



The sudden unexpected death in epilepsy grief study

Jeffrey Buchhalter^{a,*}, Catherine Andrews^b, Jeanne Donalty^c, Elizabeth Donner^d, Sarah Friebert^e, Daniel Friedman^f, Avani Patel^g, Gardiner Lapham^h, Itay Tokatly Latzer^{i,j}, Phillip L. Pearlⁱ, Rajesh Ramachandrannair^k, Sally Schaeffer^l, Thomas Stanton^m

^a Buchhalter Consulting, PLLC 13030 N. 17th Place, Phoenix 85022, AZ, USA

^b Dr. Catherine Andrews Psychotherapy, 3395 Stuyvesant Place, NW/Washington 20015, DC, USA

^c 2011 Gardenside Drive, Utica 13501, NY, USA

^d Division of Neurology, Hospital for Sick Children, Department of Paediatrics, University of Toronto, Canada

^e Haslinger Family Pediatric Palliative Care Division, Akron Children's Hospital, Department of Pediatrics, Northeast Ohio Medical University, Palliative Care Division, 215 W. Bowers St, Akron 44308, OH, USA

^f Comprehensive Epilepsy Center, Department of Neurology, New York University Grossman School of Medicine, 223 East 34th Street, New York 10016, NY, USA

^g Department of Dermatology, New York University Grossman School of Medicine 240 E 38th Street, NY 10010 NY, USA

^h BAND Foundation 1723 Hoban Rd, NW Washington 20007, DC, USA

ⁱ Division of Epilepsy and Clinical Neurophysiology, Department of Neurology, Boston Children's Hospital, Harvard Medical School, Boston, MA, USA

^j Gray School of Medicine, Gray Faculty of Medical and Health Sciences, Tel-Aviv University, Tel Aviv, Israel

^k Department of Pediatrics, McMaster University, Hamilton L8S 4K1, Ontario, Canada

^l 7512 Pine Ridge Drive Burlington, WI 53105, USA

^m Danny Did Foundation, 3008 Central Ste, Ste 203, Evanston 60201, IL, USA

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ABSTRACT

Objectives: To explore the evolution of the grief experience following Sudden Unexpected Death in Epilepsy (SUDEP) and identify factors that assist the bereaved in coping with their loss.

Methods: A survey formulated by a multidisciplinary team gathered information gathered information on decedent and respondent demographics, epilepsy details, circumstances surrounding death, postmortem experiences, descriptions of grief overtime (from 3 months to > 10 years post death), insights into coping strategies and recommendations for assisting the bereaved.

Results: A total of 206 participants completed the survey (predominantly middle-aged white females who were parents of the deceased). Most respondents (69.2 %) were unaware of SUDEP prior to the death and strongly desired to have had prior information. Negative impacts on relationships and mental health were highest at three months post-loss but gradually improved over time; feelings of sadness persisted while anger and guilt decreased, and acceptance increased. Interactions with understanding peers, supportive family or friends, and professional counseling were identified as most helpful, alongside clear communication and support from medical professionals and advocacy groups.

Conclusions: This study highlights the profound and evolving nature of grief following SUDEP, describes the importance of SUDEP disclosure as part of comprehensive epilepsy care, and illustrates the need for ongoing and dynamic support for the bereaved. Interpretation of the findings is limited as the respondents were predominantly middle-aged white females who were parents of the deceased.

* Corresponding author.

E-mail addresses: buchhalterj@gmail.com (J. Buchhalter), drcatandrews@gmail.com (C. Andrews), jdonalty@verizon.net (J. Donalty), elizabeth.donner@sickkids.ca (E. Donner), sfriebert@akronchildrens.org (S. Friebert), Daniel.Friedman@nyulangone.org (D. Friedman), avanikolla95@gmail.com (A. Patel), gardinerlapham@gmail.com (G. Lapham), Itay.TokatlyLatzer@childrens.harvard.edu (I.T. Latzer), Phillip.Pearl@childrens.harvard.edu (P.L. Pearl), rnair@mcmaster.ca (R. Ramachandrannair), schaeffer5@icloud.com (S. Schaeffer), tfstanton@dannydid.org (T. Stanton).

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1. Introduction

Sudden Unexpected Death in Epilepsy (SUDEP) is recognized as a leading cause of death in people living with epilepsy [1,2] and a major cause of potential years of life lost [3]. Although there have been robust reports of SUDEP discussions with patients and caregivers as part of routine neurology care [4–8], there is a paucity of studies in which the grief process following the tragedy of SUDEP is addressed. A study employing a descriptive qualitative methodology inquired about the reactions of relatives immediately after death, aiming to understand relatives' feelings about information regarding SUDEP antemortem [7]. Interviews with relatives of those lost to SUDEP revealed significant psychosocial consequences [9]. In a recent discussion of SUDEP and grief, SUDEP was identified with sudden infant death and sudden cardiac death in children as types of complicated grief (CG) defined by the persistence of symptoms six months or more after a death [10]. However, a significant gap exists in our understanding of the grieving process over time and any interventions that may assist the bereaved.

Partners Against Mortality in Epilepsy (PAME) has convened bi-annual conferences since 2012 in which the bereaved, people living with epilepsy, advocates, and basic and clinical scientists congregate to share information regarding premature mortality related to epilepsy [11]. A feature of the meeting is the opportunity for those who have lost loved ones to describe their experiences and emotions with one another. As participants (JD, GL, SS, TS) and observers (JB, ED, DF, RR) of these conversations, it became apparent that the journey of the bereaved was individual (with some persistent themes) and evolved over time. This experience provided the impetus for the current study, the aim of which is the first of its kind, to gain insight into the evolution of the grief experience and the factors that help the bereaved deal with the loss of a loved one.

2. Materials and methods

2.1. Survey creation

A group of investigators was assembled that included those who were bereaved (JD, GL, SS, TS), clinicians with expertise in SUDEP (JB, ED, DF, RR), and epilepsy/SUDEP advocacy organizations (SS, TS). Of note, the investigators included members external to the domain of epilepsy who could contribute their expertise based in bereavement counseling (CA), and palliative care (SF). The rationale for the survey questions was informed by the collective expertise and lived experience of the authors, who have been deeply involved in SUDEP research, have themselves experienced bereavement, and provide ongoing care and support to individuals and families affected by loss. Their combined perspectives allowed for the development of questions that were both scientifically grounded and sensitive to the emotional realities of bereavement following SUDEP. Although there were undoubtedly insights to be gained from previous grief surveys [12–14] and experts in other fields such as the social sciences [15] and literature [16], the authors chose to base the survey solely on their direct experience and observations within the SUDEP community, ensuring that the questions reflected the unique features and needs of this population. Of note, the humanities has been incorporated into teaching about grief in the medical setting [17].

This study was approved by the New York University Grossman School of Medicine Institutional Review Board (# i19-01313). A survey was developed through multiple dedicated virtual meetings and electronic correspondence beginning August 2018. The survey was made available from February through May of 2020 via the Qualtrics on-line tool. The survey intended to assess the evolution of the grieving process. Recognizing the potentially sensitive nature of such an inquiry, the survey began with up-front acknowledgment that answering questions related to the death of a loved one might be a difficult task that could evoke strong reactions, and information was provided about how to access counseling should difficulties arise. It is acknowledged that the

responses depend upon the memory of events which occurred as long as 10 years or more ago.

Furthermore, the balance between the number of questions and the likelihood of survey completion was carefully considered. The final version of the survey included such items as decedent and respondent age/gender, respondent relationship to the deceased, ethnicity, geographic location, details of the decedents' epilepsy, comorbidities, family experiences after the death, evolution of emotions, relationships with other families, and recommendations from the bereaved (Appendix). To understand how the grief process evolved, the survey asked for impressions at specific time periods after the death: 3 months, 6 months, 1–2 years, 3–5 years, 6–10 years, and more than 10 years. The rationale for the prolonged survey period was to acknowledge the reality that the grief process evolves over years in an adaptive fashion. A Likert scale was used to assess the impact of the death on certain relationships, activities, and health, with 1 indicating the most positive and 5 indicating the most negative.

2.2. Survey distribution

The survey was made available from February through May of 2020 via Qualtrics online survey software (Qualtrics, Provo, UT, USA). It was distributed to individuals known to be bereaved by the Danny Did Foundation, SUDEP Institute (Epilepsy Foundation), and the North American SUDEP Registry. In addition, organizations that were members of the Rare Epilepsy Network were asked to share the survey with individuals on their mailing lists. Responses were obtained from foundations established for Dravet Syndrome, Lennox-Gastaut Syndrome, SCN2A, SCN8A/Cute Syndrome, Phelan McDermid, Dup15q Alliance, and CDKL5/Hope 4 Harper.

2.3. Data analysis

Descriptive statistics were utilized to report characteristics of the survey participants and decedents as well as topics such as circumstances surrounding death, postmortem occurrences (e.g., autopsy, contact with the epilepsy care provider, police investigation, knowledge regarding SUDEP, and the grief experience), and thoughts regarding what can be done to assist the bereaved in managing their grief. Categorical variables were described in terms of their relative frequencies. All continuous variables in the study were normally distributed and therefore characterized by their means and standard deviations (SD). Correlations between time and scores reported for each of the effects on grief were performed using the Pearson correlation coefficient, for which a p -value ≤ 0.05 was considered significant.

The "effect score" reported in Tables 3 and 4 represents the mean Likert-scale response for each domain (e.g., relationship, health, work), where lower scores indicate more positive and higher scores more negative effects. This provides a standardized way to describe the direction and relative magnitude of change in each domain across timeframes. Regarding differences in n across time periods, we agree that identical sample sizes would be ideal; however, since this was a cross-sectional survey and not a longitudinal cohort, the number of respondents naturally varied at each timeframe. Our analytic focus was therefore on the proportion or mean score within each timeframe rather than absolute numbers, emphasizing the ratio or percentage distribution of responses to capture the evolving pattern of grief over time. This approach is consistent with descriptive cross-sectional methodology, in which group means or proportions are compared across time-since-event categories to illustrate temporal trends rather than to infer causal change. To strengthen this interpretation, correlations (Pearson r) were calculated between time since death and mean effect scores, providing a measure of the direction and strength of association between time and reported grief impact. The statistical paradigm therefore rests on trend analysis across independent respondent groups, not on paired longitudinal comparisons.

3. Results

A total of 206 surveys were returned, with 87 % of them being entirely completed. Overall response rates could not be calculated due to the survey's design. To provide clarity, the percentage of respondents at each time period is followed by the numerator and denominator used for that calculation. As not all respondents answered all questions, the denominators are not always 206 for each item.

3.1. Participant characteristics

Of the 206 respondents, 76% were female and 79% were in the age range of 35–74 years. Ninety-four percent of the 194 respondents identified as white. The geographic distribution was roughly equal (20.4—27.7 %) from the West, Northeast, Midwest, and South. Most (77 %) of the responders were the parents or primary caregivers of the deceased, and the remaining were their partner/spouse (12 %), sibling (7 %), child (2 %), grandparent (2 %), other (2 %), and friend (1 %) (Table 1).

3.2. Decedent characteristics

The age at the time of death was broad (range 0 – 64 years, mean + SD 24.3 + 12.8 years) and 67.7% male. Similarly, the age at seizure onset was distributed from the first year of life to greater than 50 years. The seizure types were dominated by convulsions (74 %), followed by focal, unaware, absence, myoclonic (38 %) (Supplemental Table 1).

Almost half (48.4 %) of individuals were taking only 1 antiseizure medication (ASM) at the time of death, 19 % taking 2, 9.9 % taking 3, 5.2 % taking 4 and 1.6 % on 5 ASMs. A minority of decedents (8.9 %) were not taking ASMs at the time of death (Supplemental Table 1). Of the 192 respondents, the living situation of 147 (76 %) was alone (n = 19), with others but in a separate room (n = 31), or with a family but in a separate room (n = 97) (Supplemental Table 1).

The 187 respondents reported a variety of co-morbidities. The deceased were reported to have a mood disorder (18 %), intellectual disability (17 %), autism spectrum disorder (9 %), and genetic or chromosomal disorder (10 %), among other less frequent associations (Supplemental Table 1).

Only 9.9% of the deceased lived alone. The majority (50.5 %) lived with family members but in separate sleeping arrangements, while an additional 15 % shared a room or bed with family. Notably, nearly 85 % of the decedents were independent in their daily activities (Supplemental Table 1).

3.3. Circumstances of death

The majority (63.1 %) of deaths took place 2–10 years prior to the survey, with 27% occurring < 2 years and 9.7 % occurring > 10 years. The respondent was the first person to find the deceased in almost 39 % of instances. The person who found the deceased was not specified in other 61 % of cases. Seventy percent of deaths occurred while asleep and, in the bedroom (Table 1).

3.4. Postmortem occurrences

An autopsy was reported in 76.6 % (151/197) of deaths. When it was not done, it was usually because the medical examiner/coroner (34.9 %) or physician (39.5 %) did not think it was necessary. SUDEP was the reported cause of death in 51.5 % of reports, followed by epilepsy/seizure (21.1 %), other (19 %), and heart disease (4.6 %). The family received the medical examiner/coroner's report within 5 months in 90 % of the autopsies (Supplemental Table 1).

Respondents reported that 69.7% (131/188) of the deceased were in the care of a general or pediatric neurologist at the time of death. However, 55.8 % (106/190) reported that care at that time was

Table 1

Demographic characteristics and SUDEP-related experiences of the study participants.

Characteristic or SUDEP-related experience	Study Participants n = 206 (100%)
Age	
18–24 years	2 (1.0)
25–34	10 (4.9)
35–44	36 (17.5)
45–54	50 (24.3)
55–64	66 (32.0)
65–74	35 (17.0)
75–84	7 (3.4)
Sex	
Male	48 (23.3)
Female	157 (76.2)
Non-binary	1 (0.5)
Race	
White	194 (94.2)
Black	5 (2.4)
Asian	2 (1.0)
Hispanic	7 (3.4)
Preferred not to answer	2 (1.0)
Region	
USA- Northwest	42 (20.4)
USA- Midwest	57 (27.7)
USA- South	45 (21.8)
USA- West	48 (23.3)
Outside of the USA	14 (6.8)
Relationship to the deceased	
Parent	24 (11.7)
Partner or spouse	159 (77.2)
Sibling	14 (6.8)
Child	12 (5.8)
Grandparent	4 (1.9)
Friend	1 (0.5)
Other	4 (1.9)
Time from SUDEP	
0–6 months	9 (4.4)
7–12 months	12 (5.8)
13–18 months	20 (9.7)
19–24 months	15 (7.3)
2–4 years	74 (35.9)
5–10 years	56 (27.2)
> 10 years	20 (9.7)
Witnessed SUDEP at home (n = 194)	
Yes	30 (15.5)
Was at home but did not witness	113 (58.2)
No	51 (26.3)
Were you the first person to find the deceased? (n = 191)	
Yes	74 (38.7)
No	117 (56.8)
Met or spoke to the provider following SUDEP? (n = 131)	
Yes	75 (57.3)
No	50 (38.2)
Unsure	6 (4.6)
Time from SUDEP until meeting or speaking to a provider (n = 75)	
< 1 week	46 (61.3)
1–4 weeks	20 (26.7)
1–3 months	6 (8.0)
4–6 months	3 (4.0)
SUDEP-related questions were answered by my provider (n = 75)	
Strongly agree	13 (17.3)
Somewhat agree	21 (28.0)
Neither agree nor disagree	17 (22.7)
Somewhat disagree	10 (13.3)
Strongly disagree	14 (18.7)
Was a police investigation done? (n = 190)	
Yes	135 (71.1)
No	41 (21.6)
Unsure	14 (7.4)
Treated with suspicion during police investigation? (n = 126)	
Strongly agree	7 (5.6)

(continued on next page)

Table 1 (continued)

Characteristic or SUDEP-related experience	Study Participants n = 206 (100%)
Somewhat agree	17 (13.5)
Neither agree nor disagree	19 (15.1)
Somewhat disagree	7 (5.6)
Strongly disagree	66 (52.4)
Don't know/remember	10 (7.9)

provided by an epileptologist, defined as a neurologist specializing in epilepsy, raising the possibility of care from multiple neurological providers (Supplemental Table 1). A meeting or phone call with the provider occurred following the death in 57.3 % (75/131) of cases; 88 % (66/75) of the time, this occurred within 4 weeks. The response to the question, "All of my questions were answered during the meeting with the provider," was answered positively (strongly or somewhat agree) only for 45.3 % (34/75) of the encounters. In comparison, another 32 % (24/75) strongly or somewhat disagreed (Table 1).

A police investigation was reported to have been performed 71.1 % (135/190) of the time; 64.3 % (85/132) of respondents indicated that they felt that the police treated them with compassion during the investigation, whereas the remainder were either neutral or disagreed to some extent. Most (58 %, 73/126), disagreed with the statement that "family members were treated with suspicion." (Table 1).

3.5. SUDEP knowledge

Most of the respondents (69.2 %, 135/195) had not known prior to their family member's death that people with epilepsy are at risk for sudden death, and 69.4 % had never heard the term SUDEP. When it was unfamiliar, the term SUDEP was primarily made known to the respondents by a doctor (42 %, 21/50), the internet (30 %, 15/50), or advocacy groups and other people affected by epilepsy (Table 1). The respondents overwhelmingly expressed a desire to have been informed about SUDEP (88 %, 126/142), but only 16.8 % (29/173) of the decedents had been told about SUDEP. Although the majority (57.3%, 94/164) indicated a desire for the decedent to have been informed about SUDEP, 17.1 % (28/164) did not wish this to occur, and 25.6 % (42/164) were unsure (Table 2). However, the effect of knowledge about SUDEP or lack thereof was not queried in this survey Tables 3 and 4.

3.6. The grief experience

The responses to the question "how did the death affect the following" (relationships with spouse/partner, surviving children, friends, work, physical and mental health) revealed that the most negative responses occurred at 3 months and gradually improved over time in all domains (Table 3). In addition, relationships with spouses/partners actually grew closer over time, whereas there was no indication of an increased divorce rate, which averaged around 10% per time period. The inclination to be more protective of surviving children was pronounced up to 1 year, then gradually declined at subsequent time points (Table 4).

A remarkable finding was the report of "Unable to focus on work or performance suffered" (Table 4). This was endorsed by 52.6 % (51/97), 50.7 % (36/71), and 39 % (21/54) of respondents at three months, six months, and one year, respectively. It was not noted with that frequency at future time periods. As expected, difficulties with sleep, lethargy, and feelings of depression were prominent in the first year after the SUDEP. These declined with time but remained present to some degree after 5–10 years. In contrast, the endorsement of "became resilient" was relatively low in the first year (11 %) and then steadily increased to 89 % at 10 years or more.

Feelings evoked by thinking about the deceased loved one changed with time (Table 4). Sadness was profound (93.5 %, 157/168) in the

Table 2

Issues relating to prior knowledge or awareness of SUDEP.

Issue related to SUDEP knowledge or awareness	Study Participants n = 206 (100%)
Prior knowledge of SUDEP (n = 195)	
Yes	60 (30.8)
No	135 (69.2)
Prior awareness of the term SUDEP (n = 199)	
Yes	52 (26.1)
No	147 (73.8)
Source of SUDEP information (n = 50)	
Doctor	21 (42.0)
Other healthcare provider	2 (4.0)
Internet	15 (30.0)
Advocacy group	9 (18.0)
Other people with epilepsy	8 (16.0)
Other	9 (18.0)
Would you have wanted to have prior knowledge of SUDEP? (n = 142)	
Yes	126 (88.7)
No	3 (2.1)
Unsure	13 (9.2)
Did the deceased have knowledge of SUDEP? (n = 173)	
Yes	29 (16.8)
No	144 (83.2)
Source of SUDEP information for the deceased? (n = 28)	
Doctor	17 (60.7)
Other healthcare provider	3 (10.7)
Internet	1 (3.6)
Advocacy group	3 (1.1)
Other people with epilepsy	2 (7.1)
Other	6 (2.1)
Would you have wanted the deceased to have prior knowledge of SUDEP? (n = 164)	
Yes	94 (57.3)
No	28 (17.1)
Unsure	42 (25.6)
Was your grief impacted by learning SUDEP was the cause? (n = 170)	
Yes	118 (69.4)
No	29 (17.1)
Unsure	23 (13.5)
How was your grief impacted by learning SUDEP was the cause? (n = 117)	
Increased regret/guilt	69 (59.0)
Provided answers or clarification	56 (47.9)
Left me with more questions	48 (41.0)
Felt angry/frustrated about not having been told about SUDEP earlier	80 (69.4)
Other	4 (34.2)

beginning (3 months), but remained prominent after 10 years (75 %, 12/16). Anger and feelings of guilt decreased from 3 months (61.9 % and 73.2 %, respectively) to much lower levels, reaching a nadir at 10 years for those who responded (6.2 % and 18.8 %, respectively). Acceptance increased over time, from an initial value of 6 % at 3 months to 81.3 % at 10 years or longer.

Learning about SUDEP as the cause of death affected the grief experience in the majority (69.4 %, 118/170), whereas it did not influence some 17.1 % (29/170), and others were unsure (13.5 %, 23/170). The effects of that knowledge were varied and included increased guilt (59 %, 69/170), provided answers or clarification (47.9 %, 56/170), left more questions (41 %, 48/170), and felt anger/frustration about not being told about SUDEP earlier (69.4 %, 80/170) (Table 1).

3.7. What can be done to help

The respondents identified several things that they found helpful in the grieving process (Table 5). The most prominent included interactions with others who understood the loss and family/friends who were willing to lend a sympathetic ear (both over 60% of the 169

Table 3

The effects of SUDEP on grief over time (lower values indicate positive and higher values negative).

Effect	3 Months	6 Months	1 Year	2–5 Years	6–10 Years	> 10 Years	Correlation between effect score and time R (p value)
Relationship with Spouse/ Partner	3.07 (n = 146)	2.78 (n = 140)	2.53 (n = 126)	2.50 (n = 103)	2.44 (n = 43)	2.27 (n = 15)	–0.801 (0.055)
Relationship with Surviving Children	2.61 (n = 158)	2.31 (n = 154)	2.20 (n = 140)	2.15 (n = 114)	1.96 (n = 50)	2.06 (n = 17)	–0.775 (0.070)
Relationship with Friends	3.08 (n = 177)	2.79 (n = 172)	2.69 (n = 154)	2.62 (n = 125)	2.42 (n = 55)	2.06 (n = 18)	–0.926 (0.008)
Work or career	3.65 (n = 155)	3.46 (n = 149)	3.20 (n = 130)	2.97 (n = 106)	2.67 (n = 46)	2.29 (n = 14)	–0.963 (0.002)
Physical Health	3.99 (n = 175)	3.70 (n = 170)	3.35 (n = 155)	3.12 (n = 124)	2.77 (n = 56)	2.56 (n = 18)	–0.935 (0.006)
Mental Health	4.29 (n = 180)	4.03 (n = 173)	3.68 (n = 152)	3.41 (n = 124)	3.04 (n = 56)	2.50 (n = 18)	–0.958 (0.003)

R- Correlation coefficient; SUDEP- Sudden unexpected death in epilepsy.

Table 4

The detailed effects of SUDEP on grief over time.

	3 Months n (%)	6 Months n (%)	1 Year n (%)	2-5 Years n (%)	6-10 Years n (%)	10+ Years n (%)
Relationship with Spouse/Partner	n = 10661 (57.5)	n = 9862 (63.3)	n = 9361 (65.6)	n = 6744 (65.7)	n = 2822 (78.6)	n = 87 (87.5)
closer	24 (22.6)	10 (9.4)	18 (19.4)	13 (19.4)	3 (10.7)	0 (0)
further apart	13 (12.3)	9 (9.2)	9 (9.7)	6 (9.0)	3 (3.6)	0 (0)
Separated or divorced						
Other						
Relationship with Surviving Children	n = 10462 (59.6)	n = 10661 (57.5)	n = 10044 (44.0)	n = 7833 (42.3)	n = 3514 (40.0)	n = 113 (27.3)
Felt more protective	49 (47.1)	19 (8.7)	67 (63.2)	10 (9.4)	5 (2.9)	10 (90.9)
Felt closer	11 (10.6)		2 (2.0)	3 (3.8)	1 (2.9)	0 (0)
Felt distance between us						
Other						
Relationship with Friends	n = 12470 (56.5)	n = 10660 (56.6)	n = 8558 (68.2)	n = 6943 (62.3)	n = 3226 (81.2)	n = 1010
Strengthened connections and contact	50 (40.3)	33 (33.0)	23 (27.1)	18 (26.1)	17 (53.1)	3 (100.0)
Weakened connections and contact	26 (26.6)	21 (16.9)	13 (12.3)	0 (0)	0 (0)	0 (0)
Formed new connections and friends	21 (16.9)	7 (5.6)	8 (9.4)	11 (15.9)	0 (0)	0 (0)
Was deserted or abandoned by friends						
Other						
Work or career	n = 9716 (16.5)	n = 7116 (22.5)	n = 5412 (22.2)	n = 4518 (40.0)	n = 2013 (65.0)	n = 85 (62.5)
I focused more on my work	26 (26.8)	3 (3.1)	12 (22.2)	9 (20.0)	2 (10.0)	1 (12.5)
I worked less or left the workforce	8 (8.0)	3 (3.1)	9 (16.7)	7 (13.0)	2 (10.0)	2 (25.0)
Sought new employment	51 (52.6)	12 (12.4)	21 (39.0)	6 (13.3)	2 (10.0)	0 (0)
Changed careers						
Unable to focus at work						
Other						
Physical Health	n = 13580 (59.3)	n = 10457 (54.8)	n = 7643 (56.6)	n = 5629 (51.8)	n = 185 (27.8)	n = 40 (0)
Weight or appetite changes	99 (73.3)	89 (53.8)	42 (55.3)	39 (51.3)	6 (33.3)	1 (25.0)
Decreased energy or fatigue	19 (14.1)	15 (14.4)	17 (22.4)	17 (30.4)	6 (33.3)	4 (100.0)
Insomnia or trouble sleeping						
Other						
Mental Health	n = 154135	n = 136104 (87.7)	n = 10366 (64.1)	n = 7541 (54.7)	n = 2915 (51.7)	n = 91 (11.1)
Felt depressed mood/sadness	79 (79.7)	85 (63.0)	60 (45.6)	35 (36.0)	8 (34.5)	10 (11.1)
Decreased energy or fatigue						
Felt anxious	2 (2.0)	13 (11.7)	7 (8.4)	31 (30.1)	3 (44.0)	2 (27.6)
Became resilient						
Other						

SUDEP- Sudden unexpected death in epilepsy.

Table 5

Interventions and services determined as helpful by individuals bereaved to SUDEP.

Helpful intervention or service	Study Participants N = 206 (100%)
Activities (N = 169)	
Finding individuals who understood the loss	105 (62.1)
The listening ear of friends/family	103 (60.9)
Meeting others who have experienced the same loss	80 (47.3)
Counselors, therapists, or psychologists	76 (45.0)
Working to prevent future SUDEP cases	68 (40.2)
Reading self-help books or attending seminars	66 (39.1)
Being alone	66 (39.1)
Seeking help through a support group	64 (37.9)
Seeking religious guidance and support	46 (27.2)
Taking medication for the emotions experienced	31 (18.3)
By healthcare professionals (n = 167)	
Offer condolences to the family after the death	128 (76.7)
Answer any questions the family may have	149 (89.2)
Allow the family space to grieve before reaching out	35 (21.0)
Other	37 (22.2)
By advocacy groups (n = 169)	
Provide a listening ear	148 (87.6)
Answer any questions the family may have	147 (87.0)
Provide support group information	137 (81.1)
Other	22 (13.0)

respondents). These were followed by counseling from professionals aimed at preventing SUDEP from occurring in the future, as well as participation in learning seminars, support groups, and religious guidance.

Recommendations for medical professionals clearly indicated that the bereaved appreciated the offering of condolences (76.7 %, 128/167) and answering questions from the family (89.2 %, 149/167). Similarly, the importance of being connected with advocacy groups that can provide a listening ear, answer questions, and offer support group information was highly endorsed in over 80% of each category (Table 5).

4. Discussion

4.1. Survey results

Ascertainment bias inherent in a survey of this nature, together with permission for respondents not to answer any upsetting questions, preclude assumptions regarding how other bereaved may feel, limiting generalizability to the whole population of those bereaved due to SUDEP. Nevertheless, important guidance can be gleaned, especially when comparing the data to previous reports that explored various aspects of this topic.

4.2. Participant characteristics

Surveys regarding attitudes towards SUDEP have involved people living with epilepsy (PWE) [5,18] as well as those bereaved due to a loss often due to SUDEP [7,8,19]. The results of these studies, regarding the patient/caregiver's desire to know about SUDEP and the lack of pre-morbid counseling, are strikingly similar to those reported in the current study. In brief, greater than 70% of patients or caregivers want to be counseled regarding SUDEP.

Participant characteristics regarding their desire to have been counseled about the possibility of SUDEP are similar to those reported in previous studies [5,18,20,21]. Decedent factors such as history of tonic-clonic seizures and the occurrence of SUDEP while in bed presumably asleep were similar to other reports [22–29].

4.3. Deceased characteristics

Some of the earliest reports indicate that SUDEP can occur at any age [30]. More recent studies have teased out more nuanced factors, such as the occurrence in childhood [31,32] and the possibility that older individuals may die of SUDEP but that a medical examiner's report may attribute the fatality to more common causes of mortality (e.g., coronary artery disease). Examples from other studies in which deceased characteristics were reported allow comparison with our population- age of death 24.3 + 12.8 years, range 0 – 64 years; 67.7% male). In the North American SUDEP Registry [33], comparable figures for age of death and gender were 26 years (range 1–70) and 62% male. The finding that the majority (76%) of the deceased were alone is concordant with the evidence that individuals with epilepsy sleeping alone or not being supervised in some manner have an increased risk of SUDEP.

4.4. Circumstances of death

The reports in this survey indicating that the majority of the deaths occurred in bed, presumably asleep, are comparable to other studies [26,33]. This very consistent finding highlights the importance of sleep in the underlying pathophysiology of SUDEP.

4.5. Autopsy

In this series, autopsy was performed in 76.6 %, whereas the diagnosis of SUDEP was reported in only half of deaths. However, the report of “epilepsy/seizure” makes it likely that SUDEP was in fact the cause in most cases. Of note, the classification of “definite SUDEP” requires an autopsy that reveals no other likely cause of death [34]. For comparison, the North American SUDEP Registry found that an autopsy was performed in 65 % of cases with 92 % of these deaths being attributed to epilepsy [33]. The importance of a carefully performed autopsy cannot be overstated as this not only provides the most accurate possible diagnosis but is also essential for surveillance purposes to facilitate the effect of potential interventions as well as other research. A survey of medical examiners using case vignettes found that lack of terminology available to diagnose SUDEP as the cause of death and lack of ICD-10 codes available, significantly impaired the identification of SUDEP cases [35]. A recent study from Canada indicated concordance for most cases (75 %) of definite SUDEP between the neurologist's diagnosis and that found by a forensic pathologist [36], emphasizing the necessity of neurologist and pathologist collaboration. In this context a critical contribution to the forensic pathology literature was a publication by the National Association of Medical Examiners in which recommendations were made for death investigation related to seizures and the possibility of using ‘SUDEP, epilepsy, sudden death due to epilepsy’ as synonymous terms for the cause of death [37]. An accurate diagnosis is key to a loved one's understanding of “what happened” to facilitate the grief process. However, the impact of an autopsy on the grief process is complex, as illustrated by a report that described how an autopsy can be

both helpful in dealing with grief (41 % of respondents) and add to suffering (42 %) [38].

4.6. Police investigation

The frequency with which the police were perceived to have expressed compassion during the death investigation (which occurred in 71 % of deaths), is an opportunity for improvement. Participants reported that compassion was expressed in 65 % of the interactions, indicating that over one-third of the bereaved did not believe that the police investigators were as suitably compassionate as desired. Although police reports are an integral part of every death investigation, reports of the behavior of police are limited. In a recent report involving interviews with 21 individuals affected by SUDEP, one bereaved person described the police officers as “inappropriate, caustic, abrasive” [9]. Although there was no comment on exactly how police interacted with the bereaved, respondents to a survey indicated that police were among “the most helpful supports following the death” [19]. A recent report regarding the effect on mental health during police notifications of death identified positive and negative behaviors that affected the grief of the bereaved [39].

4.7. The grief experience

The primary goal of this project was to enhance understanding of the grief process by charting its evolution over time and identifying potential means of mitigating that grief.

Very few published reports have queried the bereaved regarding their grief experience following SUDEP, and do not identify how long ago the SUDEP occurred. An early study [40] aimed to determine the circumstances of SUDEP by interviewing 34 individuals, comprising family members (parents, siblings, spouses/partners) and several non-family members, supplemented by information from medical records. While the study did not provide quantitative assessments, several themes were present, including feelings of guilt, lack of commonly offered counseling, and the wish that they and the deceased had been informed of the risks of seizures, with the hope of some type of prevention being possible. These themes were echoed in the current study.

A report by 6 bereaved parents who participated in a qualitative study regarding their desires for SUDEP education [8] was subsequently followed by a larger qualitative investigation by the same team. The follow-up study aimed to gather recommendations from the bereaved, including 27 family members aged 18 years or older [7]. Participants were identified via the Canadian advocacy group, SUDEP Aware (sudepaware.org). The sample consisted of 78 % females and primarily parents (86%), which is similar to the current study (76 % and 77%, respectively). The age range, race, and ethnicity were not noted, so other comparisons cannot be made. Although not quantified, parents reported feelings of shock, regret, and guilt, the latter related to the possibility of implementing preventative measures had they known that SUDEP was a risk.

In a recent report regarding bereaved experiences from a United Kingdom death registry and the SUDEP Action website [41], five bereaved family members were quoted (three parents and two siblings) [42]. They described their experiences with words such as pain, shock, trauma, devastation, isolation, grief, anger, and despair. There was the expressed feeling of “oppression by society” regarding how the bereaved should feel and behave following a loss.

In another study, 21 bereaved individuals who lost loved ones between 3- and 84-months prior were interviewed regarding their grief experiences [9]. Participants described anger, “health and social effects across multiple domains... mental health issues, depression and anxiety... [and] survivor guilt,” in addition to impact on “social and intimate relationships.”

The responses from 3 months to 10 years indicate that relationships with spouse or partner and surviving children did not really change over

this period if a 20% difference is used as a cut-off. In contrast, the effects of the loss of work or career, physical and mental health, improved over time. The trend in the relationship with the spouse or partner suggests that it strengthens over time. Furthermore, there did not seem to be an increased divorce rate following the SUDEP among the participants at each time point. Regarding the relationships with surviving children, there was a decline in feeling more protective, as well as a sense of growing closer over time. However, there can be significant mental health consequences of sibling loss [43,44]. Connections with friends were maintained over time, although there was a slight decrease in contacts during the first year.

The trajectories of the grief response following the loss of a loved one are complex and have been reported and reviewed in a variety of populations and relationships [43,45–47]. Selected studies relating to the premature death of a child report different intensities of the grief response [48] and long-term effects on social, occupational, psychological, and health measures [49].

A recent systematic review of traumatic loss of a child identified 7 publications that met study criteria [50]. Although SUDEP was not included as a cause of death, factors that influenced outcomes were the mode of death (e.g. accidents, sudden infant death), relationship type (e.g. mother, father), duration since the event, level of support from the community, and perceived justice (e.g. responses following a ferry accident). The interested reader should pursue these references, as a more detailed review is beyond the scope of this manuscript.

4.8. What can be done?

A survey of the bereaved who self-identified via Australian epilepsy-related organizations received 101 responses [19]. As in the current study, the deaths occurred from less than one year prior to the survey to greater than ten years. The supports that were mentioned as most helpful were family and friends, followed by learning more about the death, religious connections, support from other bereaved, bereavement support groups, hospital staff, and epilepsy specialist doctors, to name a few. Others identified counseling, family support, advocacy, and fundraising activities as means of coping with grief [9]. Helping families to establish or strengthen these connections represents a tangible form of support that healthcare teams and community organizations can offer.

In North America support can be found via several epilepsy-specific organizations such as PAME (pameonline.org), the Epilepsy Foundation (epilepsy.org), Danny Did Foundation (dannyydid.org), SUDEP Aware Canada (sudepaware.org), those with epilepsy based in a genetic variation (Rare Epilepsy Network (rareepilepsynetwork.org)), as well as more general grief support groups e.g. MISS Foundation (missfoundation.org). Familiarity with these organizations is essential for those working with the bereaved in any capacity, as is attention to up-to-date availability of credible information and support.

The findings in the current study support the interventions previously noted and emphasize, just as in grief from other losses, that there is no one solution applicable to all who suffer. The importance of support from family, friends, advocacy organizations and those who are similarly affected is clear. Almost 40% of respondents identified working to prevent SUDEP from happening to others to help abate their grief. The recommendations for medical professionals are straightforward: offer condolences and answer as many questions as possible. Maintaining contact is particularly important in the current era of open notes, in which health care powers of attorney and parents of minor children have transparent access to a patient's medical record.

Regrettably, we cannot know with certainty whether or not the possibility of SUDEP was discussed with either the person living with epilepsy or those who may have attended clinic with them as this question was not asked. The direct effect of not having this knowledge on the grief process is unknown, it is clear that the majority of the bereaved desire this information (88.7%, 126/142 respondents), as well as those living with epilepsy as reported in previous studies. The

discussion with young and older adults allows them autonomy and the opportunity to directly participate in their care. The knowledge of SUDEP can motivate adherence to medication and encourage the pursuit of other therapies such as epilepsy surgery or neuromodulation, thereby reducing the most important risk factor, uncontrolled seizures, and other risk factors such as unmonitored sleeping. Ideally, the conversation should include siblings, grandparents, and anyone else who is close to the person living with epilepsy, with their permission if age-appropriate, as these individuals can sometimes be left with survivor's guilt or guilt about what they last said or did to their loved one.

Notably, although improvements in several domains of the grief process occur within 1 year, others may take up to 5 years to plateau or improve. This raises the need for prolonged follow-up, as most hospices funded by the Center for Medicare and Medicaid Services (42 CFR 418.64) (<https://hospicewestaz.com/bereavement.php>) and some community services (hospicenews.com) provide support for only up to 13 months. Those working with families affected by SUDEP could strengthen longer-term follow-up and resources or offer local advocacy for longitudinal follow-up.

5. Limitations

There are several important methodological issues with this study that limit its generalizability to others who have experienced SUDEP bereavement. It should be noted that this a retrospective study with sometimes a long period of time elapsed since the deaths such that memory could confound the results. However, even if the reports may not be factually correct, they still represent reality for the bereaved. Recent research has revealed surprisingly good recall of real-world events [51]. In the context of bereavement other than SUDEP, theoretical and empirical work further shows that memories of deceased loved ones remain psychologically salient and are actively integrated into ongoing meaning-making processes years after the loss, consistent with continuing bonds models of grief [52,53]. There is an ascertainment bias inherent in the study design, as participation was completely voluntary. Due to the lack of identification of respondents, it was not possible to determine if their individual grief experiences changed with time. Respondents were given the option of not answering questions that were found to be upsetting in any way. Thus, the denominators associated with responses to questions varied. Similarly, it was not possible to determine if the grief responses (e.g. difficulty with work) varied by the relationship to the deceased. The respondents were overwhelmingly white, female, and parents of the deceased, further limiting generalizability. Similarly, the lack of ethnographic information (e.g. culture, sexual orientation, religious orientation) needs to be considered in the interpretation of the responses.

Although information was obtained on age at death, conclusions cannot be drawn regarding how respondents' individual answers were affected by their loved ones' ages at death. The responses of a parent to the death of a 35-year-old are likely different from that of a parent of a 10-year-old, and losses of other types of relationships (e.g. siblings, foster parents, grandparents) also likely differ. Finally, there was no comparison group by which to determine if and how the reactions to SUDEP grief were like and different from premature mortality from chronic or acute etiologies.

All of these limitations highlight the need to be careful in generalizing about grief, especially complicated grief, and offer windows into further areas of specific research. Nevertheless, taken together, these results suggest that providers of all disciplines can offer effective grief support through an individualized approach (which includes cultural awareness) that allows longitudinal follow-up and is enhanced by community and organizational awareness. The first step, however, is to name and discuss SUDEP at or near diagnosis of epilepsy, to enable families and healthcare teams to access preventive strategies and resources. Talking about SUDEP will not make it happen but not discussing it can significantly impair a family's grief and long-term coping should it

occur.

6. Conclusions

Despite these limitations, this manuscript offers a unique description of the grief experience of a relatively large number of individuals who have been bereaved by the SUDEP of a family member. The approach of determining feelings about the grief experience at various points in time (up to 10 years following SUDEP) in a standardized fashion has not been previously reported. Several important observations and action items can be drawn from the data. Although the grief experience is in many ways chronic, the data support that there is healing along multiple domains with time. The importance of discussing SUDEP with patients and families, as well as the impact of support from friends, family, and community, cannot be overstated. Community-based advocacy organizations can assist with bereavement support, ongoing opportunities to remember the bereaved, opportunities to participate in research, referral to registries/tissue donation and opportunity to participate in activities that advance SUDEP research and prevention.

Many bereaved were given an opportunity to meet with the provider within a month of the incident, but there is a need for the provider to be better equipped to answer questions or, at the very least, plan an opportunity to do so in the future. Delays in getting autopsy results and the reality that the “reason” for a particular death is often unknown are factors that underlie the importance of continuing basic research into the mechanisms underlying SUDEP. In addition, research regarding the evolution and potential mitigating interventions of grief experience in those bereaved by SUDEP will be of benefit to the bereaved in their journeys. Finally, a clear need for continued education of police and medical examiners has been identified. Alongside prevention strategies, open communication about SUDEP and provision of longer-term, multifaceted grief support can minimize the ripple effect of loss and empower those with epilepsy and their families to face the future with resources and hope.

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CRediT authorship contribution statement

Jeffrey Buchhalter: Writing – review & editing, Writing – original draft, Project administration, Methodology, Conceptualization. **Catherine Andrews:** Writing – review & editing, Writing – original draft, Methodology, Conceptualization. **Jeanne Donnalty:** Writing – review & editing, Writing – original draft, Methodology, Conceptualization. **Elizabeth Donner:** Writing – review & editing, Writing – original draft, Methodology, Conceptualization. **Sarah Friebert:** Writing – review & editing, Writing – original draft, Methodology, Conceptualization. **Daniel Friedman:** Writing – review & editing, Writing – original draft, Methodology, Conceptualization. **Avani Patel:** Writing – review & editing, Writing – original draft, Formal analysis. **Gardiner Lapham:** Writing – review & editing, Writing – original draft, Methodology, Conceptualization. **Itay Tokatly Latzer:** Writing – review & editing, Visualization, Formal analysis. **Phillip L. Pearl:** Writing – review & editing. **Rajesh Ramachandranair:** Writing – review & editing, Writing – original draft, Methodology, Conceptualization. **Sally Schaeffer:** Writing – review & editing, Writing – original draft, Methodology, Conceptualization. **Thomas Stanton:** Writing – review & editing, Writing – original draft, Methodology, Conceptualization.

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