

## Follow-Up Study of Complicated Grief among Parents Eighteen Months after a Child's Death in the Pediatric Intensive Care Unit

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### Abstract

**Objective:** We previously demonstrated that parents whose children die in a pediatric intensive care unit (PICU) have a high level of complicated grief symptoms 6 months after the death. In this study, we investigate the change in the extent of complicated grief symptoms among these parents between 6 and 18 months postdeath and identify factors predicting improvement.

**Methods:** One hundred thirty-eight parents of 106 children completed surveys at 6 and 18 months. Surveys included the Inventory of Complicated Grief (ICG), measures of grief avoidance, attachment, caregiving and social support, and demographics. Multivariable analysis was performed using generalized estimating equations to identify characteristics independently associated with improvement in ICG score.

**Results:** ICG scores were  $33.4 \pm 13.6$  at 6 months and  $28.0 \pm 13.5$  at 18 months, representing an improvement in ICG score of  $5.4 \pm 8.0$  (95% confidence interval [CI] 4.1–6.8,  $p < 0.001$ ). Variables independently associated with greater improvement in ICG score included traumatic death and greater grief avoidance. Variables independently associated with less improvement included being the biological parent and having more responsive caregiving. Parents with one or two surviving children had more improvement in ICG score than those with no surviving children whereas parents with three or more surviving children had less improvement.

**Conclusion:** Complicated grief symptoms decrease among parents between 6 and 18 months after their child's death in the PICU; however, high symptom levels persists for some. Better understanding of the trajectory of complicated grief will allow parents at risk for persistent distress to receive professional support.

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## Introduction

**A**CUTE GRIEF following the death of a loved one is often intensely painful but usually diminishes over time as the loss becomes integrated into ongoing life. Complicated grief, in contrast, is characterized by persistent separation distress and aspects of a chronic stress response syndrome.<sup>1-4</sup> Symptoms include intense yearning for the deceased, shock and disbelief, anger and bitterness, and intrusive or preoccupying thoughts of the deceased that last more than 6 months after the death and interfere with daily functioning. Complicated grief has recently been proposed as a new diagnostic entity to be included in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*.<sup>3,4</sup>

Research suggests that bereaved parents are at increased risk for complicated grief and other psychiatric conditions.<sup>5-8</sup> In a recent study conducted across seven U.S. children's hospitals affiliated with the National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network (CPCCRN), we found that parents whose children died in a pediatric intensive care unit (PICU) had a high level of complicated grief symptoms 6 months after their child's death.<sup>9</sup> Risk factors for complicated grief among these parents included being the child's biological mother or female guardian, trauma as the cause of death, and psychosocial factors such as insecure attachment styles and greater grief avoidance.

Little is known about the trajectory of complicated grief among parents. Bereaved parents are at increased risk of first time psychiatric hospitalization up to 5 years after their child's death.<sup>5</sup> Bereaved fathers have increased mortality from unnatural causes up to 3 years, and bereaved mothers up to 18 years after their child's death.<sup>6</sup> In this follow-up study, we investigate the change in the extent of complicated grief symptoms among parents between 6 and 18 months after their child's death in the PICU and identify factors predicting improvement in complicated grief symptoms 18 months postdeath.

## Methods

### Study design

The study is an 18-month follow-up survey of parents who participated in a survey 6 months after their child's death in one of seven PICUs affiliated with the CPCCRN.<sup>9</sup> The study was approved by the Institutional Review Board at each site.

### Participants

Parents of 872 children who died in a PICU between January 1, 2006 and June 30, 2008 were asked to complete a survey 6 months after their child's death. Of these, 264 parents of 197 children completed a 6 month survey. Three surveys were excluded due to missing data. All respondents were asked if they could be contacted again for future research participation; those who agreed were sent a follow-up survey 18 months after their child's death.

### Data collection

Parents completed 18-month follow-up surveys using methods described previously.<sup>9</sup> Parents were sent mailed surveys in English or Spanish depending on their primary

language. If surveys were not returned within 1 month, telephone contact was attempted to offer the option of completing the survey by phone. If the household was successfully contacted by phone but the survey was not completed, the parent was categorized as refusing to participate. If the household could not be contacted by phone after three or more attempts, the parent was categorized as unable to locate.

Surveys administered at 6 months requested information on parent age, gender, race/ethnicity, marital status, relationship to the deceased child (i.e., biological parent or legal guardian), number of surviving children, and deceased child's age and cause of death.<sup>9</sup> Surveys at 6 months included the Inventory of Complicated Grief (ICG),<sup>10</sup> the Grief Avoidance Questionnaire (GAQ),<sup>11</sup> the Relationship Scales Questionnaire (RSQ),<sup>12</sup> the Caregiving Questionnaire (CQ),<sup>13</sup> and the Social Support Questionnaire-Short Form (SSQ-SF).<sup>14</sup> Surveys administered at 18 months included the ICG and the GAQ only. For all survey measures, the score was calculated based on available data if at least 60% of the items were completed.

### Description of instruments

The ICG is 19-item instrument that measures the extent of complicated grief symptoms.<sup>10</sup> Respondents report the frequency with which they currently experience the emotional, cognitive and behavioral states described in the items. Responses are reported on a 5-point scale ranging from 0 ("never") to 4 ("always"). Item responses are summed to obtain total scores ranging from 0-76. Higher scores indicate more complicated grief symptoms. Scores greater than 30 at least 6 months after a death have been used to indicate complicated grief.<sup>15</sup>

The GAQ is a 7-item instrument that assesses three avoidance behaviors (i.e., avoiding thinking about, talking about, and expressing feelings about the deceased) in two contexts (i.e., with close family members and with close friends).<sup>11</sup> The avoidance of thinking about the deceased is also phrased for respondents being alone. Respondents report the frequency with which they had experienced each item in the past month on a 5-point scale ranging from 1 ("almost never") to 5 ("almost constantly"). Item responses are summed to obtain total scores ranging from 7-35. Higher scores indicate more grief avoidance.

The RSQ is a 30-item instrument that assesses adult attachment style.<sup>12</sup> Respondents rate the extent to which each item describes their characteristic style in close relationships. Responses are rated on a 5-point scale ranging from 1 ("not at all like me") to 5 ("very much like me"). Factor analysis with varimax rotation was performed to derive subscales for two underlying dimensions corresponding to attachment-related anxiety (11 items) and attachment-related avoidance (7 items). Internal reliability of each subscale was acceptable as demonstrated by Cronbach  $\alpha$  (0.88 and 0.73, respectively). Subscales are scored as the mean of the responses for the items included in the subscale. Scores for each subscale range from 1-5; higher subscale scores indicate more attachment-related anxiety or avoidance, respectively.

The CQ is a 32-item instrument that assesses caregiving style.<sup>13</sup> Respondents rate the extent to which each item describes their characteristic style of responding to and caring for romantic partners. Responses are rated on a 6-point scale ranging from 1 ("not at all descriptive of me") to 6 ("very

descriptive of me”). Two subscales are scored corresponding to responsive and compulsive caregiving.<sup>16</sup> Subscales are scored as the mean of the responses for the items included in the subscale. Scores for each subscale range from 1–6; higher subscale scores indicate more responsive or compulsive caregiving, respectively.

The SSQ-SF is a 6-item instrument that assesses availability of social support and satisfaction with social support.<sup>14</sup> For each item, respondents list the people that are available for help (i.e., 0–9 people) in the manner described, and rank their degree of satisfaction with that support on a 6-point scale ranging from 1 (“very dissatisfied”) to 6 (“very satisfied”). Two subscales are scored corresponding to availability and satisfaction. Subscales are scored as the mean of the responses for the items included in the subscale. Scores for the availability subscale range from 0–9, and for the satisfaction subscale from 1–6. Higher subscale scores indicate greater social support availability and satisfaction, respectively.

**Statistical analysis**

We compared those who did and did not respond to the 18-month survey based on characteristics reported in the 6-month survey. Responders included individuals who completed both 6- and 18-month surveys; nonresponders included those who refused future contact from the investigators and those who agreed to future contact but did not complete the 18-month survey. Categorical variables were summarized as number and percentage and continuous variables were summarized as mean ± standard deviation, reported separately for responders and nonresponders. The statistical significance of differences between the two groups was assessed based on the  $\chi^2$  test for categorical variables and the Wilcoxon rank-sum test for continuous variables. All subsequent analyses were restricted to those who completed both 6- and 18-month surveys.

Change in ICG and GAQ scores was evaluated using a paired *t* test. The change in the proportion of individuals with ICG scores greater than 30 was evaluated using McNemar’s test. For each baseline (i.e., 6 month) characteristic, we described the mean ± standard deviation of the ICG score at both time points and the improvement from 6 to 18 months with 95% confidence intervals. Relationships between ICG scores and other survey measures were summarized using Pearson correlations.

Associations between each baseline characteristic and improvement in ICG score were evaluated in univariable analyses. Variables with *p* < 0.25 were considered for inclusion in the multivariable model. The final model was determined using backward variable selection with a significance level to stay of 0.10. Results are described as effect estimates and 95% confidence intervals. Generalized estimating equations (GEE) were used to assess the statistical significance of both univariable and multivariable associations. This approach accounts for correlation in responses when both of the child’s parents completed surveys. Since the outcome is continuous, the GEE results are analogous to those obtained from a linear regression model.

**Results**

Of the 197 families participating at 6 months, 172 agreed to future participation and were sent follow-up surveys. One or

both parents from 62% of families responded to the survey, 10% of families refused and 28% could not be located. A total of 138 surveys were collected from 106 families. Seventy-eight percent of surveys were completed in English by mail, 12% in English by phone, 9% in Spanish by mail and 1% in Spanish by phone.

Parents who responded to the follow-up survey were more likely to be married than were nonresponders (Table 1). Responders were similar in age to non-responders (38.0 ± 10.1 years versus 36.4 ± 9.7 years) and in age of their children at time of death (5.8 ± 6.6 years versus 5.3 ± 6.7 years). Responders and non-responders reported a similar extent of complicated grief symptoms 6 months after the death as reflected by ICG scores (Table 2). Scores on other survey measures at 6 months were also similar between responders and nonresponders.

Parents who responded to the follow-up survey had ICG scores of 33.4 ± 13.6 at 6 months after the child’s death and 28.0 ± 13.5 at 18 months, representing an improvement (i.e., decrease) in ICG score of 5.4 ± 8.0 (95% CI 4.1–6.8, *p* < 0.001). ICG scores were greater than 30 for 82 (59%) parents at 6

TABLE 1. SURVEY RESPONSE RATES BY PARENT AND CHILD CHARACTERISTICS

	Responders (n, %)	Nonresponders (n, %)	p
Parent gender			
Male (n = 80)	37 (46.3)	43 (53.8)	0.15
Female (n = 179)	100 (55.9)	79 (44.1)	
Race/ethnicity			
White (n = 162)	94 (58.0)	68 (42.0)	0.12
Black (n = 40)	15 (37.5)	25 (62.5)	
Hispanic (n = 41)	20 (48.8)	21 (51.2)	
Other (n = 12)	7 (58.3)	5 (41.7)	
Marital status			
Married (n = 182)	110 (60.4)	72 (39.6)	<0.001
Not married (n = 75)	26 (34.7)	49 (65.3)	
Education			
High school or less (n = 72)	34 (47.2)	38 (52.8)	0.27
Some college (n = 85)	43 (50.6)	42 (49.4)	
College (n = 100)	59 (59.0)	41 (41.0)	
Biological parent			
Biological (n = 233)	118 (50.6)	115 (49.4)	0.07
Nonbiological (n = 26)	18 (69.2)	8 (30.8)	
Number of other children			
None (n = 39)	21 (53.8)	18 (46.2)	0.71
One (n = 84)	41 (48.8)	43 (51.2)	
Two (n = 69)	36 (52.2)	33 (47.8)	
Three or more (n = 65)	38 (58.5)	27 (41.5)	
Child gender			
Male (n = 139)	79 (56.8)	60 (43.2)	0.19
Female (n = 121)	59 (48.8)	62 (51.2)	
Cause of death			
Cardiac (n = 67)	37 (55.2)	30 (44.8)	0.35
Sepsis/multiple organ failure (n = 41)	21 (51.2)	20 (48.8)	
Neurologic (n = 32)	17 (53.1)	15 (46.9)	
Malignancy (n = 29)	18 (62.1)	11 (37.9)	
Respiratory failure (n = 29)	17 (58.6)	12 (41.4)	
Trauma (n = 17)	11 (64.7)	6 (35.3)	
Other (n = 34)	12 (35.3)	22 (64.7)	

TABLE 2. SIX-MONTH SURVEY MEASURES FOR RESPONDERS AND NONRESPONDERS TO THE EIGHTEEN-MONTH FOLLOW-UP SURVEY

	Responders (n = 138) (mean ± SD)	Nonresponders (n = 123) (mean ± SD)	p
Inventory of Complicated Grief	33.4 ± 13.6	34.1 ± 14.6	0.69
Grief Avoidance Questionnaire	12.3 ± 6.1	13.5 ± 6.3	0.12
Relationship Scales Questionnaire			
Attachment-related anxiety	2.3 ± 0.9	2.5 ± 1.0	0.16
Attachment-related avoidance	3.0 ± 0.8	2.9 ± 0.8	0.69
Caregiving Questionnaire			
Responsive caregiving	4.4 ± 0.9	4.4 ± 0.9	0.81
Compulsive caregiving	3.2 ± 0.8	3.2 ± 0.9	0.62
Social Support Questionnaire			
Social support availability	3.3 ± 1.7	3.1 ± 1.8	0.29
Social support satisfaction	5.3 ± 0.8	5.2 ± 0.9	0.57

SD, standard deviation.

months and 53 (38%) parents at 18 months ( $p < 0.001$ ). GAQ scores were  $12.3 \pm 6.1$  at 6 months and  $11.5 \pm 5.4$  at 18 months, representing no significant change in GAQ score (0.8 diff, 95% CI,  $-0.07$  to  $1.7$ ,  $p = 0.07$ ).

### Univariable analysis

Improvement in ICG score between 6 and 18 months was significantly greater for parents whose child died of trauma and significantly less for parents who had three or more surviving children (Table 3). Improvement in ICG score also had a significant positive correlation with grief avoidance at 6 months (Table 4). Improvement in ICG score was not significantly associated with parent age ( $r = -0.03$ ,  $p = 0.77$ ) or child age at time of death ( $r = -0.10$ ,  $p = 0.18$ ).

### Multivariable analysis

Variables independently associated with greater improvement in ICG score between 6 and 18 months in multivariable analysis included trauma as the cause of death and greater grief avoidance 6 months after the death (Table 5). Variables independently associated with less improvement in ICG score included being the biological parent and having a more responsive caregiving style. Parents with one or two surviving children had greater improvement in ICG score than those with no surviving children whereas parents with three or more surviving children had less improvement in ICG score than those with no surviving children.

### Discussion

Our findings demonstrate a decrease in complicated grief symptoms among parents between 6 and 18 months after their child's death in the PICU. Current proposals for inclusion of complicated grief in the *DSM* stipulate a 6-month time frame for diagnosis.<sup>3,4</sup> Our findings suggest that grief is still evolving at 6 months for many parents. Nevertheless, high symptom levels persist for some over this interval. ICG scores suggestive of complicated grief disorder (ICG > 30) were observed in 59% of parents 6 months after their child's death and in 38% at 18 months. By comparison, reported rates of complicated grief among community samples of older spousally bereaved adults range from 10–20% at 6 to 11 months postdeath.<sup>17–19</sup>

Trauma accounts for approximately one third of all childhood deaths in the United States.<sup>20,21</sup> Traumatic causes of death include accidents, homicide, and suicide. Proportionately fewer deaths from trauma occur in the PICU because many trauma victims die at the scene. Death from trauma was associated with a greater decline in complicated grief symptoms among parents than other causes of death. Decrease in posttraumatic stress disorder symptoms over time has also been reported in community samples post-disaster.<sup>22</sup> On the other hand, for parents who may perceive traumatic death as preventable and blame themselves for not protecting their child, grief may not resolve.<sup>23</sup> Murphy et al.<sup>24,25</sup> assessed 173 parents for mental distress using the Brief Symptom Inventory 4, 12, 24, and 60 months after their child's death from accident, homicide, or suicide. Reduction in distress over the first year was seen for mothers, but not fathers in their sample.

Family characteristics were associated with complicated grief symptoms among parents in our study. Biological parents had less improvement between 6 and 18 months than nonbiological parents. Non-biological parents were adoptive parents, stepparents, grandparents, and others with legal guardianship. The greater persistence of symptoms among biological parents may be related to stronger ties between biological parents and their children. Biological parents may be more likely to perceive their children as direct extensions of themselves; if a child dies, these parents may feel that a part of themselves has died.<sup>26</sup> Biological parents may also feel ultimately responsible for their child and experience a greater sense of failed responsibility. Bereaved parents with one or two surviving children had greater improvement in complicated grief symptoms than parents whose only child died. This finding is consistent with reports suggesting that other children in the family may be protective.<sup>7,27</sup> Bereaved parents with three or more surviving children had less improvement in symptoms than parents whose only child died. This finding may be related to additional stressors faced by parents of large families.

Attachment theory has been used as a framework for understanding grief and mourning.<sup>1,28</sup> Attachment is the innate biobehavioral system that motivates a person under stress to seek safety and security from significant others. Attachment styles can be measured that have trait-like properties and vary along two dimensions: attachment-related anxiety and

TABLE 3. SIX- AND EIGHTEEN-MONTH INVENTORY OF COMPLICATED GRIEF SCORES AND IMPROVEMENT IN INVENTORY OF COMPLICATED GRIEF SCORES BY PARENT AND CHILD CHARACTERISTICS

	n	6 months (mean ± SD)	18 months (mean ± SD)	Improvement (mean, 95% CI)	p <sup>a</sup>
Overall	138	33.4 ± 13.6	28.0 ± 13.5	5.4 (4.1, 6.8)	
Parent gender					
Male	37	31.8 ± 13.8	27.2 ± 14.5	4.6 (2.3, 6.9)	0.50
Female	100	33.6 ± 13.3	28.2 ± 13.3	5.4 (3.8, 7.0)	
Race/ethnicity					
White	94	31.5 ± 12.2	25.7 ± 11.9	5.8 (4.2, 7.4)	0.49
Black	15	30.5 ± 14.6	26.1 ± 14.4	4.4 (0.0, 8.8)	
Hispanic	20	38.3 ± 15.4	33.5 ± 15.4	4.8 (1.4, 8.2)	
Other	7	41.3 ± 8.7	39.7 ± 9.1	1.6 (−5.7, 8.9)	
Marital status					
Married	110	32.8 ± 13.1	27.7 ± 13.1	5.1 (3.6, 6.6)	0.55
Not married	26	34.7 ± 15.2	28.8 ± 15.9	5.9 (2.8, 9.0)	
Education					
High school or less	34	35.3 ± 17.1	32.2 ± 17.0	3.2 (0.8, 5.6)	0.18
Some college	43	34.7 ± 12.0	28.7 ± 12.6	6.0 (3.4, 8.5)	
College degree	59	30.8 ± 11.8	24.9 ± 11.4	5.9 (3.8, 7.9)	
Biological parent					
Biological	118	33.0 ± 13.3	28.3 ± 13.3	4.8 (3.4, 6.1)	0.09
Nonbiological	18	33.2 ± 14.7	24.4 ± 14.6	8.8 (4.6, 13.0)	
Number of other children					
None	21	33.7 ± 13.3	29.2 ± 12.3	4.5 (0.0, 9.0)	0.03
One	41	37.1 ± 11.8	29.5 ± 12.3	7.7 (5.5, 9.8)	
Two	36	31.2 ± 14.2	25.8 ± 13.8	5.4 (3.2, 7.6)	
Three or more	38	30.4 ± 14.0	27.6 ± 15.5	2.8 (0.2, 5.5)	
Child gender					
Male	79	34.5 ± 14.0	29.2 ± 13.8	5.3 (3.4, 7.2)	0.84
Female	59	31.8 ± 13.0	26.3 ± 13.0	5.5 (3.6, 7.4)	
Cause of death					
Cardiac	37	35.4 ± 13.9	30.3 ± 13.9	5.1 (2.5, 7.7)	0.004 <sup>b</sup>
Sepsis/Multiple organ failure	21	31.0 ± 12.1	23.4 ± 9.5	7.6 (3.1, 12.2)	
Neurologic	17	31.5 ± 10.3	25.4 ± 11.9	6.1 (2.4, 9.9)	
Malignancy	18	27.4 ± 13.6	23.0 ± 13.4	4.4 (0.6, 8.1)	
Respiratory failure	17	38.1 ± 15.9	34.8 ± 15.4	3.3 (−0.8, 7.4)	
Trauma	11	40.7 ± 12.8	31.6 ± 16.5	9.1 (5.5, 12.7)	
Other	12	27.6 ± 12.3	26.1 ± 12.4	1.5 (−3.6, 6.5)	

<sup>a</sup>p value assessing whether improvement in ICG differs across the different variable levels, e.g., whether males and females have significantly different improvement, on average.

<sup>b</sup>p value for cause of death reflects comparison of trauma versus all others.

SD, standard deviation; CI, confidence interval; ICG; Inventory of Complicated Grief.

attachment-related avoidance. Individuals with high anxiety tend to have a negative self-image and worry that others will not be available in times of need whereas those with high avoidance tend to have a negative view of others and keep emotional distance. We previously reported that parents with

insecure attachment styles (i.e., high anxiety and/or avoidance) have high levels of complicated grief symptoms 6 months after their child’s death in the PICU.<sup>9</sup> Our current findings continue to demonstrate positive correlations between attachment-related anxiety/avoidance and ICG score

TABLE 4. CORRELATION OF SIX-MONTH SURVEY MEASURES WITH INVENTORY OF COMPLICATED GRIEF SCORES AT SIX AND EIGHTEEN MONTHS, AND WITH IMPROVEMENT IN INVENTORY OF COMPLICATED GRIEF SCORES

	n	6 months	18 months	Improvement	p <sup>a</sup>
Grief Avoidance Questionnaire	136	0.33	0.18	0.26	0.005
Relationship Scales Questionnaire					
Attachment-related anxiety	136	0.38	0.33	0.08	0.27
Attachment-related avoidance	138	0.30	0.29	0.03	0.79
Caregiving Questionnaire					
Responsive caregiving	137	−0.22	−0.11	−0.18	0.08
Compulsive caregiving	135	0.18	0.11	0.12	0.18
Social Support Questionnaire					
Social support availability	134	−0.14	−0.13	−0.03	0.70
Social support satisfaction	133	−0.15	−0.09	−0.10	0.30

<sup>a</sup>p value for correlation of 6 month survey measure with improvement in Inventory of Complicated Grief score.

TABLE 5. MULTIVARIABLE ANALYSIS PREDICTING IMPROVEMENT IN INVENTORY OF COMPLICATED GRIEF SCORES FROM SIX TO EIGHTEEN MONTHS

Variable	Effect (95% CI)	P
Trauma cause of death	5.2 (2.3, 8.2)	0.001
Grief avoidance (GAQ)	0.19 (0.00, 0.39)	0.06
Biological parent	-6.3 (-11.0, -1.6)	0.009
Responsive caregiving (CQ)	-1.4 (-2.9, 0.1)	0.07
Number of other children		0.01
None (reference)		
One	4.7 (0.6, 8.9)	
Two	2.0 (-2.1, 6.1)	
Three or more	-1.1 (-5.4, 3.2)	

GAQ, Grief Avoidance Questionnaire; CQ, Caregiving Questionnaire; CI, confidence interval.

18 months post-death and no association between anxiety/avoidance and improvement in ICG score. These findings suggest that parents with insecure attachment styles are at risk for persistent distress and dysfunction.

Caregiving is the reciprocal biobehavioral system to attachment, motivating a person to respond to another's signals and needs.<sup>13</sup> Responsive caregiving is typified by physical and psychological accessibility, sensitivity to others' needs and cooperation with others' efforts. Attachment and caregiving styles may be related since both are influenced by prior attachment relationships.<sup>13,16</sup> For parents, being a responsive and effective caregiver is often important to their sense of identity and self-worth.

Most research on caregiving and bereavement has focused on adults caring for elderly family members with dementia or cancer.<sup>29,30</sup> In these groups, high levels of pre-bereavement mental distress, high caregiver burden as well as caregiver benefit (e.g., finding meaning in the caregiving role) are risk factors for increased grief and depression during bereavement. The relationships between caregiving styles and bereavement have not been well studied. Given that caregiving is an important aspect of the parental role, disruption of caregiving behaviors may contribute to the lost sense of identity that many parents experience after their child's death. Our findings suggest that caregiving style may moderate this effect. We found that parents who report more responsive caregiving tend to have lower levels of complicated grief symptoms at both 6 and 18 months postdeath, and less symptom improvement over this interval. Responsive caregiving may be protective in that responsive parents may feel comforted knowing their child received their love. Some responsive parents, however, may blame themselves for not being responsive enough and remain at risk for complicated grief.

Adjusting to a loved one's death requires acknowledging the reality of the death.<sup>4,31</sup> Acute grief ensues from a temporary mismatch between the bereaved person's mental representation of the deceased person and the change that must occur in their relationship after the death. Confronting reminders of the loss may motivate that mental representation to change whereas avoidance of reminders may counteract this process. However, confrontation with reminders can be highly emotional and people need to dose themselves accordingly.<sup>32</sup> Over, as well as under engagement with re-

mindings can impede the mourning process. Our findings demonstrate that more grief avoidance correlated with more complicated grief symptoms at both 6 and 18 months, but the correlation was weaker at 18 months. The relationship between grief avoidance and complicated grief may be consistent with the work of Bowlby<sup>32</sup> suggesting some degree of grief avoidance is adaptive in coming to terms with a difficult loss.

Limitations of this study include the low response rate. Only 12% of eligible families completed surveys at both 6 and 18 months. We compared characteristics for those who completed both surveys to those who only completed the 6-month survey. Although some differences were observed, only marital status was statistically significant. Strengths include the participation of racial and ethnic minorities and the geographic distribution of study sites.

In conclusion, many parents experience symptoms of complicated grief after their child's death in the PICU. Symptoms decrease between 6 and 18 month post-death suggesting that parental grief is still evolving over this period. Better understanding of the trajectory of complicated grief will allow those at risk of persistent distress to receive professional support.

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## APPENDIX A. INVENTORY OF COMPLICATED GRIEF

	<i>Never</i>	<i>Rarely</i>	<i>Sometimes</i>	<i>Often</i>	<i>Always</i>
1. I think about this person so much that it's hard for me to do the things I normally do	0	1	2	3	4
2. Memories of the person who died upset me	0	1	2	3	4
3. I feel I cannot accept the death of the person who died	0	1	2	3	4
4. I feel myself longing for the person who died	0	1	2	3	4
5. I feel drawn to places and things associated with the person who died	0	1	2	3	4
6. I can't help feeling angry about his/her death	0	1	2	3	4
7. I feel disbelief over what happened	0	1	2	3	4
8. I feel stunned or dazed over what happened	0	1	2	3	4
9. Ever since he/she died it is hard for me to trust people	0	1	2	3	4
10. Ever since he/she died I feel like I have lost the ability to care about other people or I feel distant from people I care about	0	1	2	3	4
11. I have pain in the same area of my body or have some of the same symptoms as the person who died	0	1	2	3	4
12. I go out of my way to avoid reminders of the person who died	0	1	2	3	4
13. I feel that life is empty without the person who died	0	1	2	3	4
14. I hear the voice of the person who died speak to me	0	1	2	3	4
15. I see the person who died stand before me	0	1	2	3	4
16. I feel that it is unfair that I should live when this person died	0	1	2	3	4
17. I feel bitter over this person's death	0	1	2	3	4
18. I feel envious of others who have not lost someone close	0	1	2	3	4
19. I feel lonely a great deal of the time ever since he/she died	0	1	2	3	4

From reference 10.

## APPENDIX B. GRIEF AVOIDANCE QUESTIONNAIRE

	<i>Almost never</i>	<i>Sometimes</i>	<i>Moderately often</i>	<i>Very often</i>	<i>Almost constantly</i>
When you were with <u>close family members</u> during the past month, how often did you ...					
1. Avoid <i>thinking</i> about your deceased child?	1	2	3	4	5
2. Avoid <i>talking</i> about your deceased child?	1	2	3	4	5
3. Avoid <i>showing your feelings</i> about your deceased child?	1	2	3	4	5
When you were with <u>close friends</u> during the past month, how often did you ...					
4. Avoid <i>thinking</i> about your deceased child?	1	2	3	4	5
5. Avoid <i>talking</i> about your deceased child?	1	2	3	4	5
6. Avoid <i>showing your feelings</i> about your deceased child?	1	2	3	4	5
When you were <u>alone</u> during the past month, how often did you ...					
7. Avoid <i>thinking</i> about your deceased child?	1	2	3	4	5

From reference 11.