

End-of-Life-Related Factors Associated with Posttraumatic Stress and Prolonged Grief in Parentally Bereaved Adolescents

OMEGA—Journal of Death and Dying

0(0) 1–13

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DOI: 10.1177/0030222820963768

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Abstract

Posttraumatic stress disorder (PTSD) and prolonged grief disorder (PGD) are well-documented in parentally bereaved adolescents. Whether or not the parent's death is perceived as traumatic may be influenced by several end-of-life-related factors. This study aimed to examine the associations between end-of-life-related factors, symptoms of posttraumatic stress disorder (PTSD), symptoms of prolonged grief disorder and PGD, and the association between PTSD and PGD. Mann-Whitney U tests and Spearman correlation were used to analyze the relationships between end-of-life-related factors, PTSD, and PGD. Regretting one's decision to be present or not present at the time of death resulted in a significant difference in self-reported scores for PTSD, but not PGD.

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Keywords

bereaved adolescents, prolonged grief, posttraumatic stress, regret, end-of-life-related factors

Posttraumatic stress disorder (PTSD) and prolonged grief disorder (PGD) have been well-documented in adolescents who have lost a parent under traumatic circumstances, such as suicide, a natural disaster, or an accident, as well as after a natural death (Boelen & Spuij, 2013). Watching a parent die of prolonged illness may be traumatic for an adolescent, as they are often repeatedly exposed to many potentially traumatizing stimuli, such as witnessing distress in family members, exposure to graphic medical procedures, anticipation of the death, and seeing the parent die both physically and in mental representations in anticipation of or following the parent's death (Kaplow et al., 2012). McClatchey and Vonk (2005) and McClatchy et al. (2009) found that approximately two-thirds of bereaved adolescents experienced moderate to severe levels of PTSD symptoms. There was no difference in the prevalence of PTSD between adolescents who experienced the sudden, unexpected death of a family member and adolescents who experienced the expected death of a family member following protracted illness (McClatchey & Vonk, 2005; McClatchy et al., 2009).

Most adolescents adjust to the death of a parent without complication and their grief dissipates over time (McClatchy et al., 2009; Shear, 2012; Worden, 1996). In some cases, grief can become complicated or prolonged. Prolonged grief disorder is characterized by a sense of disbelief that the death happened, feelings of anger, guilt, or bitterness, prolonged intense yearning, intense painful emotions, rumination, catastrophizing, and avoidance of reminders of the loss (Shear et al., 2011). Increased suicidal ideation and impairments in health and quality of life are common symptoms of PGD for adolescents (Spuij et al., 2013). Boelen et al. (2019) found that 12.4% of children and adolescents met the criteria for a probable diagnosis of PGD following the death of a parent or sibling, with no difference being found between those who had lost a parent or sibling due to illness and those who had lost a parent or sibling unexpectedly. Reactive distress symptoms in PGD largely overlap with PTSD symptoms such as disbelief, emotional numbness, avoidance, and difficulty trusting others to name a few although the two disorders can develop simultaneously. Identifying whether an adolescent is experiencing symptoms related to PTSD, PGD or both, may help clinicians who are working with bereaved adolescents to better understand which symptoms have developed and how best to treat them (Cohen & Mannarino, 2016) therefore, more research is needed to better understand what factors may lead to the development of PTSD, PGD or both.

Several end-of-life-related factors, including experiencing negative life events prior to losing a parent, perceiving the illness or death as traumatic, the relationship to the deceased, the perceived quality of caregiving and dying experience, preparedness for the death, and the surviving parent's reaction to the illness and death, have been identified as risk factors for the development of psychological health problems such as PTSD and PGD in adolescents (Brown et al., 2008; Hamblen & Barnett, 2006; Lobb et al., 2010). Whether the parent's death is perceived as traumatic or not may, in turn, be influenced by end-of-life-related factors, such as experiencing that the parent had pain or suffering, not being able to say goodbye in a way that was meaningful to the adolescent, and the adolescent's level of understanding that the parent would die. Physical proximity, such as visiting a sick parent in the hospital, being present at the time of death, or being present for the funeral, may also affect the adolescent's psychological wellbeing (Salloum, 2015; Worden, 1996).

While the literature provides evidence that end-of-life-related factors may affect adolescent wellbeing following the death of a parent, it is still unclear how factors related to a parent's illness, care, and death may affect an adolescent's psychological health. This study therefore aimed to examine the associations between factors related to the end of a parent's life as experienced by an adolescent and the adolescent's self-reported symptoms of posttraumatic stress and prolonged grief. A secondary aim of this study was to examine the association between symptoms of posttraumatic stress and prolonged grief in adolescents.

Methods

Participants

Self-reports were collected from 23 adolescents, aged 12–20 years, who were identified by Statistics Sweden, using the Swedish National Causes of Death Register and Multi-Generational Register, as the surviving offspring of individuals who died of cancer between 2013 and 2015. Participating adolescents had to reside in Stockholm County with their surviving parent during data collection and understand written Swedish.

Procedure

The study was approved by the Regional Ethics Committee, ref. no 2016/1192–31/1. Potential participants were sent information about the study by Statistics Sweden. The information letter included brief information about the study, a link to a website where they could sign up for the study, and contact information for the research group. As the letters were sent out by Statistics Sweden, the research group did not have access to the families' contact information and were

therefore unable to contact potential participants unless they signed up for the study. If families chose to participate, they visited to the website, provided their contact information, indicated how many children they had, and confirmed that they gave informed consent for their family's participation. In accordance with Swedish law, adolescents aged 15 years and older could give consent for participation even if their parent did not. A link to the questionnaire was sent to the email address provided when a family/adolescent signed up for the study. If families preferred to participate using a paper questionnaire, they could request that one be sent through post by the research team. If an adolescent did not fill out their questionnaire within two weeks, a reminder e-mail was sent.

Measurements

Study-Specific Questionnaire. The study-specific questionnaire covered demographics, questions about care, and family-related factors during the ill parent's last month of life. It was developed based on nine interviews conducted with four parents whose partners had died, two adult and three minor children who had been recruited from two palliative care centers following the death of a parent. A preliminary version of the questionnaire was distributed to colleagues for written feedback regarding the language used and the relevance of each question which helped to ensure content validity of the questionnaire (Charlton, 2000). The questionnaire had also been validated face-to-face with three bereaved parents, four parentally bereaved children, and one parentally bereaved adolescent who could choose to validate the questionnaire through interviews using a think aloud methodology, i.e. talking out loud about how they understand and perceive the questions, or by reading the questionnaire and writing comments concerning each of the questions in order to ensure the questions have been understood as intended by us as researchers and able to respond to by the potential participant. Questions analyzed in this study included: Did you lose your mother or father? Did you experience that your parent suffered or was in pain during their last month of life? Did you understand that your parent would die? Were you physically present when your parent died? Do you regret your decision to be present/not present at the time of your parent's death? Did you say goodbye to your parent in a way that was meaningful to you? Two validated instruments were also included to assess adolescents' self-reported symptoms of posttraumatic stress and prolonged grief.

Prolonged Grief. The Prolonged Grief Disorder-13 Child (PG-13 Child) was completed by adolescents to assess prolonged grief symptomology. The PG-13 Child is based on the PG-13 for adults (Pohlkamp et al., 2018; Prigerson et al., 2009) and is comprised of 13 items, including two on duration and impairment which are answered "yes" or "no." Items 1, 2, 4, and 5 are rated on a 5-point scale measuring frequency of symptoms with answers ranging from "not at all" to "several times a

day” and items 6–12 measure intensity of symptoms on a five-point scale with answers ranging from “not at all” to “overwhelming.” The PG-13 child total score used in this study is a continuous measure calculated by adding up the symptom items, and ranges from 11 to 55 with a score of 33 or higher indicating possible prolonged grief disorder. The PG-13 Child was translated into Swedish by the National Centre of Disaster Psychiatry at Uppsala University in 2017. Internal consistency for the PG-13 child in the current study was high, $\alpha = 0.82$.

Posttraumatic Stress (CPSS-5). The child posttraumatic stress scale for DSM-5 (CPSS-5) is a self-report instrument designed for children aged 8–18 years. It aids in the diagnosis of PTSD by providing an estimate of symptom severity and is comprised of 27 items measuring PTSD symptoms and functional impairment. Evaluation of the psychometric properties of CPSS-5 has showed high internal consistency, test-retest reliability, divergent validity, and convergent validity (Foa et al., 2018). According to the scoring instructions for CPSS-5, scores in the range 0–10 indicate minimal symptom levels, 11–20 mild, 21–40 moderate, 41–60 severe and 61–80 very severe symptom levels. A score of 31 has been identified as a cut-off score indicating probable PTSD. The first twenty items related to the frequency and intensity of symptoms were included in this study, with high internal consistency, $\alpha = 0.83$.

Analysis

Descriptive statistics are reported regarding demographic characteristics. A description of how response alternatives were dichotomized can be found in Table 1.

Mann-Whitney U tests were conducted for differences in PTSD and PGD symptomology for various groups including deceased parent gender and responses to yes/no single-item questions such as: Were you present at the time of death? Do you regret your decision to be present/not be present at the time of death? Did you understand that your parent would die? Did you experience that your parent was suffering or in pain? Were you able to say goodbye to your parent in a way that was meaningful for you?

Due to the small sample size, Spearman correlation was chosen to analyze the relationships between adolescent age, time since death, PGD symptomology, and PTSD symptomology. Analyses were conducted using IBM SPSS version 22.

Results

Participant Characteristics

Self-reports were collected from 23 adolescents aged 12–20 years, 15 girls and 8 boys, with a mean age of 16.2 years ($SD = 1.88$) and mean time since loss of

2.9 years ($SD = 0.91$). Of the 23 adolescents, 21 were attending school, one was working, and one was unemployed. Frequencies of response alternatives for the single-item questions can be found in Table 1.

Mean score for PTSD was 19.69 ($SD = 10.86$) and mean score for PGD was 23.86 ($SD = 7.36$). Five adolescents reported scores above the cut-off for PTSD and three reported scores above the cut-off for PGD. All three adolescents who scored above the cut-off for PGD also rated their symptom levels above the cut-off for PTSD. Thirteen adolescents scored in the moderate symptom level range for PTSD.

Table 1. How Response Alternatives Were Dichotomized for Analysis.

Question	Response alternative 1	n	Response alternative 2	n
Which of your parents died?	• Mom	7	• Dad	16
Did you experience that your parent suffered or was in pain during their last month of life?	• No	3	• Yes, a little ($n = 5$) • Yes, somewhat ($n = 6$) • Yes, a lot ($n = 6$)	17
Did you understand that your parent would die?	• Yes	14	• No	6
Were you present when your parent died?	• No, and I don't regret it ($n = 3$) • No, and I regret it ($n = 3$) • No, and I'm unsure if I regret it or not ($n = 4$)	10	• Yes, and I don't regret it ($n = 11$) • Yes, and I regret it ($n = 1$) • Yes, and I'm unsure if I regret it or not ($n = 1$)	13
Do you regret your decision to be present/not present at the time of your parent's death?	• Not present and I regret it ($n = 3$) • Present and I regret it ($n = 1$)	4	• Not present and I don't regret it ($n = 3$) • Present and I don't regret it ($n = 11$)	14
Did you say goodbye to your parent in a way that was meaningful to you?	• No	11	• Yes, before my parent died ($n = 4$) • Yes, after my parent died ($n = 0$) • Yes, both before and after my parent died ($n = 8$)	12

End-of-Life-Related Factors, PTSD, and PGD

Mann-Whitney U tests were conducted between adolescent total score for symptoms of PTSD and single-item questions (Table 2). Adolescents who regretted their decision to be present or not present at the time of their parent's death reported more symptoms related to PTSD than adolescents who did not ($U = 8.00$, $N_1 = 4$, $N_2 = 14$, $p = 0.035$, two-tailed). There was no significant difference in PTSD scores between adolescents who were unsure if they regretted their decision or not and adolescents who regretted or did not regret their decision.

There was no significant difference in PTSD symptoms for being present versus not present at the time of death, having lost a mother versus father, having understood versus not having understood that the parent was going to die, experiencing versus not experiencing that the parent had suffered, or having said goodbye to the parent in a way that was meaningful to the adolescent versus not having done so. There was no significant difference in PGD symptoms for responses to any of the single-item questions.

Symptoms of PTSD were positively associated with symptoms of PGD, indicating that adolescents with more PTSD symptoms also had more symptoms related to PGD ($r_s = 0.688$, $p < 0.000$). There was no association between PTSD or PGD and adolescent age or time since loss (Table 3).

Discussion

Regretting one's decision to be present or not present at the time of the parent's death was the only end-of-life-related factor associated with symptoms of

Table 2. Mann-Whitney U (p Value) for PTSD, PGD, and Single-Item Questions.

	PTSD			PGD		
	N1	N2	U (p)	N1	N2	U (p)
Physically present at time of death	10	13	56 (0.60)	10	13	37 (0.08)
Regrets decision to (not) be present at time of death	4	14	8 (0.035)*	4	14	24 (0.72)
Deceased parent gender	7	16	44.5 (0.45)	7	16	55.5 (0.97)
Understood the parent would die	14	6	37 (0.71)	14	6	41 (0.96)
Adolescent gender	15	8	45.5 (0.39)	15	8	35.5 (0.11)
Witnessed pain and suffering	6	17	36.5 (0.31)	3	17	15.5 (0.305)
Said goodbye to parent in a meaningful way	11	12	46 (0.23)	11	12	66 (1.00)

N1 and N2 represent the dichotomized response alternatives. PTSD: symptoms of post-traumatic stress disorder; PGD: symptoms of prolonged grief disorder.

* $p < .05$.

Table 3. Spearman Correlation Coefficient (p Value)
Between PTSD, PGD, Age, and Time Since Death.

	PTSD	PGD
Age	−0.314 (0.14)	−0.136 (0.53)
Time since death	−0.109 (0.64)	−0.236 (0.31)
PTSD	I	0.688 (<0.00)*
PGD	0.688 (< 0.00)*	I

PTSD: symptoms of post-traumatic stress disorder; PGD: symptoms of prolonged grief disorder.

* $p < .05$.

PTSD. None of the end-of-life-related factors resulted in a significant difference in self-reported scores for symptoms of PGD. There was a significant positive correlation between symptoms of PTSD and PGD and all three adolescents who scored above the cut-off for PGD also scored above the cut-off for PTSD. There was no association between PTSD or PGD and adolescent age or time since loss.

Regretting having been physically present or not at the time of death was associated with more symptoms of PTSD, but not PGD. The responsibility of choosing to see the parent or not, during the late stages of the illness, at the time of death, or following the death, is potentially guilt-inducing (Saldinger et al., 2003). In the present study, we found that three adolescents regretted not being present at their parent's death, and one regretted being present. It remains unclear to us if the adolescents made their decisions on their own or with the help of one of their parents or another trusted adult. Saldinger et al. (2003) suggested that parents should help their child or adolescent to make decisions regarding the level of exposure to illness and dying-related stimuli, including the dying parent, as parental involvement helps the child understand the circumstances and consequences of their decision and may help mitigate the guilt associated with making difficult decisions on their own. At the same time, it can be difficult to predict the time of death and therefore other circumstances may have influenced or even dictated whether an adolescent was present or not present when their parent died. Furthermore, adolescents may feel guilty because they are unable to tolerate exposure to the graphic stimuli associated with death and dying, such as seeing their parent suffer or die, which may lead to traumatic stress (Saldinger et al., 2003). Guilt is considered to be a common feature of PTSD, especially with repeated trauma or repeated exposure to trauma-related stimuli, which is likely in the case of parentally bereaved adolescents. Boelen et al. (2019) found that 11.7% of bereaved children and adolescents reported feelings of guilt. While we have not specifically measured guilt in this study, several theoretical and clinical models implicate guilt in the development of PTSD (Browne et al., 2012; Kaplow et al., 2012; Marx et al., 2010; Pugh et al., 2015). We may therefore be able to infer that at least some of

the adolescents were experiencing feelings of guilt. These studies, however, do not provide answers regarding the direction or nature of this mediating effect (Pugh et al., 2015). More research on guilt and PTSD in bereaved adolescents may lead to important areas of focus for clinicians working with this population.

While the majority of adolescents had scores under the cut-off for PTSD and PGD, their scores did indicate that they might, on average, be experiencing mild to moderate symptom levels of PTSD and PGD. Thirteen adolescents scored in the moderate symptom level range for PTSD. This may indicate that while the majority of adolescents who participated in this study did not meet the full diagnostic criteria for PTSD, over half of them were likely experiencing a moderate level of PTSD symptoms. Similarly, while most adolescents scored under the cut-off of 33 points, which indicates a possible diagnosis of PGD, a mean score of 23.86 does indicate that the adolescents had many symptoms of PGD. Our results also showed that symptoms of PTSD were positively associated with symptoms of PGD, indicating that adolescents with more PTSD symptoms also had more symptoms related to PGD. Boelen et al. (2019) found that bereaved children and adolescents reported a mean score of 13.64 on CPSS-5, with those who met the criteria for a possible PGD diagnosis having a mean score of 25.03 on CPSS-5.

The lack of association between PTSD or PGD and most of our single-item questions may indicate that individual-related or family-related factors are more relevant to the development of PTSD or PGD in adolescents. Saldinger et al. (2003) recommended that parents be encouraged to assume that their child will be overwhelmed by their exposure to their parent's impending death and therefore actively normalize a wide range of emotional and behavioral reactions to illness and death using open communication. Opening up a line of communication with the adolescent may also help the adolescent feel they have an opportunity to share any thoughts and feelings that they may have surrounding their parent's illness and death (Saldinger et al., 2003).

Strengths and Limitations

A strength of this study was the use of adolescent self-report questionnaires. While our results had a high level of statistical significance, they may not be generalizable to all adolescents who have lost a parent to cancer, due to the small sample size. These results should therefore be replicated in larger studies. Specific guidelines from The National Board of Health and Welfare and Statistics Sweden did affect our ability to recruit participants, as families with separated or divorced parents and adolescents who had moved out of the family home were excluded from participating. The fact that participants had to actively contact the research group in order to participate may have affected the response rate and led to a biased sample, which included only those families

already possessing adequate coping skills and possibly in better psychological health.

Another limitation of the study is that we did not have information on the family members' history of psychological health prior to the loss. Hence, we do not know if they had developed psychological health problems or symptoms prior to the parent's illness and death. Another limitation is a lack of information regarding additional stressors, such as other losses and financial problems in the families, which may have affected psychological health.

Conclusions

This study adds to the current literature on adolescent psychological health following the death of a parent to cancer by identifying regret as a potentially important factor associated with the development of PTSD symptoms. Other factors, such as being present at the time of death or having understood that the parent was dying, were not found to be associated with PTSD symptomology. In addition, there was no relationship found between any of these factors and PGD. While the sample is small, results were significant and therefore future studies should aim to examine the role of regret and other guilt cognitions in the development of psychological health problems in parentally bereaved adolescents and their families.

The significant correlation between PTSD and PGD adds to the evidence that PTSD and PGD are separate but related disorders likely influenced by different factors (Brown et al., 2008; Melhem et al., 2007). The adolescent self-reported scores for PTSD and PGD indicated that adolescents were experiencing symptoms of both PTSD and PGD, adding to the evidence that the death of a parent from cancer may be a traumatic experience for adolescents.


Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by The Kamprad Family Foundation, grant #20150044, Gålö Foundation, The Erling-Persson Family Foundation, and Ersta Sköndal Bräcke University College.

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Megan Weber Falk, PhD, MSc, received her PhD in Palliative Care from Ersta Sköndal Bräcke University college in February 2020. Her research was inspired by her clinical work as a mental health counselor working with children and families and focuses on the psychological health of children and adolescents in families where a parent has died from Cancer. She is also the creator of The Grief and Communication Family Support Intervention.

Anette Alvariza, PhD, RN, is a professor in the Department of Health Care Sciences at Ersta Sköndal Bräcke University College in Stockholm Sweden, Palliative Research Center. She also works as a care development manager at a specialist palliative care unit. Her research focuses mainly on interventions aiming to support families in palliative care. She has contributed to the development and evaluation of interventions which have been shown to be effective

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Ulrika Kreicbergs, PhD, RN, holds a professorship in palliative care for children and youth at Ersta Sköndal Bräcke University College and is also associated with Karoliska Institutet in Stockholm, Sweden. Her clinical work in pediatric oncology led to her research on children and families affected by cancer. Her work has been acknowledged worldwide and she has continued her research in the field of palliative care. Her work is focused on factors in health care that can be modified or avoided to reduce suffering and therefore enhance quality of life for children and their families.

Josefin Sveen, PhD, is an associate professor in medical psychology at the Department of Neuroscience, Psychiatry at Uppsala University and in the Department of Health Care Sciences Palliative Research Center at Ersta Sköndal Bräcke University College in Sweden. Her research focuses on psychosocial aspects of trauma and loss, including posttraumatic stress and prolonged grief. In her research she has evaluated psychosocial interventions for children and adults who have experienced a trauma and/or loss of a family member.