

The Psychological Impact of Sudden Unexplained Death in Childhood: Associations Between Early Professional Interactions and Long-Term Distress Among Bereaved Caregivers

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Abstract

Each year, approximately 500 U.S. children aged 1–18 years die suddenly and without explanation. Sudden Unexplained Death in Childhood (SUDC) is a devastating loss with profound psychological consequences for caregivers. We conducted a cross-sectional study of 174 caregivers whose child's death was classified as SUDC at least one year earlier. Using a trauma-informed framework, we assessed anxiety (GAD-7), depression (PHQ-9), prolonged grief (BGQ), posttraumatic stress disorder (PCL-6), functional impairment (WSAS), and experiences with emergency medical services (EMS) and emergency department (ED) personnel. Moderate-to-severe anxiety and depression were reported by 26.4% and 22.4% of caregivers, respectively, and 35.4% had probable PTSD. Distress was greatest among caregivers whose loss occurred 1–2 years earlier and those aged ≤40 years. Nearly half reported neutral or negative

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interactions with EMS and ED personnel, highlighting the need for trauma-informed training for professionals supporting families following a child's sudden and unexplained death.

Keywords

sudden unexplained death in childhood (SUDC), trauma-informed care, post-traumatic stress disorder (PTSD), prolonged grief, coping with grief

Introduction

The sudden and unexplained death of a child is one of the most devastating and disorienting experiences a person can endure, often leaving families with profound grief compounded by uncertainty. Sudden Unexplained Death in Childhood (SUDC) is not a cause of death; it is a classification of death that refers to the sudden and unexpected death of a child aged 12 months or older that remains unexplained after a comprehensive forensic investigation, including an autopsy, death scene examination, and review of the clinical history (Krous et al., 2005).

This sudden and unexplained tragedy is a life-shattering event for families, marked by profound grief, emotional numbness, guilt, helplessness, and an overwhelming search for answers. It thrusts caregivers into an immediate and chaotic landscape of shock, uncertainty, medical scrutiny, and urgent interactions with emergency responders, hospital personnel, and investigative systems. For caregivers, SUDC is not solely a bereavement experience but also a potentially traumatic event that can have profound and enduring psychological consequences.

Currently, the World Health Organization (WHO) International Classification of Diseases (ICD-10/ICD-11) does not have a specific classification for thoroughly investigated, unexplained deaths occurring beyond infancy leaving researchers with only proxy data in the codes for “ill-defined and unknown causes of mortality” (ICD-10 codes R95-R99). In the United States, the estimated incidence of SUDC among children 1 to 18 years of age is 0.1-1.4 per 100,000 children (Hesdorffer et al., 2015), that is approximately 429 cases reported in the United States each year (Wojcik et al., 2023). In the United Kingdom, an estimated 29 sudden and unexplained deaths occur annually among children aged 1–14 years (Garstang et al., 2025). Further compounding the difficulty in measuring the magnitude of SUDC is the lack of concordance on the upper age limit. SUDC most commonly occurs between the ages of 1 and 4 years and it is more frequent among males (Shapiro-Mendoza et al., 2018). In many cases, the death occurs during sleep and is unwitnessed (Shapiro-Mendoza et al., 2018).

Despite its rarity, SUDC has profound consequences for families. Bereavement after any death of a child is associated with substantial psychological morbidity, including persistent grief-related distress (Champion & Kilcullen, 2025; Palusci et al., 2019; Suttle et al., 2022), depression (Suttle et al., 2022), anxiety (Suttle et al., 2022),

and posttraumatic stress symptoms (Palusci et al., 2019; Suttle et al., 2022). The absence of a clear cause of death distinguishes SUDC from other forms of child loss and may intensify the psychological burden on bereaved caregivers and complicate adaptation to loss (Champion & Kilcullen, 2025; Palusci et al., 2019).

Prior work has shown that bereaved parents often struggle with uncertainty, self-blaming, and unanswered questions after sudden unexplained deaths of a child (Garstang et al., 2025; Rosenberg et al., 2012). These concerns can become intertwined with broader grief and trauma responses intensifying distress and complications in the bereavement process (Champion & Kilcullen, 2025; Palusci et al., 2019; Suttle et al., 2022).

Qualitative accounts from bereaved families highlight the acute and complex nature of early grief following sudden and unexplained child loss. Reports from organizations such as Red Nose Grief and Loss (Red Nose Grief and Loss, 2016) describe immediate reactions including shock, numbness, isolation, panic, and withdrawal, all of which can significantly impair daily functioning in the short term. Likewise, reviews of bereaved-parent outcomes have shown elevated rates of prolonged grief and posttraumatic stress (Champion & Kilcullen, 2025; Palusci et al., 2019; Suttle et al., 2022), while longitudinal work suggests that although symptoms may lessen over time for some parents, distress remains clinically significant for many (Suttle et al., 2022).

A growing body of qualitative and practice-oriented literature suggests that early professional interactions play a critical role in shaping parents' experiences (Garstang et al., 2025). Bereaved parents consistently identify compassionate, clear, proactive, and knowledgeable communication as essential, whereas poor communication, lack of follow-up, and insufficient information may worsen distress and leave lasting negative memories of care (Brooten et al., 2013; Garstang et al., 2025; Sieg et al., 2019).

Despite its significant importance, relatively little empirical work has examined how the circumstances surrounding SUDC and caregivers' early interactions with law enforcement, emergency medical service (EMS), and healthcare professionals relate to later grief- and trauma-related distress. This gap remains important because those factors are potentially modifiable and may represent targets for improving family care after sudden child death. Accordingly, the present study examined psychological distress among caregivers following SUDC, including grief and probable PTSD, and evaluated whether distress varied according to time since the child's death, caregiver and child characteristics, and experiences with EMS, emergency department personnel, and other early post-death circumstances.

Materials and Methods

Participants

Study participants were identified through the Sudden Unexplained Death in Childhood Foundation (SUDCF) registered family database. The SUDCF, was incorporated in 2014 as a 501(c)(3) not for profit. The SUDCF is the leading organization serving families and professionals worldwide whose mission is to raise awareness, fund

research, and serve those affected by Sudden Unexplained Death in Childhood (SUDC). Families in the U.S. and around the world who are impacted by SUDC can reach out directly or be referred to the Foundation for support. Eligible participants included adults 18 years and older who were the caregivers (e.g., biological parent, legal guardian, foster parent, or adoptive parent) of a child between the ages of 1 and 18 years whose death was deemed unexplained, or the cause remained unknown due to pending investigation, and occurred more than one year before the administration of the survey. An introductory letter of invitation from the Principal Investigator was emailed to potentially eligible Family First registrants who indicated that they were willing to receive communication from the Foundation. The letter provided information related to the study purpose and that participation was strictly voluntary. A unique and secure link to the survey and consent form was included in the body of the text. No identifying information of participants was collected, making participation anonymous. Only caregivers who answered “true” to the question “The child’s death was unexpected, and their cause of death was initially unknown” were included in the analyses.

Survey Measures

Sociodemographics. Sociodemographic data were gathered from each participant, including relationship to the deceased child, age, sex, race/ethnicity, highest level of educational attainment, and current marital status. Additionally, age of the child at the time of death, child’s sex and race/ethnicity, and length of time since the child’s passing were collected.

Psychological Distress

Anxiety. To assess anxiety, we included the Generalized Anxiety Disorder Scale (GAD-7) (Spitzer et al., 2006) that consisted of seven items. Questions examined how often the respondent has been bothered by the items over the last two weeks. Each item was scored as 0, 1, 2, and 3 which corresponded to responses “not at all,” “several days,” “more than half the days,” and “nearly every day,” respectively. Scores were summed to obtain a total score ranging between 0 and 21. Total scores <4 represented minimal anxiety, 5-9 showed mild anxiety, 10-14 indicated moderate anxiety, and 15-21 reflected severe anxiety.

Depression. We evaluated depression using the Patient Health Questionnaire-9 (PHQ-9) (Kroenke et al., 2001), a multipurpose instrument for screening, diagnosing, monitoring and measuring the severity of depression. The questionnaire was comprised of nine questions that determined how often the respondent has been bothered by the problems listed over the past two weeks. As with the GAD-7, items were coded as 0-3 with responses “not at all” to “nearly every day.” Scores were summed (range 0-27); 0-4 corresponded to none-minimal depression, 5-9 showed mild depression, 10-14 indicated moderate depression, 15-19 represented moderately severe depression, and 20-27 reflected severe depression.

Prolonged Grief. Complicated grief is defined as debilitating feelings of loss that do not improve over time. Although the Brief Grief Questionnaire (BGQ) (Shear et al., 2006) was developed to identify symptoms historically referred to as complicated grief, the terminology is conceptually related to what is now recognized as Prolonged Grief Disorder.

Five questions assessed symptoms and were rated on a 3-point Likert scale, from “not at all” (0) to “a lot” (2). The total score ranged from 0-10 with higher scores indicating greater emotional disturbance as a result of grief. In the clinical setting, scores of 4 or greater would trigger further assessment and intervention.

Functional Impairment. To assess the impact of grief, we examined functional impairment using an adaptation of a subscale of the Work and Social Adjustment Scale (WSAS) (Mundt et al., 2002). This brief scale measured the degree of functional impairment caused by mental or physical conditions. Difficulties in specific life domains including work/study, home management, social leisure, private leisure, and relationships were identified and rated on a scale of 0 (not at all) to 8 (very severely) indicating the degree to which the ability to carry out the activity was impacted. Scores were summed (range 0-32). Scores ≤ 7 indicated no impairment or subclinical impairment, 8-15 was associated with moderate impairment, and a score ≥ 16 suggested severe impairment.

Posttraumatic Stress Disorder (PTSD). The Abbreviated Post-Traumatic Checklist (PCL-6) (Lang & Stein, 2005) was used to determine the prevalence of PTSD among respondents. The PCL-C is a standardized measure of post-traumatic stress comprising 6 items that correspond to the key symptoms of the disorder related to DSM-5 criteria. It is used as a screening instrument. Respondents were queried how much they have been bothered in the past month by each problem related to the passing of their child. Items were scored on a 1-5 scale with 1 = “not at all” through 5 = “extremely.” A total score was obtained by summing the ratings of the 6 items (range 6-30). Scores of 14 or more suggested difficulties with post-traumatic stress (probable PTSD) and should be followed by further assessment.

Details Surrounding Death. Circumstances of the child’s death that were gathered included whether the death was witnessed, if the caregiver was the last to see the child alive or was the first to discover the child, and if the caregiver attempted resuscitation.

Experiences With Emergency Responders and/or Emergency Department Personnel. Whether emergency medical services (EMS) were called and if EMS personnel pronounced the child’s death was asked of participants. Participants were also asked to evaluate the quality of their interactions with emergency responders by rating them as positive, neutral, or negative. For cases in which the child was transported to the emergency department (ED), participants reported whether they were present at the hospital, and how they would rate the quality of their interactions with ED personnel in the hospital (positive, neutral, or negative).

Data Analysis

We conducted descriptive analyses that included frequency distributions and the median value and interquartile range. Chi-square, Fisher's exact test, and the Mann-Whitney U test were used to perform univariable analyses for categorical and continuous variables, respectively. We evaluated associations between study variables and the time since the death of the child, dichotomized as 1-2 years vs. >2 years and ≤ 5 years vs. >5 years. The rationale for the comparison of two time frames was to give sufficient time for the "natural" course of grief following a loss of this magnitude, erring on the side of being overly conservative, and to explore differences at a time further from the initial traumatic event. Prolonged grief and PTSD scores were dichotomized at the value corresponding to potential clinical indication of the condition that would indicate the need for further assessment and possible intervention. Differences between respondents with low (score <4) vs. high (score ≥ 4) prolonged grief and no PTSD (score <14.0) vs. probable PTSD (≥ 14.0) were examined for selected sociodemographic characteristics, distress, coping, circumstances surrounding the death, and experiences with allied health professionals within the first hours after the child's death using chi-square analysis.

All analyses were performed using IBM SPSS Statistics for Windows (2023). P values <0.05 were considered statistically significant. Study procedures were reviewed by IntegReview (now Advarra) Institutional Review Board (#2020-01) and deemed to be exempt research, as this study presented no more than minimal risk to participants and no personally identifiable information was collected.

Results

Of the 574 potentially eligible registrants, 174 completed evaluable surveys (30.3% response rate). The majority of respondents were biological parents (96.6%), 50 years of age or younger (84.5%), female (80.5%), White (94.3%), and had college-level or higher education (82.2%) (Table 1). Nearly 80% of deceased children passed between the ages of 1 and 4 years, most were male (55.2%) and the majority were White (87.9%).

Table 2 displays distress reported by caregivers who lost their child 1-2 years ago (21.8%) vs. >2 years ago (78.2%) and ≤ 5 years ago (56.3%) vs. >5 years ago (43.7%). For current distress, 26.4% reported moderate to severe anxiety and 22.4% reported depression that was moderate, moderately severe, or severe. Median prolonged grief scores (3.0 [IQR 5.0]) demonstrated no prolonged grief overall. Nearly half (47.7%) of the respondents indicated having moderate to severe functional impairment, and more than one-third (35.4%) responded in a manner that suggested probable PTSD.

When examining the various distress measures by time since the child's passing, probable PTSD was reported more frequently by respondents whose loss occurred 1-2 years ago compared to respondents who lost their child more than 2 years ago (52.6% vs. 31.8%, $p = 0.02$). Prolonged grief scores were statistically higher among those whose child passed ≤ 5 years ago compared to participants whose child died >5 years ago (median 4.0 [IQR 4.0] vs. 3.0 [IQR 4.0], $p = 0.028$), but given that both groups had relatively low median scores, these results may not be clinically important.

Table 1. Sociodemographic Characteristics of Study Participants and Deceased Children (n = 174)

	Total
Caregiver	
Relationship to deceased child	
Biological parent	168 (96.6)
Adoptive parent	4 (2.3)
Foster parent	2 (1.1)
Age	
≤40 years	82 (47.1)
41-50 years	65 (37.4)
51-60+ years	26 (15.0)
Missing	1 (0.6)
Sex	
Male	33 (19.0)
Female	140 (80.5)
Missing	1 (0.6)
Race/ethnicity	
White	164 (94.3)
Other	10 (5.7)
Education	
≤High school diploma	31 (17.8)
College degree	78 (44.8)
Graduate/post-graduate degree	65 (37.4)
Marital status	
Married	149 (85.6)
Not married	25 (14.4)
Deceased Child	
Age at death	
1-4 years	140 (80.4)
5-10 years	20 (11.5)
11-14 years	4 (2.3)
15-18 years	8 (4.6)
Missing	2 (1.1)
Sex	
Male	96 (55.2)
Female	76 (43.7)
Missing	2 (1.1)
Race/ethnicity	
White	153 (87.9)
Other	16 (9.2)
Missing	5 (2.9)

Table 2. Measures of Caregiver (n = 174) Psychological Distress Following the Sudden, Unexplained Death of a Child

	Total	1-2 years since death (n = 38, 21.8%)	>2 years since death (n = 136, 78.2%)	p value	≤5 years since death (n = 98, 56.3%)	>5 years since death (n = 76, 43.7%)	p value
Anxiety							
Minimal	70 (40.2)	13 (34.2)	57 (43.2)	0.55	35 (36.8)	35 (46.7)	0.52
Mild	54 (31.0)	12 (31.6)	42 (31.8)		31 (32.6)	23 (30.7)	
Moderate	22 (12.6)	5 (13.2)	17 (12.9)		13 (13.7)	9 (12.0)	
Severe	24 (13.8)	8 (21.1)	16 (12.1)		16 (16.8)	8 (10.7)	
Missing	4 (2.3)	--	--		--	--	
Depression							
None to minimal	79 (45.4)	14 (36.8)	65 (48.9)	0.09	42 (43.8)	37 (49.3)	0.33
Mild	53 (30.5)	11 (28.9)	42 (31.6)		27 (28.1)	26 (34.7)	
Moderate	23 (13.2)	8 (21.1)	15 (11.3)		17 (17.7)	6 (8.0)	
Moderately severe	12 (6.9)	2 (5.3)	10 (7.5)		7 (7.3)	5 (6.7)	
Severe	4 (2.3)	3 (7.9)	1 (0.8)		3 (3.1)	1 (1.3)	
Missing	3 (1.7)	--	--		--	--	
Prolonged grief				0.10			0.028
Median [IQR]	3.0 [5.0]	3.5 [5.0]	3.0 [4.0]		4.0 [4.0]	3.0 [4.0]	
Range	0-10	0-10	0-10		0-10	0-9	
Functional impairment							
None to minimal	89 (51.1)	17 (44.7)	72 (53.7)	0.33	44 (45.4)	45 (60.0)	0.057
Moderate to severe	83 (47.7)	21 (55.3)	62 (46.3)		53 (54.6)	30 (40.0)	
Missing	2 (1.1)	--	--		--	--	
PTSD							
No PTSD	108 (61.7)	18 (47.4)	90 (68.2)	0.02	59 (60.8)	49 (67.1)	0.40
Probable PTSD	62 (35.4)	20 (52.6)	42 (31.8)		38 (39.2)	24 (32.4)	

Table 3 depicts sociodemographic factors and distress status associated with prolonged grief (no prolonged grief vs. prolonged grief) and PTSD (none vs. probable). Prolonged grief was reported more often among respondents with a high school diploma or less education (28.9% vs. 6.7%, $p < 0.001$) and was greater among individuals with moderate to severe anxiety (53.1% vs. 3.3%, $p < 0.001$), moderately severe to severe depression (18.3% vs. 1.1%, $p < 0.001$), and moderate or severe functional impairment (80.7% vs. 18.0%, $p < 0.001$). Factors related to probable PTSD included younger age (≤ 40 years, 54.9% vs. 43.9%, $p = 0.03$), lower educational attainment ($\leq$ high school diploma, 27.4% vs. 11.1%, $p = 0.024$), moderate to severe anxiety (65.6% vs. 5.6%, $p < 0.001$), moderately severe to severe depression (24.2% vs. 0.9%, $p < 0.001$), and moderate to severe functional impairment (93.5% vs. 21.3%, $p < 0.001$).

The impact of death circumstances and experiences with health providers in the early aftermath of the SUDC on the development of prolonged grief and PTSD can be found in **Table 4**. Most caregivers were the last to see the child alive (59.8%) and the first to discover the deceased child (54.4%). The majority of caregivers called EMS (96.6%). Respondents with higher levels of prolonged grief more often reported negative or neutral interactions with EMS personnel (66.7% vs. 37.8%, $p < 0.001$) as did respondents with probable PTSD (63.8% vs. 46.0%, $p = 0.03$).

About 60% of respondents stated that the child was transported to the emergency department and most (85.6%) followed the child to the hospital (**Table 4**). Ratings of interactions with personnel in the ED were mixed with roughly half (52.8%) reporting a positive experience and 47.2% having a neutral or negative experience. Respondents with prolonged grief more frequently reported that EMS personnel made the pronouncement of death (65.6% vs. 47.2%, $p = 0.026$), had a neutral or negative interaction with the EMS personnel (68.2% vs. 40.4%, $p < 0.001$), and the child was not transported to the ED at the hospital (47.1% vs. 29.9%, $p = 0.025$). Individuals who scored in the “probable PTSD” range, more often reported a neutral or negative interaction with EMS (63.8% vs. 46.0%, $p = 0.03$) as well as a neutral or negative interaction with ED personnel (62.1% vs. 40.0%, $p = 0.05$).

Discussion

This study provides one of the first quantitative examinations of psychological distress among caregivers bereaved by Sudden Unexplained Death in Childhood (SUDC), and, to our knowledge, the first to systematically link the quality of early interactions with emergency responders and ED personnel to longer-term grief and trauma outcomes. Caregivers in this sample reported substantial rates of anxiety, depression, prolonged grief, and probable PTSD but the key clinically actionable finding was the association between caregivers’ negative/neutral EMS and ED interaction evaluations and prolonged grief and probable PTSD. Nearly half of caregivers rated these interactions as neutral or negative, and these caregivers were significantly more likely to screen positive for both outcomes. This association was observed for interactions with emergency responders at the scene and, to a similar degree, with ED personnel,

Table 3. Evaluation of Sociodemographics, Distress, and Prolonged Grief and PTSD of Caregivers (n = 174) Following the Sudden, Unexplained Death of a Child

	Prolonged Grief*		PTSD**		p value
	Total	<4 (n = 89, 51.7%)	>4 (n = 83, 48.3%)	<14 (n = 108, 63.5%)	>14 (n = 62, 36.5%)
Sociodemographics					
Age					0.03
≤40 years	82 (47.1)	43 (42.7)	43 (52.4)	47 (43.9)	34 (54.9)
41-50 years	65 (37.4)	35 (39.3)	29 (35.4)	40 (37.4)	23 (37.1)
51-60+ years	26 (14.9)	16 (18.0)	10 (12.2)	20 (18.7)	5 (8.1)
Missing	1 (0.6)	--	--	--	--
Sex					0.72
Male	33 (19.0)	16 (18.0)	17 (20.7)	20 (18.7)	13 (21.0)
Female	140 (80.5)	73 (82.0)	65 (79.3)	87 (81.3)	49 (79.0)
Missing	1 (0.6)	--	--	--	--
Education					0.024
≤High school	31 (17.8)	6 (6.7)	24 (28.9)	12 (11.1)	17 (27.4)
College degree	78 (44.8)	42 (47.2)	35 (42.2)	53 (49.1)	24 (38.7)
Graduate/post-graduate degree	65 (37.4)	41 (46.1)	24 (28.9)	43 (39.8)	21 (33.9)
Marital status					0.91
Married/living as married	149 (85.6)	76 (85.4)	72 (86.7)	93 (86.1)	53 (85.5)
Not married	25 (14.4)	13 (14.6)	11 (13.3)	15 (13.9)	9 (14.5)
Distress					<0.001
Anxiety					
Minimal	70 (40.2)	55 (61.8)	15 (18.5)	63 (58.9)	5 (8.2)

(continued)

Table 3. (continued)

	Prolonged Grief*			PTSD**		
	Total	<4 (n = 89, 51.7%)	≥4 (n = 83, 48.3%)	p value	<14 (n = 108, 63.5%)	≥14 (n = 62, 36.5%)
Mild	54 (31.0)	31 (34.8)	23 (28.4)		38 (35.5)	16 (26.2)
Moderate	22 (12.6)	2 (2.2)	20 (24.7)		4 (3.7)	18 (29.5)
Severe	24 (14.1)	1 (1.1)	23 (28.4)		2 (1.9)	22 (36.1)
Missing	4 (2.3)	--	--		--	--
Depression				<0.001		<0.001
None to minimal	79 (45.4)	64 (71.9)	15 (18.3)		71 (66.4)	7 (11.3)
Mild	53 (30.5)	23 (25.8)	30 (36.6)		32 (29.9)	20 (32.3)
Moderate	23 (13.2)	1 (1.1)	22 (26.8)		3 (2.8)	20 (32.3)
Moderately severe	12 (6.9)	1 (1.1)	11 (13.4)		1 (0.9)	11 (17.7)
Severe	4 (2.3)	0 (0.0)	4 (4.9)		0 (0.0)	4 (6.5)
Missing	3 (1.7)	--	--		--	--
Functional impairment				<0.001		<0.001
None to minimal	89 (51.1)	73 (82.0)	16 (19.3)		85 (78.7)	4 (6.5)
Moderate to severe	83 (47.7)	16 (18.0)	67 (80.7)		23 (21.3)	58 (93.5)
Missing	2 (1.1)	--	--		--	--

*Brief Grief Questionnaire (BGQ); ** Abbreviated Post-Traumatic Checklist (PCL-6).

Table 4. Evaluation of Child Death Circumstances, Caregiver Experiences With Allied Health Providers in the Early Aftermath of SUDC on Prolonged Grief and PTSD

	Prolonged Grief*			PTSD**		p value
	Total	<4 (n = 89, 51.7%)	≥4 (n = 83, 48.3%)	p value	<14 (n = 108, 63.5%)	≥14 (n = 62, 36.5%)
Details Surrounding Death						
Death witnessed						
Yes	14 (8.0)	9 (8.8)	5 (7.1)	0.69	9 (8.3)	5 (8.1)
No	158 (90.8)	93 (91.2)	65 (92.9)		99 (91.7)	57 (91.9)
Missing	2 (1.1)	--	--		--	--
Caregiver last to see child alive						
Yes	104 (59.8)	54 (60.7)	50 (60.2)	0.95	64 (59.3)	38 (61.3)
No	68 (39.1)	35 (39.3)	33 (39.8)		44 (40.7)	24 (38.7)
Missing	2 (1.1)	--	--		--	--
Caregiver first to discover child						
Yes	93 (54.4)	50 (56.2)	43 (52.4)	0.62	58 (53.7)	34 (55.7)
No	78 (44.8)	39 (43.8)	39 (47.6)		50 (46.3)	27 (44.3)
Missing	3 (1.7)	--	--		--	--
Caregiver attempted resuscitation						
Yes	65 (37.4)	37 (36.6)	28 (40.0)	0.66	39 (36.4)	25 (40.3)
No	110 (60.9)	64 (63.4)	42 (60.0)		68 (63.6)	37 (59.7)
Missing	3 (1.7)	--	--		--	--
First Responder Experience						
Emergency medical services (EMS) called				0.65		
Yes	168 (96.6)	87 (97.8)	81 (97.6)		105 (97.2)	61 (98.4)
No	4 (2.3)	2 (2.2)	2 (2.4)		3 (2.8)	1 (1.6)

(continued)

Table 4. (continued)

	Prolonged Grief*			PTSD**		p value
	Total	<4 (n = 89, 51.7%)	≥4 (n = 83, 48.3%)	p value	<14 (n = 108, 63.5%)	≥14 (n = 62, 36.5%)
Missing	2 (1.1)	--	--		--	--
Death pronounced by EMS				0.028		0.66
Yes	82 (47.1)	34 (38.2)	48 (57.8)		48 (44.4)	32 (51.6)
No	68 (39.1)	43 (48.3)	25 (30.1)		45 (41.7)	23 (37.1)
Unsure	22 (12.6)	12 (13.5)	10 (12.0)		15 (13.9)	7 (11.3)
Missing	2 (1.1)	--	--			
Quality of interaction with EMS professionals				<0.001		0.03
Positive	77 (44.3)	51 (62.2)	26 (33.3)		54 (54.0)	21 (36.2)
Negative/neutral	83 (47.8)	31 (37.8)	52 (66.7)		46 (46.0)	37 (63.8)
Emergency Department Personnel Experience						
Child transported to Emergency Dept/hospital				0.025		0.44
Yes	104 (59.8)	61 (71.8)	43 (53.8)		68 (66.0)	36 (60.0)
No	61 (35.1)	24 (28.2)	37 (46.3)		35 (34.0)	24 (40.0)
Don't know	6 (3.4)	--	--		--	--
Missing	3 (1.7)	--	--		--	--
Present in Emergency Dept/hospital (n = 104)				0.31		0.46
Yes	89 (85.6)	54 (88.5)	35 (81.4)		60 (82.2)	29 (76.3)
No	15 (14.4)	7 (11.5)	8 (18.6)		13 (17.8)	9 (23.7)

(continued)

Table 4. (continued)

	Prolonged Grief*		PTSD**		p value
	<4 (n = 89, 51.7%)	≥4 (n = 83, 48.3%)	<14 (n = 108, 63.5%)	≥14 (n = 62, 36.5%)	
Total					
Interaction with Emergency Dept professionals (n = 89)					0.05
Positive	47 (52.8)	35 (59.3)	12 (40.0)	36 (60.0)	11 (37.9)
Negative/neutral	42 (47.2)	24 (40.7)	18 (60.0)	24 (40.0)	18 (62.1)

*Brief Grief Questionnaire (BGQ); ** Abbreviated Post-Traumatic Checklist (PCL-6).

aligning with qualitative literature showing that families' treatment in the immediate aftermath of a child's death can have lasting psychological consequences (Brooten et al., 2013; Garstang et al., 2025; Sieg et al., 2019).

Specifically, more than one-quarter of respondents reported moderate to severe anxiety, 22.4% reported moderate to severe depression, 48.3% had prolonged grief and more than one-third met the screening criteria for probable PTSD. The majority of caregivers reporting this distress were more than two years removed from their child's death. For context, moderate to severe anxiety and depression in the general U.S. population have been estimated at 6.7% and 7.5%, respectively (Terlizzi & Zablotzky, 2024), and national estimates of PTSD among American non-military civilians are approximately 5% (U.S. Department of Veterans Affairs, 2025); the prevalences observed here far exceed these benchmarks. Although median prolonged grief scores fell below the clinical threshold, a meaningful subgroup of caregivers scored in the clinically elevated range, underscoring that aggregate medians may obscure substantial distress among some respondents. Our findings are consistent with, and extend, prior literature documenting elevated psychological morbidity among parents bereaved by SUDC (Champion & Kilcullen, 2025; Palusci et al., 2019; Suttle et al., 2022) highlighting that SUDC bereavement carries not only the burden of loss but also features of traumatic stress and is echoed in high levels of functional impairment which is a particularly important indicator in this context, as even subclinical levels can disrupt daily living and impede recovery (Boelen & Spuij, 2024; Wen et al., 2022).

The finding that probable PTSD was substantially more common among caregivers whose loss occurred 1 to 2 years prior (52.6%) compared with those further out from the death (31.8%) is notable, indicating that risk in the early years after SUDC is considerably higher than the overall sample prevalence suggests. This pattern aligns with the broader bereavement literature suggesting that acute traumatic stress responses are most intense in the early years following a loss and may attenuate, though not necessarily resolve, over time for many parents (Suttle et al., 2022). Although this pattern should not be interpreted as evidence of a simple or uniform recovery trajectory, it is consistent with bereavement models that describe adaptation as a nonlinear process, in which bereaved individuals move back and forth between confronting the loss and managing ongoing life changes (Stroebe & Schut, 1999). Similarly, Meaning Reconstruction Theory proposes that bereaved individuals gradually rebuild their worldview and sense of identity following profound loss (Neimeyer, 2019). Within this framework, the persistence of clinically meaningful distress beyond five years in a subset of our sample should not necessarily be understood as maladaptive but rather interpreted as reflecting ongoing adaptation and meaning-making for caregivers whose grief does not follow a typical trajectory (Champion & Kilcullen, 2025; Palusci et al., 2019). The absence of a clear cause of death (a defining feature of SUDC) and the enduring uncertainty may be a key driver of this prolonged distress. Caregivers are left without an explanatory narrative that might otherwise support meaning-making and adaptive grief processing (Garstang et al., 2025; Rosenberg et al., 2012) that may magnify the importance of compassionate, trauma-informed early

interactions with professionals involved in the child's death investigation and care.

In light of these findings, an important distinction must be drawn between traumatic bereavement and PTSD, as these should not be treated as synonymous constructs. PTSD symptoms may include intrusive recollections related to discovering the child, hyperarousal, avoidance of trauma reminders, and re-experiencing the circumstances surrounding the death (Jellestad et al., 2021), whereas grief-related responses more often involve yearning for the deceased child, searching behaviors, disruption in identity and future expectations, and efforts to maintain an enduring connection with the child (Coelho et al., 2025). These symptom profiles frequently overlap following sudden pediatric death and distinguishing between trauma-related and grief-related distress carries important implications for assessment and intervention and supports the need for comprehensive, bereavement-informed clinical care (Jann et al., 2024).

Younger caregiver age and lower educational attainment were associated with both probable PTSD and prolonged grief, aligning with existing literature linking lower education with more severe grief responses (Szuhany et al., 2021). Clearly, mechanisms cannot be determined from this cross-sectional design but rather suggest that these characteristics may reflect broader vulnerabilities, including fewer accumulated coping resources, more limited access to grief-specific support, lower health literacy, less flexible employment, or competing caregiving demands (Buur et al., 2024; Champion & Kilcullen, 2025; Jann et al., 2024; Rodriguez Grieve et al., 2024; Suttle et al., 2022). These patterns warrant further investigation and may help identify caregivers at heightened risk who could benefit from targeted outreach rather than a uniform bereavement response.

Caregivers whose child's death was pronounced by EMS, rather than in a hospital setting with additional support, and those whose child was not transported to the emergency department also reported higher prolonged grief. Although causality cannot be established, these findings suggest that the context in which death is confirmed may be meaningful for family outcomes. These circumstances may limit opportunities for parents to remain near the child, receive structured explanations, or feel that the event was fully witnessed and cared for by professionals. They may also reflect other unmeasured aspects of the death, such as abruptness or perceived finality. Overall, these findings highlight how procedural details that may appear operational from a systems perspective can be deeply consequential from a caregiver perspective (Garstang et al., 2025; Myall et al., 2020; O'Malley et al., 2014).

Taken together, these findings lend empirical support to the premise that trauma-informed approaches in the immediate post-death period are not merely compassionate practice but may have measurable, long-term implications for caregiver mental health. In the aftermath of traumatic loss, social support is not limited to family and friends; it also includes the emotional, informational, and practical support conveyed by professionals, and research on sudden or violent bereavement suggests that the quality of such support is especially important for psychological wellbeing after an unexpected death (Scott et al., 2020). Even brief encounters with EMS and ED personnel may function as trauma exposures in their own right, separate from the loss itself. Work on

traumatic grief has emphasized that compassionate presence, validation, clear information, and practical guidance are central components of “good grief support” (Cacciatore et al., 2021), and trauma-informed care principles (emphasizing safety, trustworthiness, transparency, choice, and avoidance of re-traumatization) offer a practical framework for EMS personnel and ED staff, as well as law enforcement and death investigators, interacting with families in the acute aftermath of SUDC. Key components include clear and timely communication, support for family presence when appropriate, involvement of multidisciplinary teams such as social work, and compassionate, comprehensible death notification practices (Cooper et al., 2025; Deutsch et al., 2022; SAMHSA’s *Concept of Trauma and Guidance for a Trauma-Informed Approach*, 2014). Because these early interactions are time-limited, identifiable, and amenable to training-based intervention, they represent a meaningful target for improving outcomes in a population for which the underlying cause of death often cannot be changed or explained.

The current findings further highlight the value of interdisciplinary bereavement care that extends beyond the acute medical response. Pediatric social workers, bereavement clinicians, child life specialists, chaplaincy and spiritual care providers, and grief-informed mental health professionals each have complementary roles in supporting families following sudden child death (Schuelke et al., 2021). Beyond emotional support during hospitalization, these professionals can provide coordinated post-death outreach, structured bereavement follow-up systems, anticipatory guidance regarding traumatic grief responses, opportunities for memory-making, and referral to community grief resources; potentially increasing adaptive coping while reducing caregiver isolation. Qualitative work on grief group participation, however, suggests that such resources are not uniformly beneficial: support groups can be experienced as either validating or burdensome depending on participants’ individual needs and symptom profiles (Dyregrov et al., 2014), emphasizing the importance of tailoring referrals rather than assuming a single model of support fits all bereaved caregivers. An additional consideration unique to SUDC is the persistent uncertainty surrounding the child’s death: unlike many other forms of bereavement, families must cope with the enduring absence of a medical explanation, which may perpetuate unresolved questioning, parental self-blame, hypervigilance regarding surviving siblings, and diminished trust in medical systems (Jaaniste et al., 2017). Recognizing and validating this uncertainty through transparent communication, ongoing follow-up, and compassionate acknowledgment of unanswered questions should therefore be considered an essential component of comprehensive bereavement care for families affected by SUDC. At the same time, the broader intervention literature suggests caution against assuming that generic bereavement services are uniformly effective: reviews indicate that available bereavement interventions for parents remain limited and heterogeneous (Ainscough et al., 2022; Forte et al., 2004), arguing for flexible, tiered, and SUDC-informed support rather than a single point of intervention immediately after the death.

Several limitations should be considered. The cross-sectional design prevents conclusions about whether negative interactions with first responders contributed to later distress or were recalled more negatively by caregivers experiencing greater

distress. The voluntary SUDCF registry sample and 30.3% response rate introduce potential selection and non-response bias, and the predominantly White, female, and college-educated sample limits generalizability. Although approximately 90% of registered SUDCF members identify as White, it remains unclear why families from more diverse racial and ethnic backgrounds are less represented among those who seek support through the Foundation. Additional limitations include reliance on retrospective self-report, screening measures that indicate probable rather than diagnosed conditions (Han et al., 2016), dichotomization of time since death, and univariable analyses that do not account for potential confounding.

Despite these limitations, this study is among the first to quantitatively assess psychological distress in a relatively large, geographically diverse sample of caregivers bereaved by SUDC. The use of validated screening tools allowed comparison with established clinical thresholds and other bereavement populations, while recruitment through the SUDCF registry provided access to a rare and difficult-to-identify population. Importantly, the focus on modifiable factors, including early interactions with emergency and emergency department personnel, identifies actionable targets for intervention.

Conclusions

Caregivers bereaved by SUDC experience substantial and, for many, persistent psychological distress, including clinically significant rates of anxiety, depression, prolonged grief, and probable PTSD. Distress was most pronounced among caregivers who were younger, less educated, and within the first one to two years of loss, though meaningful symptoms persisted well beyond this period for a subset of respondents. The quality of caregivers' early interactions with EMS personnel and emergency department staff was significantly associated with prolonged grief and probable PTSD in our sample. While the cross-sectional design precludes causal inference, these findings suggest that negative or neutral interactions with EMS personnel and emergency department staff during the child's death and its immediate aftermath may be associated with greater psychological distress among bereaved caregivers.

Although the child's sudden and unexplained death is itself a profoundly traumatic event, the quality of these early interactions represents a plausible and modifiable target for intervention and supports the integration of trauma-informed care principles into the training of first responders, emergency department personnel, and death investigators who interact with families in the immediate aftermath of a child's sudden and unexplained death. Because the cause of death often remains unknown and may never be determined, improving the quality of early interactions may represent one of the few immediately actionable opportunities to influence long-term outcomes for bereaved caregivers. Improving the compassion, transparency, and clarity of these early interactions may not only ease the acute crisis but also help mitigate the long-term psychological burden carried by bereaved caregivers. Future longitudinal and multivariable research is needed to clarify the causal pathways linking early post-death experiences to long-term mental health outcomes, to include more diverse caregiver

populations, and to evaluate whether trauma-informed training interventions for emergency personnel can measurably reduce prolonged grief and PTSD among SUDC-bereaved families.

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Declaration of Conflicting Interests

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Data Availability Statement

The data that support the findings of this study are available from the corresponding author, Grace Clarke Hillyer, upon reasonable request.

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