothesis 2.2: Level of parental PTG will be positively associated with primary control engagement coping (problem solving, emotional expression), secondary control engagement (cognitive restructuring, positive thinking, acceptance, distraction), and negatively associated with disengagement coping (avoidance, denial, wishful thinking).

Aim 3: Explore the role of parental caregiving experiences in parental PTG.

Hypothesis 3. Parents will describe positive personal benefits gained through recollection of caregiving experiences after children's HSCT.

Definition of Terms

Trauma. The trauma of HSCT is defined as the precipitating event to PTG where there is imminent threat or actual witness of or personal experience of death or serious injury and is accompanied by fear, horror, or helplessness (American Psychiatric Association, 2013).

Caregiving. Caregiving is defined as provision of care to other human beings who cannot provide care for themselves (Cambridge Dictionary Online, 2019). In the context of HSCT, this includes providing personal and medical care; transportation and mobility assistance; monitoring and reporting health status; managing household and financial responsibilities; and offering the recipient emotional, physical, and behavioral support (Oberst, Thomas, Gass, & Ward, 1989). Caregiving is different from the everyday experience of parenting, which is defined as culturally derived practices a father or mother use to provide care to a child in preparation for the child to manage one's own life (Bornstein, 2013).

Coping. Coping is defined as the behavioral and cognitive attempt to minimize the trauma, which given the severity of the stress has overcome the individual's resources (Lazarus, 1993).

Distress. Distress is defined as an emotional response to a stressor induced by trauma that has the ability to cause temporary or permanent harm (Ridner, 2004).

Rumination. Rumination is defined as a type of cognitive processing, which involves recurrent positive or negative thinking that is centered on the trauma and can occur with and without cues from the environment (Martin & Tesser, 1996). Automatic rumination occurs initially after trauma is described as intrusive and can impair one's ability to participate in daily activities. As time passes, automatic rumination transitions to deliberate rumination, which

supports the individual to recover and make sense of the trauma (Tedeschi, Park, & Calhoun, 1998).

Posttraumatic Growth. PTG is defined as a positive change following a traumatic event that can be reflected in a sense of new life opportunity, enhanced relationships and connectedness to others, increased personal strength, enhanced appreciation for life, and deepened spirituality (Tedeschi et al., 1998).

Significance of the Issue and Need for Study

The population of children treated with HSCT is steadily increasing. Approximately 4,700 children between 0 and 17 years of age received allogeneic HSCT between 2014 and 2017 compared to approximately 4,500 between 2010 and 2013 and 3,500 between 2006 and 2009 (National Marrow Donor Program, 2017). Estimates project that the total population of HSCT survivors who received transplant prior to age 18 will approach 64,000 by the year 2030 (Majhail, Tao, et al., 2013). Pediatric HSCT is performed only at specialized hospitals as curative therapy for rare, life-threatening medical conditions. Allogeneic HSCT is performed at 157 hospitals across 45 US states with even the largest HSCT institutions performing only 50 to 100 HSCTs each year (Preussler, Farnia, Denzen, & Majhail, 2014; Pulsipher et al., 2010). HSCT expenses within the first 100 days are immense, ranging from \$150,000 to \$300,000 with more than 40% of that cost acquired from hospital room and board alone (Majhail et al., 2010). Pediatric HSCT costs are 1.6 times higher than adults (Preussler et al., 2014). The significant cost of HSCT, particularly among pediatric HSCT survivors, requires healthcare providers to consider strategies to reduce the most costly aspects of HSCT, such as inpatient length of stay.

These costs do not reflect long-term monitoring and treatment for chronic conditions associated with HSCT. Nearly 80% of pediatric HSCT survivors have a least one chronic health condition, 60% have two or more chronic conditions, and nearly 25% of these are life-threatening (Armenian et al., 2011). As a result HSCT survivors report more activity limitation and worse general health than pediatric cancer survivors who did not receive HSCT (Armenian et al., 2011). Significant financial burden and the child's long-term health limitations may provide a basis for understanding parent loneliness, low perceived social support, depression, and long-lasting psychological distress after a child's HSCT (Pulsipher et al., 2012; Rizzo et al., 2006).

The cumulative stressors of children's health, lost income, and health-associated expenses further challenge parents' adaptation following HSCT. Out-of-pocket costs can total more than \$2,000 over the first two months after HSCT, and these costs can be sustained for more than three years (Khera et al., 2014). Temporary relocation can add an additional \$5,000 to out of pocket expenses (Majhail, Rizzo, et al., 2013). These costs accompanied by decreased income can lead to food, energy, or housing insecurities (Bona et al., 2015; Majhail, Rizzo, et al., 2013). Some survivors withdrew money from retirement accounts, assumed a second mortgage, sold a home, or declared bankruptcy following HSCT (Khera et al., 2014). This financial burden is further compounded due to chronic health difficulties, increasing the likelihood for HSCT survivors' unemployment as they enter adulthood (de Boer, Verbeek, & van Dijk, 2006).

Psychological care for parent caregivers is integral to children's HSCT journey. Aside from the social stigma of seeking psychological services, there are logistical issues regarding wait time and location of services. Parents have described that children's needs take highest priority, and as a result, parents typically do not leave the children's bedsides for self-care

(Devine et al., 2015). Parents focus on their children's health rather than their own health and well-being, which may impact their caregiving role.

The Center for International Blood and Marrow Transplant Research (CIBMTR) and the American Society of Blood and Marrow Transplantation (ASBMT) both recommend that healthcare providers screen children who have undergone HSCT and their caregivers every 6 to 12 months for depression and psychosocial difficulties (Rizzo et al., 2006). Additionally, the Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC) and Children's Oncology Group (COG) emphasize the importance of frequent screening of parent caregiver mental health (Children's Oncology Group, 2013; Kearney, Salley, & Muriel, 2015). COG recognizes parents may experience negative and positive consequences during survivorship, such as PTG, though current screening recommendations only detect declining mental health (Children's Oncology Group, 2013). The number of survivorship clinics screening and treating long-term HSCT complications is growing, yet the primary emphasis is the HSCT recipient rather than the caregiver (Hashmi, Carpenter, Khera, Tichelli, & Savani, 2015).

Caregivers find more reward providing care to HSCT recipients when they feel prepared for the role and responsibilities (Eldredge et al., 2006). Nurses provide education and support, which is identified by parents and caregivers of adult HSCT recipients as important in minimizing distress associated with HSCT (Fife, Monahan, Abonour, Wood, & Stump, 2009; McDowell et al., 2010). Nurses describe meaning from this connection with patients and their families and their ability to lessen and alleviate suffering following HSCT (Sabo, 2011). Nurses are integral members of the healthcare team and provide substantial psychosocial care to children and their parents before, during, and after a HSCT. Nurses care for children and their parents throughout HSCT and recovery, typically lasting between 36 to 57 days for the initial stay and

additional days for the almost 60% who are readmitted within the first 6 months after HSCT (Bona et al., 2015; Majhail et al., 2010). Nurses offer integral support including family education and parent self-care. Considering the annual size of the pediatric HSCT population and the average inpatient stay, nurses provide on average 1.6 to 2.6 million patient care hours each year for the initial HSCT inpatient stay alone.

Early work of COG nurse researchers dating back to the 1980's has forged the way for the current research agenda described in the COG nursing discipline 2013 Blueprint for Research (Landier, Leonard, & Ruccione, 2013). The Blueprint for Research coupled with the COG nursing research framework "Resilience in Individuals and Families Affected by Cancer" identify that caregiver distress, coping, and derived meaning affect the cancer experience (Landier et al., 2013). These documents outline the need for research to understand and promote caregiver resilience, health, and well-being (Landier et al., 2013).

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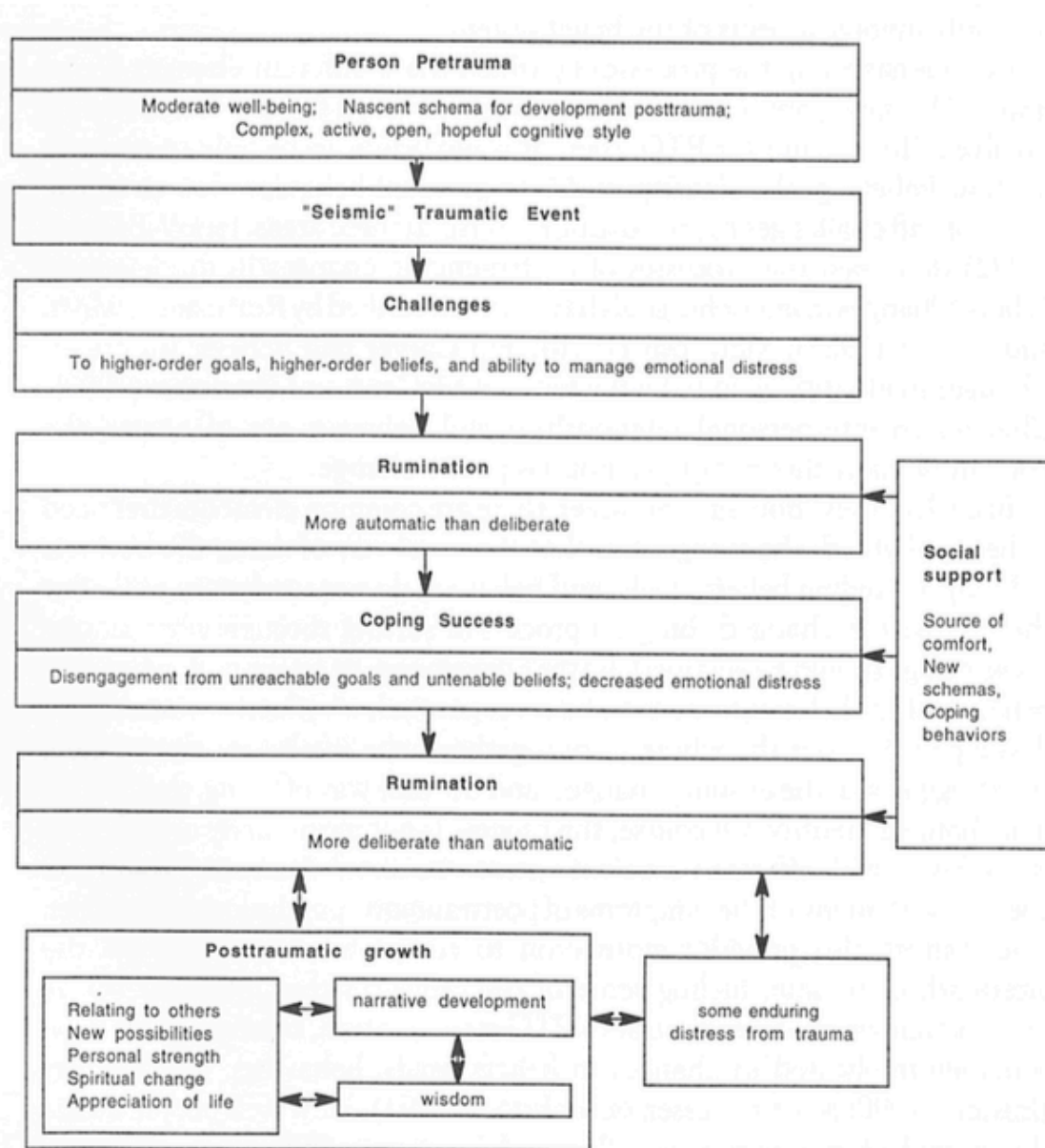


Figure 1. Tedeschi & Calhoun's functional descriptive model of PTG. Tedeschi, R.G., Park, C.L., & Calhoun, L.G. (Eds.). (1998). *The LEA series in personality and clinical psychology. Posttraumatic growth: Positive changes in the aftermath of crisis.* Mahwah, NJ: Lawrence Erlbaum Associates Publishers.

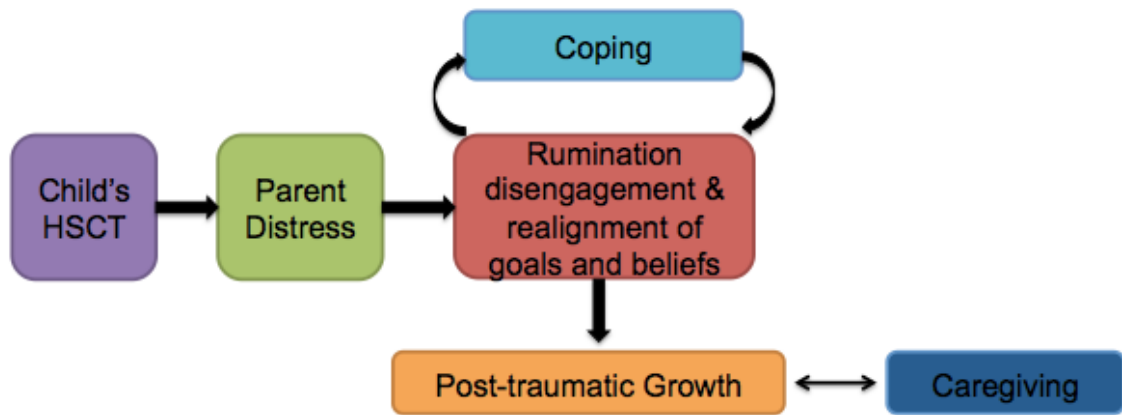


Figure 2. Conceptual framework illustrating relationships among the child's HSCT, distress, rumination, coping, caregiving, and PTG.

Chapter 2

Parental Posttraumatic Growth after Pediatric Hematopoietic Stem Cell Transplant

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Abstract

Parents of children recovering from hematopoietic stem cell transplant (HSCT) experience high distress related to their children's caregiving needs and illness uncertainty. While many parents describe long-term positive benefit after enduring this experience, little is known about the role of posttraumatic growth (PTG) in the immediate HSCT recovery. The purpose of this study is to describe parental posttraumatic growth 100 days after pediatric HSCT. **Methods.** This is a cross-sectional, descriptive study of 24 parents, approximately 100 days after their children received HSCT. Participants reported environmental, personal, and disease characteristics and completed measures of distress, coping, rumination, and posttraumatic growth. **Results.** Evidence of parental PTG was described in each of the 5 PTG dimensions (relating to others, new possibilities, personal strength, spiritual change and appreciation of life). PTG was positively associated with parental distress, disengagement coping, and rumination measures of involuntary engagement and disengagement ($r = .44-.47, p < .05$). Appreciation of life demonstrated the strongest associations with distress and rumination ($r = .53-.61, p < .01$). Curvilinear relationships were observed for the association of distress, disengagement coping, and

involuntary engagement with PTG ($p < .05$). **Conclusions.** Parental PTG developed within the first 100 days after children's HSCT. Parents' appreciation of life observed in this early recovery period may reflect attempts to minimize distress through disengagement coping and focus on positive aspects of daily life.

Introduction

Parents of children recovering from hematopoietic stem cell transplant (HSCT) experience a myriad of stressors related to children's physical and psychological needs. These stressors may be compounded by fears regarding failure to engraft, disease relapse, and life threatening complications during 100 days of recovery. The journey of HSCT begins with 7 to 10 days of preparative conditioning chemotherapy prior to infusion of stem cells, followed by 2 to 4 weeks of inpatient symptom management while awaiting white blood cell count recovery (1). Outpatient monitoring, which requires children to reside near the hospital, continues until the critical first 100 days post-HSCT have passed (1, 2).

The preparative chemotherapy, prolonged and isolating hospitalization, and potential adverse late effects from the transplant may lead to significant complications and may even result in the child's death (3, 4). Initially, children experience immune suppression resulting in infection risk, bleeding, mucositis, nausea, vomiting, appetite suppression, graft versus host disease, and mood changes (1). Children have described this period of time as tortuous (5). In the months and even years following HSCT, nearly 80% of children have at least 1 chronic health condition after HSCT, 25% of which are considered severe or life threatening (6).

Parents are responsible for providing ongoing care throughout their child's HSCT recovery. Frequent medical appointments, complex medication regimens, and infection

prevention strategies become routine, yet time-intensive aspects of everyday life. Parents prioritize children's needs over their own, often overlooking their own self-care (7). Not surprisingly, parental distress has been shown to increase prior to transplant, peaks three weeks post-HSCT when physical effects of chemotherapy are most prominent, and then again increases at the time of discharge from the hospital (8). These peaks coincide with times when caregiving responsibilities are highest.

Despite this distress, parents have described positive life change after HSCT (9-14). These beneficial changes that occur after the trauma of HSCT are summarized by the term posttraumatic growth (PTG). There are five dimensions of PTG, including increased appreciation for life, enhanced relationships, connectedness to others, increased personal strength, and deepened spirituality (15). PTG can fulfill a human need to make sense of traumatic events and promote psychological healing (16). PTG may be a protective and positive benefit to parental distress following HSCT.

While previous literature describe that parents develop new life priorities, appreciation for life, and increased personal and religious strength in the years after children's cancer treatment or HSCT (11, 17, 18), little is known about the role of parental PTG during the first 100 days following HSCT. During the early recovery period, healthcare providers are in frequent contact with children and their parents, readily able to screen and offer support for HSCT-related distress. Healthcare providers are in an ideal position to implement strategies to promote parental PTG. The ways in which parents adapt and assign meaning early after HSCT may have long-term psychological implications not only for themselves but also their children.

A conceptual framework based upon the relationships between distress, rumination, coping and PTG described within Tedeschi and Calhoun's (15) functional-descriptive model of

PTG guided our study. HSCT elicits significant parental distress and destroys previously held desires and expectations parents have for their children's development and life experiences. HSCT disrupts a sense of normalcy and requires parents to adapt to this new life circumstance. This produces a repetitive, unconscious rumination about thoughts related to HSCT. Rumination is a normal cognitive process, which involves recurrent positive or negative thinking about HSCT and can occur with and without cues from the environment (19). As parents implement strategies to cope with HSCT distress, a deliberate rumination pattern assigns positive reappraisal to HSCT-related experiences. Parents may experience any of the five dimensions of PTG (e.g. enhanced relationships with others, new life possibilities, increased personal strength, deepened spirituality, and increased appreciation for life) (15).

The purpose of this descriptive, cross-sectional study was to explore PTG 100 days after a child's HSCT. The 100-day HSCT anniversary denotes when a majority of children are transitioning from the risk of many life-threatening HSCT complications and have less stringent medical care regimens, which allows families to reside further away from the hospital (1, 2). The specific aims of this study were to examine the (a) associations among parental personal, environmental, and HSCT-related factors, and parental PTG and (b) relationships of distress, rumination, and coping with parental PTG.

Methods

Participants and Setting

Parents of children treated with allogeneic HSCT at a pediatric institution in the Upper Midwest were invited to participate in the study. Parents were eligible for the study if they were the primary parent caregiver of a child 0 to 21 years of age, surviving at 100 days after

allogeneic HSCT. The primary caregiver was defined as the legal parent guardian who spent the most amount of time caring for the child after HSCT. Parents were excluded from the study if the child was deceased, relapsed, or failed to engraft following allogeneic HSCT. Parents were also excluded from the study if parent had cognitive impairment or was unable to speak or understand English.

Procedures

Approval for this study was obtained from the Institutional Review Board at the University of Minnesota #00000852 and Vanderbilt University #171856. Data collection was completed May 2018 to April 2019. The principal investigator (PI) introduced parents to the study at an outpatient clinic visit within two weeks of the child's 100-day HSCT anniversary appointment. Parents who expressed interest in the study provided the PI their email and telephone contact information. The PI then emailed parents a link to the electronic informed consent and survey.

The PI called parents within 48 hours of the email to verify they received the email and coordinate a convenient time for the parent to complete an interview to discuss the parent's HSCT experiences. Parents were instructed to complete the survey within seven days or prior to the interview, whichever was sooner. Parents received email reminders for surveys not completed within five days. Parents who did not respond to email reminders were considered dropouts.

Measures

After completing the e-consent, parents completed the electronic survey. The survey included measurements of PTG, distress, rumination, coping, and demographic characteristics of the parent and child. Parents were asked to reflect on the time period since children's HSCT to

answer survey items. Participants completed all measures electronically via REDCap, a secure, web-based application for building and managing online surveys and databases.

Demographics. Measured demographic characteristics included parent age, gender, ethnicity, socioeconomic status, education and marital status. Parents reported the number of other children in the home and if the parent needed to relocate for the child's HSCT.

Characteristics of the child's disease process and HSCT recovery included diagnosis, time since diagnosis, number of days hospitalized after HSCT, and presence of graft versus host disease post-HSCT.

PTG. The Post-Traumatic Growth Inventory (PTGI) is a 21-item, 6-point Likert response scale ranging from 0 "I did not experience change" to 5 "I experienced this change to a very great degree" as a result of a an identified crisis (31). Parents were instructed to rate their degree of change experienced from their children's HSCT. Total scores range from 0 to 105. Validity has been established through evidence that individuals affected by trauma had more PTG compared to those unaffected by trauma (20). Similar to prior reports (9, 13, 17, 21-27), the Cronbach's alpha coefficients for the scores in this study were .93 for the total score, 0.85 for relating to others, 0.87 for new possibilities, 0.79 for spiritual changes, 0.76 for personal strength, and 0.57 for appreciation for life. Scores for each PTG factor as well as PTG as a whole were calculated by summing responses to the items.

Distress. The Impact of Events Scale-Revised (IES-R) is a 22-item survey with three subscales: intrusion, avoidance and hyperarousal. The measure asks respondents to report how distressing an event has been within the last seven days on a Likert scale from 0 "not at all" to 4 "extremely" (28). Validity was established by high correlation with the PTSD Checklist and has previously been used among parents of children who underwent HSCT (14). Consistent with

prior reports of reliability (29), the Cronbach alpha coefficients for the scores in this study were: 0.90 for the total IES-R scores, 0.81 for intrusion, 0.87 for avoidance, and 0.65 for hyperarousal. The IES subscale scores (intrusion, avoidance, and hyperarousal) were generated by averaging the responses to their respective set of items within the 22 items, resulting in 3 scores ranging from 0 to 4. Up to 20% randomly missing item responses within each scale were allowed. Prorated total scale scores were generated from available item responses.

Coping & Rumination. The pediatric cancer version of the Responses to Stress Questionnaire (RSQ-PC) is composed of 57 self-report survey items asking parents to rate how they react to and cope with 11 different cancer-related stressors. (30). The PI obtained authorization from the Vanderbilt University Stress and Coping Lab to replace the word “cancer” with “stem cell transplant” throughout the survey. Likert scale responses range from 0 “not at all” to 4 “a lot” (30). The RSQ has been validated by strong correlations with the COPE Inventory (31). Higher scores indicate higher levels for each of three coping subscales: primary control engagement (emotional expression, problem solving), secondary control engagement (cognitive restructuring, positive thinking, acceptance), and disengagement (denial, avoidance, wishful thinking). (25). The Cronbach’s alpha reliability coefficient was .94 for the total RSQ values. Three of the five factor scores (primary, secondary, and disengagement) measure coping in this study. The Cronbach’s alpha reliability coefficients for coping were 0.76 for primary control coping, 0.49 for secondary control coping, and 0.80 for disengagement coping.

Rumination was measured by the RSQ-PC is subscales of involuntary engagement (rumination, intrusion, involuntary action, physiological and emotional arousal) and involuntary disengagement (cognitive interference, escape, inaction, impulse, and emotional numbing). The involuntary engagement subscale measures rumination and the physiological and emotional

responses that accompany intrusive thoughts. The involuntary disengagement subscale measures the cognitive, emotional, and physiologic impairment on daily activity and decision-making that may occur with rumination. Validity for the subscales has been demonstrated by positive correlation between involuntary stress responses and physiological arousal in a laboratory-based stress-evoking situation (32). Cronbach's alpha reliabilities for scores in this study were consistent with previous work, 0.89 for the involuntary engagement subscale and 0.91 for the involuntary disengagement subscale (32).

Ratings of stress from the RSQ were described using frequencies for each item response, then summarized using medians and interquartile ranges. Proportion scores for the RSQ were generated by dividing each subscale total score with the total score for the entire measure.

Analysis

Statistical data analyses were conducted using IBM SPSS (version 24.0). Descriptive statistical and graphical methods were used to describe the sample demographics and evaluate observed data distributions. Frequency distributions summarized nominal and ordinal data; means and standard deviations summarized normally distribution continuous data; medians and inter-quartile ranges for skewed distributions.

Mann-Whitney tests assessed PTG differences between the child gender groups and between those with and without GvHD. Spearman's Rho correlations assessed the associations of the remaining demographic characteristics, IES-R, and RSQ subscales with PTGI scores. Curve analyses were used to test for a curvilinear component of the associations of the IES-R and RSQ subscale scores with PTGI scores. The IES-R Avoidance and Total Score distributions were positively skewed; the log (Avoidance) and square root (Total) sufficed to transform those

distributions for appropriate application of curve analyses. Decisions regarding statistical significance maintained an alpha of 0.05 ($p < .05$).

Results

Of 38 eligible parents, 31 participated in the study. Seven declined participation because of lack of interest ($n=4$) and time ($n=3$). Seven of the 31 participants completed only the demographic component of the survey. Therefore, 24 participants were included in the analysis sample.

Demographic characteristics of the 24 participants are presented in Table 1. They were primarily mothers ($n = 21, 87.5\%$) and a median of 38 years of age (IQR = 33 to 47.8). The majority were white ($n = 18, 75.0\%$) and married ($n = 18, 85.0\%$). Parents tended to be well educated; 18 (75%) reported earning a bachelor's or post-graduate degree. In addition to ill children recovering from HSCT, parents had a median of two other children living in the home (min = 0, max = 10). Thirteen (54.2%) parents temporarily relocated from their homes to live near the hospital for the child's HSCT. Ten boys (41.7%) and 14 girls (58.3%) who underwent HSCT were a median of 5.2 years of age (IQR = 1.1 to 16.3). More than half of the children ($n = 15, 62.5\%$) were diagnosed with the disease requiring HSCT less than one year prior to HSCT. No statistically significant associations of parent or child demographic and disease characteristics with PTG were observed ($p > 0.5$).

The most prominent sources of parent stress identified on the RSQ surrounded children's health. Parents reported very high stress with not knowing how preparative chemotherapy conditioning for HSCT would affect their child (66.7%, $n = 16$) and whether or not their child's disease would improve after HSCT (62.5%, $n = 15$). Lack of time and energy for their other

children and significant others were very stressful for 7 parents (29.2%). Stress surrounding employment was very high for 6 parents (25%). The ability to pay bills and family expenses was a significant source of stress for 4 parents (16.7%).

Descriptive summaries for each of the PTGI, IES-R, and RSQ scores are shown in Table 2. The mean total PTGI score was 66.8, though there was wide variability ranging from a low score of 20 to a score of 105. Median distress scores were relatively low for both the total IES-R as well as the three subscales (intrusion avoidance and hyperarousal).

Relationship Between Distress and PTG

Levels of distress were positively correlated with levels of PTG (Table 3). Higher PTGI scores indicate a higher degree of growth. The positive direction of the associations between PTGI and the IES-R suggests that at 100 days after HSCT, higher distress was correlated with a greater degree of PTG. The total IES-R score, as well as each of the IES-R subscales of intrusion, avoidance, and hyperarousal, were positively correlated with the total PTGI values ($r_s = 0.28$, hyperarousal to 0.47 , total, $p < .05$). The strongest association between distress and PTG measured by these instruments was between IES-Intrusion and PTGI-Appreciation ($r_s = 0.61$, $p = .001$), indicating that parents who reported repetitive thoughts and emotions about HSCT also tended to have more growth in the dimension of life appreciation. The next strongest association was the IES-R avoidance scores with the PTGI-spiritual values ($r_s = 0.51$, $p = .010$) indicating that parents who avoided thoughts and emotions related to HSCT tended to also report a greater growth in their spirituality as measured by the PTGI. Curvilinear analysis found a statistically significant quadratic component to the associations of total IES-R ($R^2 = .34$, $p = .012$), IES-R avoidance ($R^2 = .38$, $p = .032$), and IES-R intrusion ($R^2 = .42$, $p = .003$) with PTGI (Figure 3). These findings suggested that while from low levels of distress, increasing distress was

associated with increasing PTG to a certain level of distress. However, as distress levels continued to increase, scores on the PTG measure tended to decrease.

Relationship Between Coping and PTG

Statistically significant association was observed between the RSQ disengagement coping scores and total PTGI scores ($r_s = 0.44, p=.032$). Most of that association appeared to be accounted for by the association of disengagement coping with the PTGI appreciation subscale ($r_s = 0.63, p=.001$). This association indicated that parents with higher disengagement coping scores tend to have more had more growth from appreciation of life than parents with lower disengagement scores (see Table 3). A curvilinear relationship was also observed between RSQ disengagement coping and PTGI ($R^2 = .28, p = .031$). As with the prior curvilinear findings, increasing scores on the adaptive use of disengagement coping was associated with higher parental PTG to a certain level above which higher levels were associated with lower PTG.

Relationship Between Rumination and PTG

Finally, the RSQ rumination scores were more strongly associated with the PTGI appreciation subscale scores than the other PTGI subscales. This was expected due to strong correlations between the IES-R scores with involuntary engagement ($r_s = 0.79, p < .001$) and involuntary disengagement ($r_s = 0.52, p = .009$). The IES-R subscales measure the level of distress caused from specific thoughts while the rumination subscales measure the frequency and responses (cognitive, emotional, physiological) to these thoughts. There was a positive association between total PTGI and RSQ involuntary engagement ($r_s = 0.44, p = .032$). The curvilinear findings demonstrated increasing scores on the RSQ involuntary engagement was associated with higher parental PTGI scores until reaching a certain level, at which point higher RSQ involuntary engagement scores were associated with lower PTG ($R^2 = .30, p = .024$).

Discussion

This study aimed to explore parental PTG during the early recovery after children's HSCT. Our mean PTGI scores compared with previous studies revealed parental PTG in early recovery was not significantly different from several studies with time since cancer treatment or HSCT months to years longer (23, 24, 26, 33). In only one parent sample of children with cancer, PTGI scores were significantly higher than our sample (27) compared to three studies with lower PTGI scores (9, 17, 21). Compared to our results, less PTG was observed among parents of children who died or experienced long-term poor health (9, 17).

Our sample of parents included children with diverse diseases treated with HSCT. Characteristics about children's disease and HSCT recovery provide a basis to consider caregiving burden during HSCT recovery. Previous results highlight parental PTG among children predominantly with malignancy, especially leukemia (9, 12, 14). Though time since diagnosis and duration of HSCT hospital stay both had negative correlations with PTG, neither reached statistical significance. Similarly, there were no notable differences in PTG among children who developed GvHD compared to those who did not.

Interestingly, there were relatively low levels of parent distress 100 days after HSCT. This may be related to the decline in parent caregiving activities and decreased risk for HSCT complications that occur at this time. There were statistically significant positive correlations between distress and all dimensions of PTG except new possibilities and enhanced personal strength. Distress during the HSCT recovery may limit parents' ability to forecast or envision life after HSCT, particularly if there is fear surrounding a negative outcome such as children's relapse or death (34). It may not be until parents return to pre-HSCT daily routines and can reflect on the HSCT experience, that they identify changes in worldview and personal strength.

No significant relationship between PTG with primary or secondary coping was observed in this study. However, there was a statistically significant positive association between PTG and disengagement coping. Disengagement coping is characterized by strategies including avoidance, denial, wishful thinking, and distraction (32). Among parents of children with cancer, these strategies have been associated with long-term parental maladaptation and depressive symptoms (30). Parents may continue to use avoidance of certain memories or reminders of HSCT to minimize distress for years after HSCT (35). However, disengagement coping strategies used to address transient, uncontrollable stressors of HSCT may be adaptive in managing distress in the short term (36). For example, wishful thinking during HSCT recovery may represent hope and optimism, concepts both associated with PTG (12, 23, 37, 38). An alternative explanation for the correlation between disengagement coping and PTG is that parent PTG compensates for disengagement coping. Parents of children with cancer who used more avoidant coping strategies also were found to have stronger positive correlations between benefit finding and quality of life (39).

There was a significant positive association between rumination and parental PTG. Consistent with PTG theory (15), repetitive involuntary and voluntary thinking about children's HSCT is necessary to align previously held expectations and wishes parents had for their children with life after HSCT. Rumination is a cognitive response to distressing thoughts and feelings. Both the IES-R and RSQ measure hyperarousal and avoidance that results from intrusive thoughts. Therefore, it was not surprising that both distress and rumination were positively correlated to the PTG dimension of life appreciation. To suppress HSCT distress, parents may redirect their thoughts to appreciate the present moment and be grateful for each day (34, 40).

While parents reported positive change in all dimensions of PTG, life appreciation was the strongest dimension of growth reported by parents. Parents sought ways to appreciate and adjust priorities to recognize the value of each day during recovery. This approach may be misinterpreted as wishful thinking, disengagement, and avoidance. Notably, distress, disengagement coping, and involuntary engagement all correlated with PTG until reaching a threshold level, at which point the degree of parent PTG declined. This suggests that unmanaged, high levels of distress and rumination or dependence on disengagement coping strategies are not supportive for PTG and may predispose parents to poor psychological outcomes and adaptation to life after the child recovers from HSCT.

Study Limitations

This study is limited by the cross-sectional design, small sample size, and predominance of mothers' perspectives. Parents who declined participation may have introduced a selection bias. Parents who did not participate due to time constraints may have been experiencing more distress than our participants. Those who were interested in the topic of PTG may be more inclined to exhibit PTG. It was not possible to assess pre-HSCT levels of PTG, which limits the ability to separate HSCT-specific changes in PTG from other aspects of the child's disease and treatment prior to HSCT. However, our study contributed to insights on parent PTG and factors associated with PTG during early HSCT recovery, an understudied time period filled with uncertainty, high caregiving demands, and emotional intensity. Our study also added new knowledge about PTG among parents of children with diverse diseases treated by this life saving treatment.

Clinical Implications

Our study builds a foundation for the healthcare team to influence PTG from early recovery into long-term survivorship. Parent distress should be expected during the HSCT recovery and can support PTG. Healthcare providers are in a unique position to offer reassurance and support to parents during a time period when parents feel other social supports cannot relate to the challenges of HSCT (11). However, parents should be screened frequently during HSCT recovery to identify and support parents with high levels of distress, disengagement coping, or rumination that extends beyond children's initial HSCT recovery to reduce risk for maladaptation and poor psychological health.

Future Directions

Future work should measure how changes in distress, coping, and rumination affect parent PTG longitudinally from early recovery into survivorship. Further research is needed to describe how the intensive care and monitoring parents provide children influences PTG. This knowledge may be used to develop interventions healthcare providers can use to support PTG. A more robust sampling of fathers' perspectives is necessary to better understand children's HSCT journey from both parent perspectives. Future work should measure PTG more frequently and at earlier time intervals after HSCT to more clearly understand the evolution of PTG over time. Collectively, this information should be used to inform the long-term influence of parental PTG on adaptation and psychological health.

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Conflict of Interest Statement

The authors declare no conflicts of interest.

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Table 1. Participant demographic characteristics

	N=24 Median (IQR) Min, Max	
	Parent	Child
Age (years)	38 (33, 48) 29, 59	5.2 (1, 17) 0.5, 19.8
Gender	n (%)	
Male	3 (12.5)	10 (41.7)
Female	21 (87.5)	14 (58.3)
Ethnicity		
Hispanic	1 (4.2)	2 (8.3)
Non-Hispanic	23 (95.8)	21 (87.5)
Race		
White	18 (75)	16 (66.7)
Hispanic	1 (4.2)	2 (8.3)
Asian	5 (20.8)	5 (20.8)
More than 1 race	-----	1 (4.2)
Parent Education	n (%)	
High school diploma/GED	3 (12.5)	
Some College/Associate's Degree	3 (12.5)	
Bachelor's Degree	10 (41.7)	
Post-graduate Degree	8 (33.3)	
Marital Status		
Never Married	3 (12.5)	
Married	18 (85)	
Divorced/Separated	2 (8.3)	
Annual household income		
Less than \$49,999	4 (16.7)	
\$50,000-\$99,999	5 (20.8)	
\$100,000-149,999	3 (12.5)	
\$150,000 or more	8 (33.3)	
I'd rather not say	4 (16.7)	
Child's Disease		
Malignancy	6 (25)	
Hemoglobinopathy	2 (8.3)	
Metabolic Disorder	9 (37.5)	
Immune deficiency	5 (20.8)	
Bone marrow failure	2 (8.3)	
Time Since Child's Diagnosis		
Less than 1 year	15 (62.5)	
More than 1 to 3 years	7 (29.2)	
More than 3 years	2 (8.3)	

Table 2. Description of scores for Posttraumatic Growth Inventory (PTGI), Impact of Events Scale Revised (IES-R), and Responses to Stress Questionnaire (RSQ). (N=24)

Measure	Mean	Std Dev	Min, Max
PTGI			
Total	66.8	21.3	20, 105
Relating to Others	24.1	6.8	7, 35
New Possibilities	12.8	7.3	0, 25
Personal Strength	12.3	5.0	4, 20
Spiritual Change	6.1	3.3	1, 10
Appreciation of Life	11.54	2.8	6, 15
	Median	IQR	Min, Max
IES-R			
Total	0.8	0.4, 1.4	0, 2.4
Intrusion	0.9	0.5, 1.5	0, 2.1
Avoidance	0.5	0.2, 1.0	0, 3.5
Hyperarousal	0.8	0.2, 1.6	0, 2.3
RSQ			
Primary Control Coping	26	21.3, 30	16, 34
Secondary Control Coping	35	30, 37	23, 43
Disengagement Coping	15	12, 17.5	9, 30
Involuntary Engagement	29.2	25.5, 38	17, 53
Involuntary Disengagement	19.5	15.5, 22.8	12, 48

Table 3. Associations of distress, coping, and rumination with posttraumatic growth (PTG) (N=24)

	PTG (PTGI)					
	Total	Relating to Others	New Priorities	Personal Strength	Deepened Spirituality	Life Appreciation
Distress (IES-R)						
Total	.47* (.020)	.47* (.020)	.37 (.075)	.36 (.082)	.41* (.045)	.61** (.001)
Intrusion	.41* (.047)	.44* (.031)	.21 (.326)	.43* (.035)	.31 (.140)	.60** (.002)
Avoidance	.41* (.043)	.38 (.066)	.37 (.072)	.33 (.112)	.51** (.010)	.41* (.045)
Hyperarousal	.28* (.043)	.28 (.183)	.25 (.239)	.10 (.660)	.16 (.468)	.50* (.014)
Coping (RSQ)						
Primary Control	.26 (.213)	.10 (.628)	.27 (.199)	.12 (.563)	.30 (.148)	.23 (.272)
Secondary Control	.31 (.141)	.32 (.122)	.19 (.381)	.37 (.074)	.24 (.268)	.13 (.553)
Disengagement Coping	.44* (.032)	.45* (.028)	.41* (.047)	.27 (.194)	.41 (.049)	.64** (.001)
Rumination (RSQ)						
Involuntary Engagement	.44* (.032)	.35 (.095)	.37 (.076)	.27 (.210)	.34 (.106)	.67** (.000)
Involuntary Disengagement	.29 (.172)	.30 (.152)	.27 (.210)	.08 (.705)	.03 (.905)	.53** (.008)

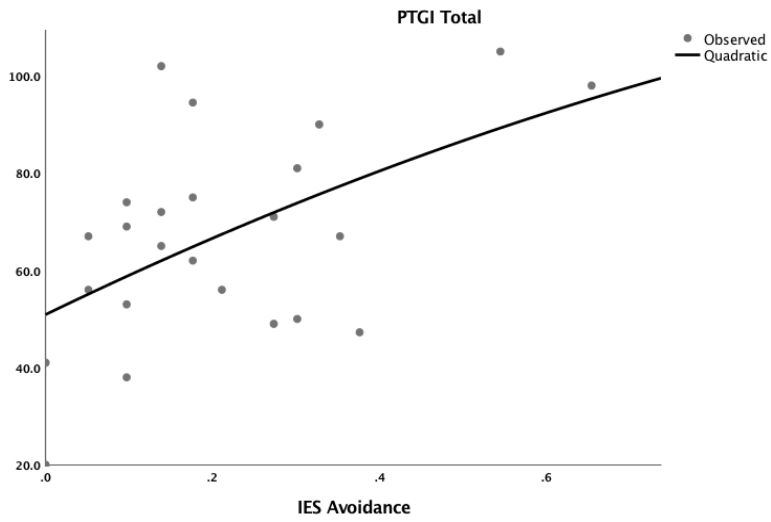
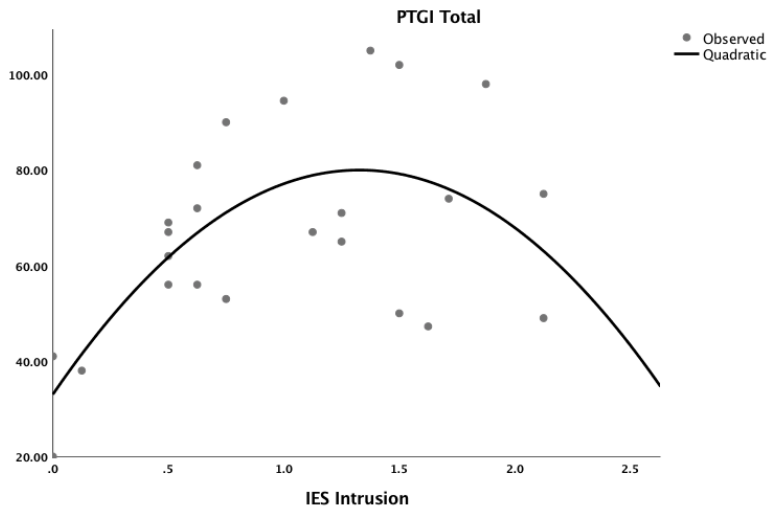
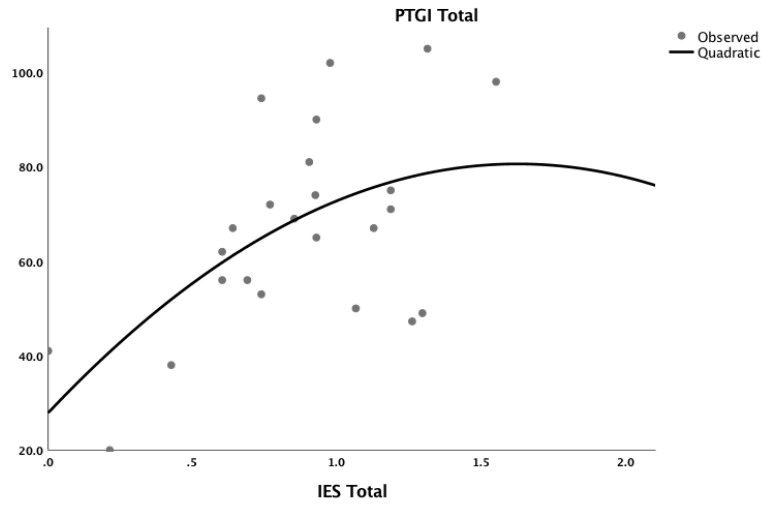
† Impact of Events Scale Revised (IES-R), Responses to Stress Questionnaire (RSQ), Posttraumatic Growth Inventory (PTGI)

‡ Note: Values in cells are r_s (p-value), * $p < .05$ ** $p < .01$

§ Higher PTGI scores indicate more PTG

¶ Higher IES scores indicate more distress

Higher RSQ scores indicate more coping, engagement, or disengagement



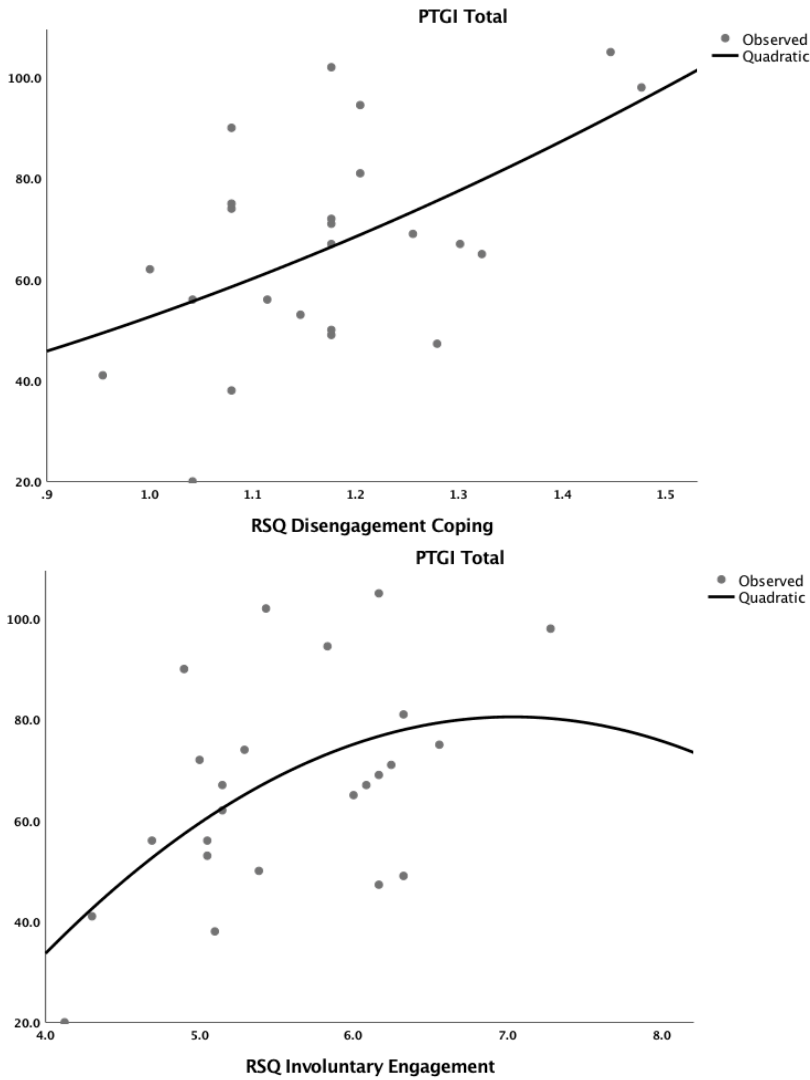


Figure 3. Curvilinear relationships of the Impact of Events Scale-Revised (IES) scores and Stress Questionnaire (RSQ) scores with the Posttraumatic Growth Inventory (PTGI) scores. IES-R total ($R^2 = .34$, $p = .012$), IES-R avoidance ($R^2 = .27$, $p = .032$), IES-R intrusion ($R^2 = .42$, $p = .003$), RSQ disengagement coping ($R^2 = .28$, $p = .031$), and RSQ involuntary coping ($R^2 = .30$, $p = .024$) with the PTGI total scores.

Chapter 3

Parental Posttraumatic Growth and Caregiving after Pediatric Hematopoietic Stem Cell Transplant

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Abstract

Parents of children recovering from hematopoietic stem cell transplant (HSCT) experience significant distress due to unpredictable and potentially life-threatening complications. Distress is heightened by intensive caregiving parents provide the child during the first 100 days after HSCT. Management of distress and adaptation to caregiving responsibilities may be enhanced if parents find benefit in their experiences through posttraumatic growth (PTG), yet little is known about how parents' experiences after HSCT foster PTG. The aim of this study was to explore how parents experience caregiving and PTG 100 days after children's HSCT. **Methods:** Thirty-one parents completed semi-structured interviews approximately 100 days after children received HSCT. **Results:** Four major themes emerged from the data to describe parent experiences after HSCT: (a) psychosocial and healthcare contextual factors (b) cognitive, affective, and social support reactions to HSCT (c) problem-based, emotion-based, and cognitive coping strategies and (d) PTG. **Conclusions:** Results increase understanding of how parents' experiences and caregiving responsibilities contribute to PTG. These findings may guide future research to

understand how these experiences influence PTG. Nurses are integral to the parents' experiences. Future work should focus on nursing interventions that enhance positive reinterpretation of parents' experiences after their children's HSCT.

INTRODUCTION

Allogeneic hematopoietic stem cell transplant (HSCT) offers a lifesaving treatment for a growing number of children diagnosed with life-threatening and rare blood, immune, metabolic, and malignant diseases.^{1,2} Children endure seven to ten days of intense conditioning chemotherapy prior to the matched donor hematopoietic stem cell infusion and spend the next two to four weeks hospitalized while awaiting neutrophil engraftment.³ During the inpatient recovery children experience distressing symptoms including nausea, vomiting, bleeding, mucositis, and appetite suppression.^{3,4} Readmissions for life-threatening complications such as organ toxicity, immune suppression, and graft versus host disease are highest in the first 100 days after HSCT.^{3,5,6} Despite these risks, parents making the difficult decision to proceed with HSCT focus on its lifesaving capability and long-term improved quality of life for the child.⁷

Children require around-the-clock care and monitoring for at least three months following HSCT.⁸ Upon children's HSCT admission, parents provide care within an unfamiliar environment filled with unit-specific policies, procedures, and communication norms.⁹ Children have described the early HSCT recovery period as slow "torture."¹⁰ After discharge, parents follow intensive medication administration regimens and restrictive hygiene practices, which contribute to a deeper sense of isolation from normal life.¹¹ A primary coping mechanism for children is social support from family to comfort, distract, and normalize life following HSCT.^{4,10}

There is a dyadic link between parental emotional health and children's distress, which highlights the importance of parents' caregiving experience.¹² Psychological support for parent caregivers is integral to children's HSCT journey, yet proves difficult for many parents. Aside from the stigma of seeking psychological services, there are logistical issues regarding wait time for services and the location of the services. Caregivers experience difficulty caring for themselves while also meeting the competing needs of HSCT recipients and other family members.¹³ Parents have described children's needs as their highest priority and anxiety and guilt when leaving the hospital for self-care.^{13,14}

Distress is a predictable and natural response to children's HSCT. Trends in heightened parental distress match periods of increased caregiving responsibilities prior to HSCT admission, during the two to four weeks post-HSCT when chemotherapy effects are most prominent, and again at the time of hospital discharge.¹⁵ Caregivers describe emotional intensity, anxious worry, and information overload as sources of distress during these time periods.^{9,16} For caregivers of adults undergoing HSCT, this distress is further heightened if the caregiver is female, develops caregiver burden, or uses avoidant coping mechanisms.¹⁷

Positive reappraisal of aspects of HSCT caregiving may improve caregiver adaptation and temper HSCT-related fear.¹⁸ Posttraumatic growth encompasses several dimensions of HSCT positive reappraisal including new found personal strength, priorities, appreciation of life, closer relationships with others, and deepened spirituality.¹⁹ Caregivers who experience PTG fulfill a human need to make sense of this traumatic event and promote psychological healing.²⁰ According to Tedeschi and Calhoun,²¹ a distressing event such as HSCT results in involuntary rumination and efforts to cope with the event. Over time, more purposeful rumination aims to

construct a new worldview which allows parents to identify positive reappraisal of HSCT within the dimensions of PTG.²¹

Previous literature has demonstrated PTG among parents after their children's HSCT.²⁵⁻²⁹ What remains unexplored is the role of caregiving in development of parental PTG. The aim of our study was to explore what aspects of the parent caregiving experience might support PTG following a child's hematopoietic stem cell transplant.

A conceptual framework describing parental PTG and caregiving after children's HSCT was developed for this study based on relationships between distress, coping, rumination and PTG described within Tedeschi and Calhoun's²¹ functional-descriptive model of PTG. After children's HSCT, parents experience heightened distress, which is followed by automatic rumination characterized by repetitive and intrusive thoughts about HSCT stressors. Parents respond by initiative coping efforts and then are able to purposefully ruminate about HSCT experiences to assign meaning and purpose to HSCT. The process lays the foundation for dimension of PTG including strengthened relationships with others, new life priorities, enhanced spirituality, personal strength, and appreciation of life. Caregiving was added as a secondary outcome of PTG based on a synthesis of previous caregiving literature. The resultant conceptual framework (Figure 1) guided the study.

METHODS

Participants and Setting

Primary parent caregivers of children who received allogeneic HSCT at a pediatric institution in the upper Midwest were invited to participate in the study. Parents were eligible if they self-identified as the legal parent guardian of a child 0 to 21 years of age surviving

approximately 100 days after transplant. Parents were excluded if the child was deceased, relapsed, or failed to engraft following allogeneic HSCT. Parents were also excluded from the study if they did not speak or understand English or had cognitive impairment.

Procedures

Approval from the Institutional Review Boards was obtained from Vanderbilt University and the pediatric institution prior to recruitment. The principal investigator (PI) conducted the recruitment, consenting, and data collection for the study. Parents were approached during an outpatient clinic visit within two weeks of the child's 100-day HSCT anniversary appointment. They were asked to identify the child's primary caregiver after HSCT, defined as the parent who spent the most amount of time caring for the child. The purpose and methods of data collection for the study were introduced to the eligible primary parent caregiver. If the parent expressed verbal interest in participation, a link to an electronic consent and quantitative measures of distress, coping, rumination, and PTG was emailed to the parent. The parent was called to verify receipt of the study link and arrange for a convenient time and location for the interview. All parents elected to complete the interview by telephone or in a private space within the outpatient clinic. Prior to conducting the interview, the PI verified completion of the e-consent. After completion of data collection, parents were mailed a \$25 check in appreciation of their participation. This paper presents qualitative findings from the parent interviews.

Measures

Participants provided demographic information about themselves and their child treated by HSCT through the electronic survey link. The PI completed individual, semi-structured interviews with all participants using an interview guide (Table 4) consisting of open-ended questions designed to understand the aspects of caregiving that shape PTG. The interview guide

was revised prior to use based on feedback from two PhD prepared nurse scientists with content expertise and two parents of children who had received HSCT.

All interviews were audio-recorded and transcribed verbatim. Audio files were submitted to an IRB-approved transcription service (rev.com). Once an acceptable transcript was confirmed, it was saved to encrypted password-protected electronic files. Each interview was assigned and stored via a unique participant ID number.

Analysis

The qualitative research core at Vanderbilt University (VU-QRC) conducted coding and analysis of the qualitative data. Qualitative analysis occurred in three interrelated phases: 1) individual quotes were isolated in the transcripts; 2) a hierarchical coding system was developed to organize the quotations in relationship to the study questions and capture the full range and depth of participant response; and 3) the structure, frequency, and interrelationships of the coded quotes were used to develop a schematic model of how parents experienced PTG.

The hierarchical coding system was developed based on the overall purpose of the study and a preliminary review of the transcripts. The study's conceptual framework of parental PTG and caregiving (Figure 4) was used a priori to guide the initial coding scheme. Each major category was subdivided, and the subcategories were further expanded to describe the information related to the study question. Two trained research assistants served as coders. They were trained to code on 6 selected transcripts. After this, discrepancies in coding were resolved through review of additional transcripts and discussion between the two coders until agreement was reached.

The analysis began by reviewing simple frequencies of codes and proceeded towards a final coding scheme. The process included both inductive analysis (fact to theory) and deductive

analysis (theory to fact).³⁰ The resultant framework was communicated using diagrammatic models supported by a narrative text. The text below illustrates and communicates important constructs and relationships. Management of transcripts, quotations, and codes was performed using Microsoft Excel 2016 and SPSS version 26.0.

RESULTS

Participants

Demographic characteristics of parents and their children are described in Table 5. Participants included 31 parents (28 mothers and 3 fathers). Parents were a median of 38 years of age (IQR = 33 to 46.3). The majority of parents were married (n = 22, 71%) and white (n= 22, 77%). Twenty parents (64.5%) had earned a bachelor's degree or higher. Their children were a median age of 5.1 years of age (IQR = 1.2 to 13.5) at time of HSCT. The length of the initial hospital stay was 24.5 days (IQR = 17.3 to 36.5), and relocation for HSCT-related care was required for 54.8% (n= 17) of parents.

Four major themes of the HSCT caregiving experience emerged from the data: context, crisis reactions, coping strategies and PTG. Table 6 lists the major themes and their associated subthemes. Major themes are further described below with illustrative quotes that include the parent participant's study number and the child's disease category treated by HSCT.

Context

Parents reported that they were affected by both psychosocial factors and the healthcare system. Parents described how life dramatically changed prior to HSCT. The significant psychosocial changes were balanced by interactions parents had within the healthcare system. Social isolation occurred in response to increased caregiving and infection prevention even

before HSCT. This prevented many parents from working, engaging in activities outside the home, or interacting with friends and family.

Contextual Psychosocial Factors

The child's caregiving needs leading up to and after HSCT made it difficult for parents to maintain their careers and sustain employment. Parents forced to leave their jobs due to relocation faced financial strain, though this worry was lessened if parents had financial support from friends, family, or their local community. For example, one mother said, "*It's remarkable that a community can say to itself, 'let's help this family so they aren't going into debt to buy gas and service cars for a lot of hospital-related travel.' It meant we weren't stressing over every penny in our checking account. What a relief.*" (Participant 5, bone marrow failure). Parents who returned to work during HSCT recovery described appreciation for the return of normal life routine but some also encountered guilt and worry while away from the child. One mother shared, "*When I go to work, he's in my head, on the other side, my work, my job is there too, but on the other hand I have him thinking, 'Is he running a high fever? Is he eating? Is he drinking? Is he playing? Is he sleeping? What is he doing right now?'*" (Participant 22, metabolic disorder).

Parents described increased caregiving responsibility leading up to HSCT that disrupted normal family activities and resulted in isolation. This isolation became heightened after HSCT due to infection prevention measures and demands of caring for the child's healthcare needs. Parents felt unable to leave the child to complete routine errands or interact socially outside of the home. This was especially true for parents who temporarily relocated for the child's HSCT. The impact of isolation was described by one mother who reported, "*So it's a combination of sort of busying yourself and trying to be vaguely productive, except you can't really be. It's a nether*

space... And I'm not from here, so I don't really have community. We live in an apartment building, so I get to know the neighbors a little bit... We're not exactly intersected, except for this moment, up until day 100" (Participant 5, bone marrow failure).

HSCT stressors led parents to think about their relationships with friends and family differently. Some friends and family remained connected during the child's HSCT and recovery while others distanced themselves. One mother described, "*...We had friends who volunteered to come and stay with us at the hospital or to come by... then the people that we thought would do that didn't show up for us. So, it just really showed us who cared.... We were able to learn about each other too, about how we handle stress and work with each other during challenging family times like this.*" (Participant 19, bone marrow failure). Parents felt guilty being away from their spouse and other children at home but when parents returned home some felt like outsiders to family dynamics and routines that had changed while they were away.

A child's prior medical treatment helped some parents adjust to intensive HSCT caregiving. During the HSCT hospital admission parents distracted, monitored, and helped to manage distressing symptoms such as fever, pain, and nausea after HSCT. After discharge the children's frequent medications and appointments compounded parental responsibilities. Stress was heightened if parents had to give the child intravenous medications or tube feedings. For example, one mother said, "*Now, dressing changes. Me having to do dressing changes. Me having to take care of her G-tube. Me having to give medicines on time or doing the IV meds and the overnight foods. That's just something that I had to learn that I didn't even know existed...*" (Participant 17, metabolic syndrome). Fatigue and sleeplessness were the most commonly reported consequences of caregiving responsibilities. Despite this, many parents described caregiving activities as rewarding.

Contextual Healthcare Factors

Nurses played a central role in parents' caregiving experiences. Parents appreciated when nurses offered comfort and reassurance, clarified information discussed at family-centered rounds, and taught parents how to care for their child after HSCT. Negative interactions with nurses occurred when nurses didn't follow parent care preferences or offer explanations when providing care, such as administering medications. Parents admired nurses' strength, humility, and genuine passion for their work. The bonds parents formed with nurses led to a sense that nurses were an extension of their family. One mother shared, *"The way nurses treated him... It was like that he was part of the family, and they're part of the family and we are sharing the pain. It was not that I was taking all the pain or hardship... they were equally concerned."* (Participant 4, metabolic syndrome)

Family-centered rounding communication encouraged parents to gain knowledge and participate in the child's medical decision-making on a daily basis. Parents anxiously waited for report of signs of HSCT success, such as neutrophil recovery and donor engraftment. Knowledge about possible HSCT complications gave parents a sense of control and predictability. One father recalled, *"Doctors come in everyday to talk. They gave me a lot of comfort. You know, I guess just like talking to them and them giving me the information. Even if everything's normal, just telling me everything's normal. That was really helpful."* (Participant 20, malignancy). Conflict arose when parents were not included in making decisions about the child's care. This circumstance increased parent hypervigilance and mistrust of the healthcare team. Primary nursing assignments and consistency of healthcare providers minimized distress and promoted trust.

Hospital programs, such as volunteer programming and the parent resource center, which promoted self-care and social interactions outside the child's room provided a necessary break from HSCT. Parents found comfort when they met other families going through HSCT with their children because they could relate to HSCT challenges and worries. One father stated, *"People wouldn't say going to a hospital is a great experience, but that helped me because [of] that social interaction. You're not getting that when you have an immune suppressed child...I had to look at it that way because otherwise, I guess you really would feel like you were in a black hole."* (Participant 26, metabolic syndrome). This extended after discharge to special hospital events and resources that promoted relaxation and enjoyment for the entire family. Ronald McDonald House accommodations supported ongoing relationships with other parents and alleviated negative impact of parent isolation.

Crisis Reactions

Parents reacted to the need for HSCT and subsequent recovery in a variety of ways. Parental distress throughout HSCT was exhibited in cognitive and affective ways. Reactions to the child's HSCT from social supports affected parents positively and negatively.

Cognitive

Cognitive responses to the child's HSCT included synthesis of information, planning, and multitasking the child's care. Parents were shocked that their child had acquired a life threatening diagnosis that could only be treated by HSCT. Parents were confused about what to expect during the HSCT recovery. Frequent thoughts parent had related to the child's complex medical care, recovery, and monitoring after HSCT. This mental exhaustion led to sleep loss and fatigue. Thoughts concerning the child's survival, suffering, and quality of life were especially distressing. The intensity of one mother's thoughts was illustrated by the following description

"...we're doing this for a reason. We have to keep that in the back of our mind. We're doing this for a reason and it's going to make his life a longer better quality of life... through transplant it's just it goes from one stressful struggle to the other... stressing about numbers coming in. Then once those are in it's kind of your stress about is he going to engraft, is the sickness from chemo going to wear off, is he going to get his appetite back? Just like little things that pop up post transplant." (Participant 1, metabolic syndrome).

Affective

Parents had positive and negative emotional reactions to HSCT. These mixed emotions are clear in one mother's description, *"It was an emotional roller coaster. It's like every single emotion that you could ever have all concentrated into a super short period of time. Everything from being so overwhelmed with his diagnosis, to now we have a transplant, and the medications and the chemotherapy side effects, and seeing our baby go through that and how hard that is, but also so elated by the progress."* (Participant 2, immune deficiency). Parents had gratitude for HSCT as a treatment option and for the healthcare team. Parents felt fortunate for the close time spent with the child during recovery. Parents were optimistic about the future after HSCT and felt that this positively affected the child's hope during recovery. There was relief in locating a HSCT donor and again when HSCT was successful. Feelings of happiness were associated with the child's cure and improved quality of life after HSCT.

Negative emotions surrounded the fears of the child's survival and suffering related to HSCT. Parents reported anger and frustration initially that the child needed HSCT but then again in response to the child's physical suffering after HSCT. Sadness, anxiety and dread surrounded the impending HSCT admission and uncertainty about both the child's recovery and survival, especially among those at risk for cancer relapse. Guilt was common if parents left the child to

care for themselves or other children in the home. Parents also felt pressure to thank their friends, families, and communities for their support.

Social support

Parents recognized that social support was important to adjusting to life after HSCT. Family, friends, and the parent's community all responded to the child's HSCT. Spouses experienced similar stressors and could relate to each other in ways that other social supports could not. One mother reflected, *"You hear about some families that their marriages don't make it through this kind of experience 'cause it's just horrible. It's incredibly stressful and you're scared and you lash out at who's closest to you...it was a different experience for us...when one of us is having a hard time, the other one kind of steps up and takes over. And then just being able to have someone there who can relate 100% to what you're going through. Your friends and family are good for support, but they don't really understand what you're going through. "* (Participant 25, malignancy). Family members often supported parents by offering childcare to siblings. Family caring for children after HSCT expressed discomfort and fear related to the child's medical complexity. The parents' communities most frequently offered monetary and written forms of support to families, which eased the stress of HSCT. For friends and family that lived afar, social media technology and prayer helped parents feel connected and supported.

Coping

Parents coped with HSCT distress through a variety of strategies. Coping responses were different depending on the stressor and point of time in the HSCT journey. Collectively, parents used 14 different coping strategies to overcome HSCT stressors. Coping strategies included problem-based, emotion-based, or cognitive ways of coping.

Problem-based

Parents felt more in control if there was a plan of parental tasks to follow after HSCT. Since HSCT recovery was unpredictable, parents focused on managing problems present today without thinking about the future. There was a focus on adequately managing the child's physical suffering, minimizing risk for infection, and implementing strategies to offer the child comfort. One mother shared, *"My husband and I, we tried to just take it one day at a time because we didn't really know what to expect beyond that. Either it was the mucositis or having an increase of fluids in her body, we just tried to resolve some of those issues as they came. And not to think too much of okay, what else could go wrong?"* (Participant 19, bone marrow failure). Parents regularly monitored the child's symptoms, laboratory results, and medications. They also sought reassurance from the healthcare team that the child's progress was normal and expected.

Emotion-based

Management of distressing emotions involved avoidance, spirituality, boundary setting, and self-care. Parents described ways to avoid thoughts and emotions about HSCT by eliminating reminders, occupying themselves with other activities, or drinking alcohol. Spirituality and prayer was a way for parents to surrender control and accept the child's HSCT outcome. Similarly, if parents developed accepted HSCT unpredictability, parents reported less worry and increased ability to adapt when complications arose. One mother expressed, *"I guess I have to get used to the idea that there's going to be these setbacks. Even though you think everything's going just fine, you have to prepare yourself for something coming up. Now, like her neutrophils trending downward drastically. That's another thing I wasn't prepared for, so you just kind of get used to the idea that it's not just going to be a clear task to healthiness or*

wellness." (Participant 29, hemoglobinopathy). Professional counseling, massage, journaling, and participating in activities that encouraged normality decreased negative HSCT emotions.

Cognitive

Cognitive coping strategies used by parents centered on reframing the distressing aspects of HSCT. In moments of distress, parents reminded themselves of HSCT life saving capability, the necessity of HSCT, and the child's future. One mother recalled, *"the anxiety almost instantly stopped the moment we walked in the door of the fourth floor and closed the door behind us. Then it was, 'okay, we're here let's do it' and you look at things in a different perspective. You just want to get out. You concentrate your energy and everything onto how many days before you can go home again."* (Participant 18, immune deficiency). Parents felt fortunate comparing themselves to other parents who seemed to have a worse scenario. An emphasis on positive thinking also supported parents after HSCT. Parents found that their positive thoughts and living in the present helped them and their children focus on goals of HSCT and adapt to unexpected changes during recovery.

PTG Outcomes

Parents experienced multiple aspects of growth in the early recovery period after HSCT. As a consequence of the child's HSCT, parents described stronger relationships with their spouses, family members, and friends. Parents described empathy for others and a desire to help others through life-threatening illness. Many parents reported a deepened relationship with their children who received HSCT and a renewed personal strength to endure life-threatening events. HSCT caused parents to reevaluate life priorities and become more appreciative of the present moment. Parents described a new meaning and appreciation for everyday activities post-HSCT. One mother summarized her experience stating, *"With getting through all of the heartache and*

all the horrible things that happened, you know? It just kind of makes you more appreciative of the good things in your life and the happy things. To just be more aware of everybody really around you, because it's just the support and the comfort and the love and consideration and respect... It's enlightening, like in a world where everyone talks about how bad everybody is and all the violence and horrible things going on." (Participant 15, hemoglobinopathy). For many parents there was religious commitment to faith and trust in God. Parents were appreciative of HSCT, regardless of how difficult the distressing recovery was for the parent and child. In particular, parents expressed gratitude for the healthcare team, medical technology, and the child's recovery.

DISCUSSION

Our findings give new insight into parent caregiving experiences in the time period leading up to HSCT through the child's early recovery. The results show contextual elements, parent reactions, and coping responses that may support parents' PTG after children's HSCT. The themes identified in this study identify variables that may mediate parental PTG and provide a deeper understanding of the relationships between distress, coping, and PTG in the acute recovery period after HSCT. The results provide greater insight in the experiences of parents after children's HSCT and how nurses can support PTG.

In response to the child's HSCT, parents made numerous lifestyle changes to accommodate increased caregiving responsibilities. Parents were unable to work, participate in everyday activities, or interact socially with friends and family due to child's activity limitations and isolation. Consistent with previous work,^{13,16} caregiving responsibilities after HSCT included

provision of complex medical care, activities of daily living, and emotional comfort and entertainment for the isolated child.

Nurses, other healthcare providers, and hospital services provided knowledge, support, and tangible resources for parents to care for themselves and their children. Parents expressed guilt and anxiety when leaving the child for self-care or to interact with friends and family. Not surprisingly, parents were more likely to access care services when they were located within the hospital setting. Family-centered rounds and continuity of members of the healthcare team alleviated parent distress and established trust. This is consistent with previous research, showing that during the HSCT hospital stay parents found it difficult to adjust to changes in the child's healthcare team.¹⁶

Nurses related to the difficulty parents experience after the child's HSCT and comforted, reassured, and taught parents how to care for the child. Caregivers of adult HSCT recipients also described that friends or family members could not provide the same level of support that nurses could to decrease caregiver distress.^{17,28} Parents desired social interaction with other HSCT families. The value of this interaction is unclear. Previous research has described that parents find it difficult to interact and support other parents while attempting to manage their own distress.¹¹

Emotional and cognitive responses to the child's HSCT affected caregiving. The shock of HSCT was often accompanied by negative emotions such as dread, sadness, guilt, anger, and fear. In response, parents became hypervigilant about monitoring and managing the child's care. This may represent parental reactions to fear and daily uncertainty common to HSCT.^{31,32} Mental exhaustion coupled with loss of sleep and physical fatigue were common. Previous work shows that fatigue and severity of the child's symptoms impaired caregiving, decreasing the

ability of the parent to provide physical and emotional support to the child.⁹ Positive emotional responses early after HSCT centered on finding hope and remaining optimistic for a good outcome. Optimism has previously been associated with caregivers' abilities to assign positive meaning to life-threatening illness.^{27,33} As time passed after HSCT, parents adapted to caregiving responsibilities and expressed more happiness and relief, particularly as children felt increasingly well.

An overarching theme in parent coping was a desire to gain a sense of control through the unpredictable HSCT recovery. Parents accomplished this by gathering information about possible complications, providing post-HSCT care adherent to prescribed guidelines, and being attentive to the child's needs. Previous research shows that communication about HSCT risks and complications increased caregiver preparedness.¹¹ During the hospital stay, parents assisted the healthcare team with symptom management, comfort, and monitoring. The burden of care increased significantly upon discharge when parents were required to administer medical care and monitoring independently. Other studies have also described increased care burden at discharge due to parent's desire to properly comply with discharge instructions and avoid life-threatening complications.^{11,16} Parents were able to cope with this transition more easily if the child had complex medical care needs caring prior to HSCT, if parents found caregiving activities rewarding, and if the parent was able to reestablish meaningful connections with family and friends outside the hospital. Religious faith and spirituality also helped many parents alleviate the threat of HSCT uncertainty. Use of faith-based coping strategies to relinquish control to a higher power can offer comfort in the setting of life-threatening circumstances.³⁴

Parents in the study described their caregiving experiences as transformative, resulting in a new worldview. Parents expressed great appreciation for healthcare received throughout HSCT

and a new personal strength after caring for the child during HSCT recovery. This highlights the importance of the HSCT healthcare experiences in supporting parents and preparing them to care for the child in ways that support PTG. Caregiving self-efficacy, for example, has been shown to reduce parental distress related to cancer treatment.³⁵ Caregivers who focus on positive HSCT outcomes, assign meaning to caregiving, and establish caregiving routines are less likely to experience high levels of distress that impair their health.^{28,31,36} Parental benefit finding is associated with improved caregiver quality of life.³⁷

Parental PGT after HSCT may be especially important to long-term parental adaptation. The child's medical caregiving needs persist for years after HSCT. Pediatric HSCT survivors report more activity limitation and worse general health than pediatric cancer survivors.³⁸ More than half of HSCT survivors have two or more chronic health conditions and over a quarter of HSCT survivors have severe or life-threatening chronic conditions.³⁸ Survivorship introduces new stressors for the patient and family such as unwanted recall of unpleasant memories and attempts to avoid reminders of cancer.³⁹ Collectively, this description provides some basis for understanding how parent caregiving experiences may contribute to PTG.

Limitations

Subjectivity bias may have been introduced as the PI was a healthcare provider within the pediatric blood and marrow transplantation program, however, the PI was not actively caring for any of the participants in the study to minimize this risk. Additionally, the coders were made familiar with HSCT but have no active roles in this specialty. The population was fairly homogenous, representing primarily white mothers. Compared to those who declined participation, parents who completed the interviews may be more open or likely to experience PTG.

Clinical Implications

The Center for International Blood and Marrow Transplant Research (CIBMTR), the American Society of Blood and Marrow Transplantation (ASBMT), Children's Oncology Group (COG) and the Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC) all recommend routine screening and support for caregiver mental health.³⁹⁻⁴¹ HSCT survivorship clinics are still in their infancy and despite the need for caregiver research, the services available for caregivers are limited.⁴² While the literature is growing, there are few interventions to support caregivers after HSCT.^{8,43} This study provides a foundation for understanding how nurses can affect parent caregiver experience in ways that promote PTG.

Nurses are in excellent position to explore the impact of parental caregiving on PTG and inform psychosocial care interventions to promote parental PTG before, during, and after the child's HSCT. Nurses care for parents and their children during the initial HSCT hospital stay and additional days for the nearly 60% of children who are readmitted within the first 6 months after HSCT.^{22,23} Nurses offer integral support including family education and support, which includes parent self-care. The relationship between parents and HSCT nurses is mutually beneficial. Nurses identify significant meaning from their connection with patients and their families and have a desire to lessen and alleviate suffering following HSCT.²⁴

Research Implications

The schematic model of caregiving factors that influence PTG can guide further research advance the knowledge of how caregiving fits within existing PTG theory. Future work is needed to evaluate the relationship of PTG with additional aspects of caregiving after pediatric HSCT, including competence, meaning, satisfaction, and burden. This work lays a strong

foundation needed to support interventions to enhance parental PTG through caregiving after children's HSCT.

CONCLUSION

This study contributes to a deeper understanding about factors that influence parental caregiving after PTG. This study highlights caregiving activities that help parents react to and cope with the uncertainty and distress parents experience before and after HSCT. Our results show that healthcare experiences are influential in caregiver responses to the child's HSCT and subsequent ability to find PTG. Future work should focus on development of caregiving interventions that can positively affect parent reactions and coping to HSCT in ways that support PTG.

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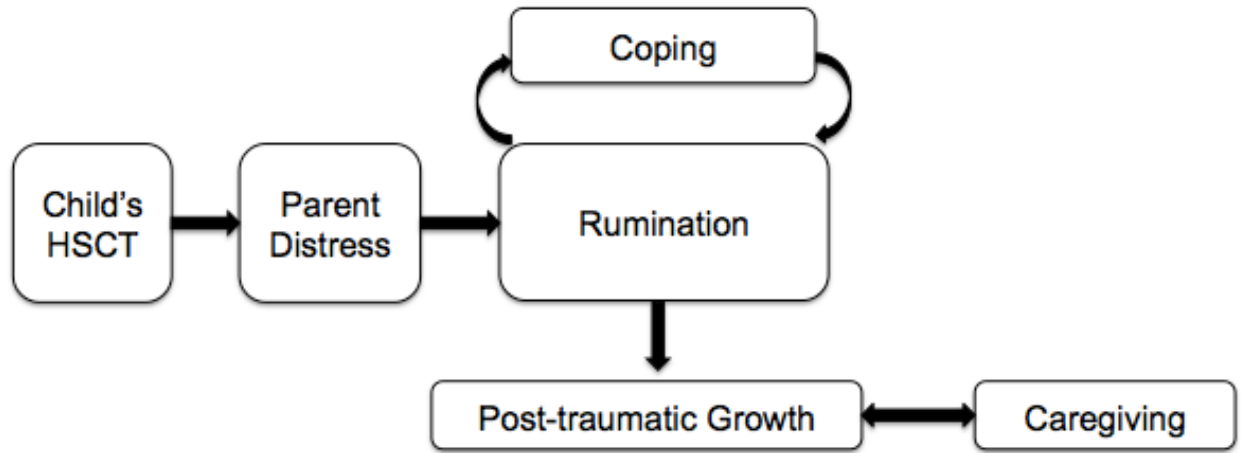


Figure 4. Parental PTG and caregiving conceptual framework.

Table 4. Qualitative interview guide

Parent Interview Questions
1. What was life was like caring for your child before you came for transplant?
2. How about after transplant, what was life like caring for your child over the last 100 days?
3. The first 100 days after a child's stem cell transplant are hard for many parents. What was this time like for you and how did you get through it?
4. What positive things have you experienced as a result of your child's transplant?
5. Based on everything you have shared with me, tell me how your child's nurses affected the transplant journey for you and your child? Is there anything your nurses could have done better?
6. When you think about what life looks like in the future, what do you envision?

Table 5. Parental PTG caregiving participant demographics

	N= 31 Median (IQR) Min, Max	
	Parent	Child
Age (years)	38 (33, 46.3) 24, 58	5.1 (1.2, 13.5) 0.5, 19.8
Gender	n (%)	
Male	3 (9.7)	14 (45.2)
Female	28 (90.3)	17 (54.8)
Ethnicity		
Hispanic	2 (6.5)	3 (9.7)
Non-Hispanic	29 (93.5)	27 (87.1)
Race		
White	22 (71)	20 (64.5)
Hispanic	2 (6.5)	2 (6.5)
Asian	6 (19.4)	6 (19.4)
Black	1 (3.2)	1 (3.2)
More than 1 race	-----	2 (6.5)
Parent Education	n (%)	
Less than high school diploma/GED	1 (3.2)	
High school diploma/GED	3 (9.7)	
Some College/Associate's Degree	7 (22.5)	
Bachelor's Degree	11 (35.5)	
Post-graduate Degree	9 (29)	
Marital Status		
Never Married	5 (16.1)	
Married	22 (71)	
Divorced/Separated	3 (9.7)	
Annual household income		
Less than \$49,999	8 (25.8)	
\$50,000-\$99,999	5 (20.8)	
\$100,000-149,999	3 (9.7)	
\$150,000 or more	8 (25.8)	
I'd rather not say	7 (22.6)	
Child's Disease		
Malignancy	9 (29)	
Hemoglobinopathy	3 (9.7)	
Metabolic Disorder	12 (38.7)	
Immune deficiency	5 (16.1)	
Bone marrow failure	2 (6.5)	
Time Since Child's Diagnosis		
Less than 1 year	21 (67.7)	
More than 1 to 3 years	8 (25.8)	
More than 3 years	3 (9.6)	

Table 6. Factors shaping caregiver Posttraumatic Growth (PTG) after pediatric hematopoietic stem cell transplant (HSCT)

Major Themes	Subthemes
Context	
Healthcare system	Nursing interactions
	Family Centered Care
	Hospital setting
	Other HSCT families
	Accommodations
Psychosocial factors	Family & friends
	Social isolation
	Vocational
	Activity limitation
	Financial
	Increased responsibility
Crisis reactions	
Cognitions	Cognitive load
	Confusion/shock
	Mental & physical fatigue
	Hypervigilance
	HSCT expectations
Social support	Family life
	Community
	Parent friendships
	Supportive & unsupportive behaviors
Affective response	Positive
	Gratitude
	Hope/optimism
	Relief
	Happiness
	Negative
	Fear/stress/anxiety
	Guilt
	Dread
	Anger/frustration
	Sadness/depression
Coping strategies	
Problem based	Task management
	Being present
	Clinical updates
	Infection prevention
	Information-seeking
	Situational Control

Emotion based	Avoidance
	Spiritual practice
	Mental boundaries
	Self-care behaviors
Cognitive	Acceptance
	Purpose of experience
	Positivity
	Compartmentalization
PTG outcomes	Relating to others
	New possibilities
	Personal strength
	Spiritual Change
	Appreciation of life/healthcare

Chapter 4

Summary of Findings, Implications, and Directions for Future Research

The purpose of this study was to explore parental PTG during the early recovery period following the child's HSCT. This study evaluated the relationships between PTG with parental and child characteristics, distress, rumination, and coping. Parental PTG and caregiving experiences were also explored. This chapter will summarize key findings and limitations from the study. Lastly, the implications and recommendations for future PTG research will be discussed.

Aim 1: Parent & Child Characteristics

The first aim of this study was to examine the associations of parent and child characteristics with parental PTG. This included parent characteristics of age, gender, ethnicity, education, and marital status in addition to environmental characteristics of the number of children in the home, the need to relocate for HSCT, and socioeconomic status. Characteristics of the child and HSCT recovery were child age, diagnosis, time since diagnosis, number of days hospitalized for the initial HSCT stay, number of hospital readmissions, presence of child graft versus host disease, and nursing care during hospitalization. The analyses showed that there were no statistically significant associations of parental PTG with any parent or child characteristics or demographic characteristics, however our qualitative work illustrated the ways in which nurses may support positive parental adaptation after the child's HSCT.

The findings from the qualitative content analysis conveyed the diverse ways nurses contributed to parental PTG after HSCT. Nurses provided education and guidance about the child's care after HSCT. Parent caregiver confidence in managing the child's care was a way parents reported gains in personal strength. Nurses offered parents emotional support, comfort,

and reassurance. These nursing actions promoted self-discovery that influenced appreciation for life and new life priorities. Parents developed great appreciation for healthcare and many had a desire to give back and help other parents through HSCT. Nursing support helped parents manage HSCT-related distress so parents could find joy in everyday moments and begin to envision a future for their child beyond HSCT.

Aim 2: Associations of PTG Concepts

The second aim of this study was to evaluate associations of parental distress, coping, and rumination with parental PTG. The positive correlation between PTG with measures of distress, disengagement coping, and rumination were statistically significant. Higher PTG scores were associated with higher measures of distress, rumination, and disengagement coping. The PTG dimension of appreciation of life had the strongest and most statistically significant positive association with measures of distress, disengagement coping, and rumination. There was an equally strong positive correlation between avoidance distress and deepened spirituality. A curvilinear relationship was found between measures of distress and rumination with PTG suggesting that there is a positive association between these concepts with PTG until there are high levels of distress or rumination. No statistically significant association was found between coping measures of primary control engagement coping (emotional expression, problem solving) or secondary control engagement (cognitive restructuring, positive thinking, acceptance).

Aim 3: Caregiving & PTG

The final aim of this study was to explore the role of parental caregiving experiences in parental PTG. Themes from the qualitative interviews provided insight on how parent caregiving experiences influence PTG. This lays a strong foundation for further development of a conceptual model that explains the relationship of caregiving with PTG. Parents are influenced

by both healthcare and psychological factors. In caring for the increased needs of the child and maintaining isolation, parents had limitations interacting with friends and family or participating in everyday activity. Parents also faced the financial impact of absence from work and, for some, relocation for the child's HSCT. The healthcare system alleviated some of the isolation through the interaction with nurses, the medical team, and other HSCT families. Parents found the healthcare system as the primary source of information, education on caring for the child, and emotional support. Family resources within the hospital and Ronald McDonald House restored parent self-care, social interaction, and a sense of normalcy.

Parents reacted to the need for HSCT and stressors associated with HSCT in a variety of ways. The ways parents reacted to HSCT was strongly influenced by parents' social support network. Spousal and family support was instrumental in parental emotional support and providing childcare both for children who received HSCT and other children in the home. Parents found some friendships strengthened while others dissolved when friends distanced themselves during the child's HSCT. Some parents found support in new friendships with other HSCT families. The broader community often alleviated the financial hardship through fundraising.

Cognitive responses of shock and confusion were more common approaching HSCT and were accompanied by feelings of anger, dread, and anxiety. Though there was a sense of relief after HSCT, parents reported hypervigilance and described immense mental and physical fatigue from worry, sleep deprivation, and caregiving responsibilities. Parents thought frequently about how their child's progress compared to normal HSCT recovery expectations. Parents experienced sadness, fear, and frustration due to uncertainty and unpredictability of the child's

recovery. However, this was countered by parents' ability to find happiness, gratitude, hope, and remain optimistic during the HSCT journey.

Parents coped with the child's HSCT using problem-based, emotion-based, and cognitive strategies. Parents were able to control HSCT distress and uncertainty by becoming knowledgeable about the HSCT recovery and complications, proficient in the child's medical care, and present in the moment to care for the child's needs. Parents found they could manage their emotions through spiritual practices, self-care, and setting mental boundaries. Some parents avoided negative emotions or thoughts about the future. Parents also found comfort accepting the uncontrollability of the child's recovery and finding purpose in the child's HSCT. These approaches also encouraged parents to compartmentalize distressing HSCT thoughts and focus on positive thoughts about the child's progress after HSCT.

Parents recognized PTG in each of the dimensions defined by Tedeschi and Calhoun's (1998) functional-descriptive framework. Areas of parental growth included increased appreciation of life, spiritual change, personal strength, ability to relate to others, and new life priorities. As a consequence of the child's HSCT journey, parents recognized deeper personal strength and stronger relationships with the child as well as friends and family. For some parents, there was a commitment to religious faith while other parents had more existential benefit in assigning meaning to difficult life events. Parents were able to self-reflect on what is most important to them in life and set new goals and priorities that aligned with these values. The most prominent area of growth was a general appreciation for life that allowed parents to find joy in simple everyday activities and express gratitude and admiration for healthcare and the providers and nurses who commit their lives to helping families through HSCT.

Summary of Results

This study was the first to examine parental PTG 100 days after HSCT. This time period is significant because most children have recovered from the most distressing symptoms of HSCT and have significantly less risk for life-threatening HSCT complications. This is accompanied by decreases in parental distress and caregiving responsibilities. This study describes the ways in which parents experience PTG in the early HSCT recovery period. No specific parent or child characteristic was associated with PTG. Rather it was the parent's responses and coping in the context of these characteristics that was influential in parent PTG. After HSCT, the parent's priority is the child. Unsurprisingly, parents manage distress and cope with the HSCT through the care they provide to the child. This connection provides a foundation to understand how nurses can support caregivers to manage distress, adaptively cope, and promote PTG.

Implications

Consistent with the functional-descriptive PTG theory, there is a relationship between distress, coping, and rumination with PTG. This study demonstrated that dimensions of PTG are present relatively soon after the child's HSCT when the healthcare team has frequent interaction with parents and are likely to influence parental PTG. Study limitations include the small sample size at a single institution, homogenous participant characteristics, and cross-sectional approach. Despite this, the study describes parental PTG among diverse child diagnoses treated with HSCT. The results also identify numerous opportunities for nurses to influence parent caregiver experiences and promote parent adaptation to HSCT through PTG.

Clinical practice implications. The results of the qualitative interviews highlight the impact nurses have on caregiving and shed light on the ways nurses can influence PTG. Nurses

can encourage caregiving confidence and competence through anticipatory guidance about HSCT expectations. Nurses should engage parents early in the hospital stay to learn about the child's complex medical care, such as dressing changes, intravenous medications, and parenteral and enteral nutrition. This anticipatory guidance helps parents manage fear, worry, and uncertainty. Nurses' abilities to relate to parents' experiences creates opportunities for them to screen for levels of distress, offer emotional support, and support adaptive coping strategies. These examples of how nurses can impact parental PTG demonstrate the need for nurses to study and develop interventions that alleviate caregiver distress, support adaptive coping, and nurture PTG.

Theoretical framework. The theoretical framework that guided this study evolved from components of Tedeschi and Calhoun's (1998) functional-descriptive model of PTG and synthesis of caregiving literature. The framework describes the relationships between distress, rumination and coping as the primary outcome of PTG. Caregiving was proposed as a secondary outcome having a bidirectional relationship with PTG. However, qualitative findings suggest that parental caregiving influences how parent distress, automatic and deliberate rumination, and coping give rise to PTG. Aspects of caregiving that are hypothesized based on the qualitative interviews to be important to the model include knowledge, competence, meaning, satisfaction, and burden. Therefore, the conceptual framework has been revised to represent five attributes of caregiving that are hypothesized to mediate the relationships between parental distress, automatic and deliberate forms of rumination, and coping with PTG (Figure 5).

Recommendations for Future Research

Future work is needed to quantitatively examine the associations among caregiving characteristics with distress, coping, rumination, and PTG. These characteristics include

caregiving knowledge, competence, meaning, satisfaction, and burden. The association between disengagement coping with PTG needs further exploration. Parents in this study described the ways in which religion and faith allowed them to surrender control and worry to God. Future research should explore the association between spiritual distress and coping with PTG to determine if this provides further insight into the disengagement coping found in this study.

Future longitudinal work can explore how changes in distress, coping, and rumination influence parental PTG 100 days after children's HSCT. It is anticipated that changes in these variables may be most notable during the pre-HSCT work-up evaluation, the day of HSCT infusion, the day of neutrophil engraftment, and the days following initial hospital discharge. Additional research is needed to understand if parental responses differ based on the children's HSCT diagnoses and prognoses. Furthermore, longitudinal work should also measure PTG changes beyond the child's acute recovery to better understand how PTG changes over time and how these changes affect caregiver psychological health and adaptation during the child's survivorship.

Future research should also explore similarities and differences in our quantitative and qualitative study results, particularly related to coping. A strength of study included use of both qualitative and quantitative approaches to measure coping as described within the study's conceptual framework based on Tedeschi and Calhoun's (1998) PTG model. Themes emerging from qualitative data included problem-based, emotion-based, and cognitive parental coping strategies that correspond to Lazarus and Folkman's transactional model of stress and coping (Lazarus, 1993). However, coping was operationalized quantitatively with the RSQ, which contrarily characterizes ways of coping as primary control engagement, secondary control engagement, and disengagement. A mixed methods approach could compare our qualitative and

quantitative data related to coping and advance our conceptual understanding related to coping in parents of children enduring HSCT.

Conclusions

This study provides important insight into the parental PTG 100 days after the child's HSCT. The results describe positive change in each of the five dimensions of PTG within the child's early recovery period. Neither children's nor parent's characteristics appear to influence PTG 100 days after HSCT. However, the findings lay the foundation for future research to understand how parent caregiving skills and attributes can affect PTG. This research is needed to guide development of nursing interventions to support parental PTG.

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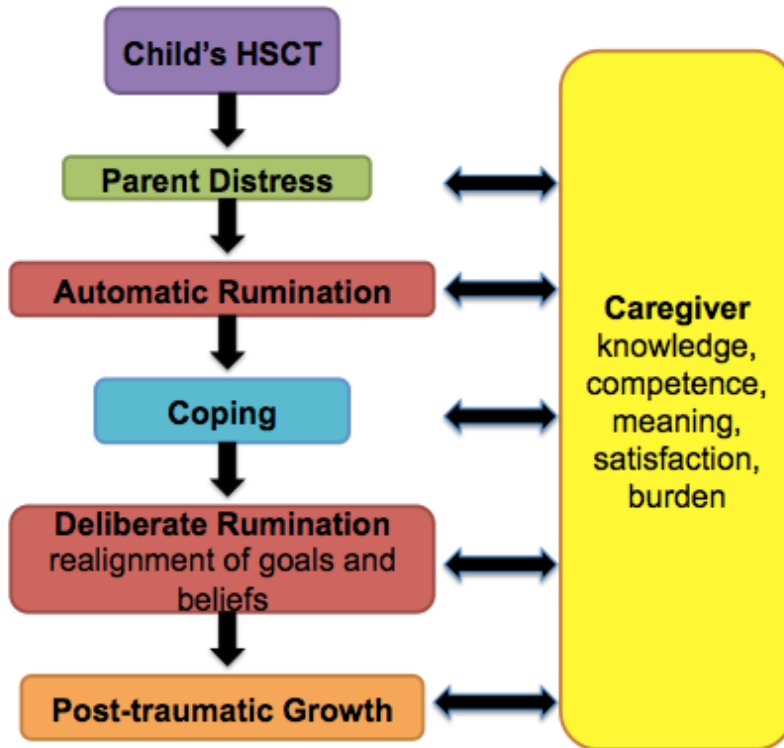


Figure 5. Revised conceptual framework for parental PTG after pediatric HSCT