RESEARCH ARTICLE

SUDEP Awareness and Effect on Parental Trauma, Grief, and Coping After the Death of a Child

A Qualitative Investigation

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Abstract

Background and Objectives

Sudden unexpected death in epilepsy (SUDEP) is the leading cause of seizure-related deaths in people with epilepsy. Despite evidence that SUDEP counseling does not cause stress, improves treatment adherence, and empowers people with epilepsy and their caregivers, it remains underdiscussed. This study aimed to explore the in-depth perspectives of parents who have lost a child to SUDEP, focusing on their experiences, grief, and coping strategies, while factoring in their demographics, the clinical features of their deceased children, and their previous awareness of SUDEP, all aspects that have not been systematically investigated before.

Methods

This qualitative phenomenological study involved in-depth semistructured interviews with 51 parents of 43 children who died of SUDEP. Transcripts were analyzed using immersion/crystallization qualitative methodology with Dedoose software, using an iterative consensus-building process. Thematic analysis revealed common perspectives, grief narratives, coping strategies, and perceived needs among parents after their child's SUDEP.

Results

Of the 51 participating parents (mean age 54.1 ± 9.4 years, 71% female), 27 reported being unaware of SUDEP before it occurred, whereas 24 reported previous awareness of it. These groups shared similar demographics and clinical characteristics. However, "unaware" parents expressed more intense trauma and prolonged maladaptive grief, characterized by guilt, extreme anger, and medical distrust. By contrast, "aware" parents described mitigated trauma, with less guilt- and anger-ridden grief, and reduced reliance on specialized support groups. Previous SUDEP awareness provided emotional preparation, buffering the devastating reality and fostering agency and acceptance. Another theme highlighted the struggles parents faced immediately after SUDEP, particularly with law enforcement and treating physicians. Unanimously, parents emphasized the paramount importance of counseling about the known relationship between epilepsy and SUDEP.

Discussion

Previous awareness of SUDEP (or lack thereof) has complex and far-reaching effects on the subsequent parental perceived trauma, grief, and coping processes. Furthermore, emergency responders, official personnel, and treating physicians may mishandle the aftermath of SUDEP. This study's findings strongly advocate for a paradigm shift in SUDEP-related practices across multiple disciplines, including legislation. Emphasis should be placed on increasing proactive SUDEP counseling to mitigate the traumatic effect and subsequent grieving process when SUDEP occurs.

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Glossary

PWE = people with epilepsy; **SUDEP** = sudden unexpected death in epilepsy.

Introduction

Sudden unexpected death in epilepsy (SUDEP) is the leading cause of death in people with epilepsy (PWE),[1] with an incidence of approximately 1/1,000 patient-years in adults and children.[2,3] Globally, SUDEP is the second most common neurologic cause of lost potential years of life, trailing only stroke.[4] Despite concrete evidence from multiple global sites,[4-6] official guidelines,[7] and expert consensus[8] advocating for SUDEP counseling for PWE and their caregivers, it remains underdiscussed.[9]

SUDEP not only claims lives but profoundly affects the bereaved. Studies on SUDEP-bereaved relatives indicate they may experience prolonged grief disorder,[10-12] leading to work and relationship disruptions, as well as psychiatric disorders.[13] The traumatic effect of witnessing this sudden death and the importance of early intervention for mitigating traumatic grief has also been highlighted.[14] However, studies addressing this topic have not explored how parents' perspectives, grief duration, and course are shaped by various factors, such as parental demographics, the deceased child's age, family structure, clinical parameters (e.g., epilepsy type, control level, intellectual disability), time elapsed since SUDEP, and previous SUDEP awareness.

Acknowledging the enduring ripple effect SUDEP may have on grieving parents, this study aimed to provide an in-depth examination of their experiences, issues related to their child's epilepsy journey, the circumstances surrounding the SUDEP event, the immediate post-SUDEP period including the interaction with their child's treating physician, the grief process, effects on marriage and social relationships, support systems, and coping strategies. Our investigation factored in the parents' demographics, grief duration, previous SUDEP awareness, and the deceased children's clinical characteristics.

Methods

This qualitative phenomenological study was based on semistructured interviews using purposeful sampling combining criterion sampling[15] of parents of children who died from SUDEP, all of whom were the children's primary parents. Participants were recruited through Partners Against Mortality in Epilepsy, North American SUDEP Registry, and the Danny Did Foundation. Parents were contacted after expressing interest to these organizations' representatives or their direct communication with our research team. The study's original intent was to explore how previous SUDEP awareness shaped parental perspectives, and it was not specifically designed to compare "aware" or "unaware" parents. However, during the early stages of thematic analysis, it became evident that previous SUDEP awareness was associated with distinct patterns of grief and coping. As these differences emerged, we decided to examine the 2 groups in comparison. Accordingly, because our initial participant pool had a higher proportion of "unaware" participants, we modified our recruitment strategy to seek "aware" parents actively, enabling a more balanced and meaningful comparison between the groups. Recruitment concluded when data saturation was reached across the data set as a whole and within the subthemes identified for each group.[16]

The interviews were conducted between March and June 2025 by the first author, an epileptologist with no previous association with the interviewees. All interviews were conducted in English with participants, all native English speakers, who took part either individually or as couples. The interview's initial areas of inquiry were informed by previous literature on SUDEP and parental grief, and the clinical experience of the first and last authors. Each interview began with the collection of parent and child demographic and clinical details and then covered 5 domains: (1) child's life and epilepsy, (2) circumstances of SUDEP, (3) immediate and long-term emotional/relational responses, (4) coping strategies and support, and (5) previous SUDEP awareness and perceived effect (eAppendix 1). Within the context of grief, symptoms of prolonged grief disorder were defined according to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5).[10] Reflective debriefing between the first and last authors occurred after every few interviews, focusing on questioning techniques to improve interview quality (e.g., using more interviewee-driven probing). Verbatim transcripts were deidentified using pseudonyms and uploaded to Dedoose (version 10.0.25, Los Angeles, CA). Thematic narrative analysis followed the immersion/crystallization method, involving iterative and successive readings of the data.[17] Investigator triangulation of shared analysis methodology was used to enhance trustworthiness.[15] The first and last authors, both board-certified epileptologists trained in qualitative analysis, independently coded transcripts after jointly developing an initial codebook from the first 4. Duplicate codes were removed by clustering related codes into categories, and coding disagreements were resolved by revisiting transcripts and specific quotes within context, consistent with the immersion/crystallization method. An external qualitative research expert guided an iterative discussion process to achieve consensus on emerging themes, ensuring data-grounded findings. The analysis included a horizontal inquiry into individual experiences, followed by a vertical analysis substantiating the cross-interview and group comparisons.[18]

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Statistical Analysis

We conducted a quantitative analysis comparing parents with and without previous SUDEP awareness to assess whether demographic or clinical differences of their deceased children accounted for qualitative contrasts. Data were analyzed using SPSS Statistics (version 29, IBM, Armonk, NY). Categorical variables were summarized as within-group frequencies and compared using the χ^2 or Fisher exact tests when expected counts were <5. Continuous variables were tested for normality (Kolmogorov-Smirnov test and histogram inspection); normally distributed data were reported as mean ± SDs and compared with independent *t* tests, whereas skewed data were summarized as median and interquartile ranges and compared with Mann-Whitney tests. Statistical significance was set at $p < 0.05$ for all analyses.

Standard Protocol Approvals, Registrations, and Patient Consents

The study was approved by the Boston Children's Hospital Institutional Review Board (#P00050508). All participants reviewed and electronically signed an informed consent form.

Data Availability

Anonymized data not published within this article may be requested by qualified investigators.

Results

The study included 51 parents of 43 children who died from SUDEP (Table 1). Our thematic analysis identified 4 themes, overarching 12 subthemes, reflecting parental perspectives on SUDEP (Tables 2–5). Parent demographics and children's characteristics informed observations on how these factors influenced the themes. Initial shock and trauma were consistent across all participants, regardless of sex, family structure, or time since loss. However, grief varied: Women and single parents reported more intense, prolonged grief disorder symptoms,[10] and more recent SUDEP events correlated with greater emotional intensity. Coping strategies also differed, with women more likely to seek therapy, and spousal relationships and employment aiding coping. Notably, although many participants mentioned continued employment as helpful for coping, the small number (n = 11) of unemployed respondents limits these conclusions. Moreover, of the 11 unemployed participants, 5 (2 "aware," 3 "unaware," $p = 0.69$) stopped working after SUDEP, whereas the remainder were unemployed beforehand or retired. The child's age, epilepsy type, seizure control, and epilepsy duration did not significantly affect trauma, grief, or coping.

Previous awareness of SUDEP (or lack thereof) emerged as the most impactful intrinsic factor, influencing initial shock, trauma, grief, and coping. Hence, we focused on presenting narratives from "aware" (n = 24) and "unaware" (n = 27) parent groups. These groups did not differ significantly in demographics or in most of the demographic clinical characteristics of their deceased children, although children of "aware" parents had a significantly higher rate of drug-resistant epilepsy ($p = 0.05$) (Table 1). The main themes and subthemes are outlined below, with further representative quotations available in Tables 2–5. Quotations are attributed to participants using identifiers indicating participant (P) number, sex ("F"—female; "M"—male), and group affiliation ("A" for parents who were previously "aware" of SUDEP and "UA" for those who were "unaware" of it). For example, (P3, M, UA) denotes participant 3, male, from the "unaware" group.

Theme 1: Immediate Upheaval

Shock and Trauma

Parents described substantial trauma after the experience of finding their child dead in their homes and participating in failed resuscitation efforts or being informed of their child's death and arriving at the scene: "One challenge we're having is that we have PTSD over the trauma. You wake up one day and find your kid dead in his room. I can't imagine anything worse as a parent than that" (P3, M, UA). Mitigation of the immediate trauma was recounted by parents who had previous awareness of SUDEP, and linked to having that foresight: "… yes, knowing about SUDEP before softened the blow, because the minute I rolled him over, I'm like, this is it. It happened. The thing I dreaded is here. I think not knowing you would be like, what the hell is going on?" (P2, F, A).

Police and Procedures

In the immediate aftermath of SUDEP, parents frequently encountered a distressing lack of understanding and insensitive handling from first responders, law enforcement, and emergency room personnel: "Neither the EMT or the detective made any connection between his medical history of epilepsy and his death, you know, no more than I would have" (P42, M, UA). This mishandling often escalated their already immense emotional turmoil: "They made my husband go to the police station, and they were saying stupid things like, 'Why wasn't your wife sleeping in the same room as your child?'" (P1, F, A). Many also voiced frustrations over legal battles to obtain autopsies and expressed a strong desire for a dedicated point person to simplify the chaotic period after their child's death (Table 2). Previous SUDEP awareness was reported as a mitigating element of these adverse experiences:

> It's a weird thing to say, but it was nice to have something to point to right away. Seriously, the second I saw him, I knew what this was, and I didn't have to wait for any official. But if I hadn't known about SUDEP, that would have been a very weird sensation to come home and go, okay, I have no clue why my son passed away (P37, F, A).

Interaction With the Treating Physician

Dismissive or absent interactions with treating physicians, including their failure to acknowledge SUDEP or offer empathy and resources, compounded parents' distress in the immediate post-SUDEP period:

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Table 1 Demographic and Clinical Characteristics of the Study Participants and Their Children Who Died From SUDEP

Characteristic	Parents of the entire study group (N = 51 [100%])	"Aware" parents[a] (n = 24 [100%])	"Unaware" parents[a] (n = 27 [100%])	*p* Value[b]
Age, y, mean ± SD	54.1 ± 9.4	52.0 ± 8.4	56.0 ± 10.0	0.12
Sex (male/female), n (%)	15 (29)/36 (71)	8 (33)/16 (67)	7 (26)/20 (74)	0.39
Race, n (%)				
White	44 (86)	21 (87)	23 (85)	0.63
Black	6 (12)	3 (12)	3 (11)	
Other	1 (2)	0 (0)	1 (4)	
Employment status after SUDEP, n (%)				
Employed	40 (78)	20 (83)	20 (74)	0.64
Unemployed	11 (22)	4 (17)	7 (26)	
Family setting, n (%)				
Biological	36 (71)	14 (58)	22 (81)	0.07
Blended	8 (16)	4 (17)	4 (15)	
Single parent	7 (14)	6 (25)	1 (4)	
Marital status, n (%)				
Married	36 (72)	16 (67)	20 (74)	0.51
Divorced	11 (20)	6 (21)	5 (18)	
Widowed	1 (2)	0 (0)	1 (4)	
Single	3 (6)	2 (13)	1 (4)	
Time from SUDEP to interview, y, mean ± SD	4.7 (2.0–7.8)	3.8 (2.2–6.0)	5.7 (1.5–9.9)	0.38
Duration of interview, minutes, median (IQR)	57.1 (47.3–65.2)	54.4 (47.3–60.1)	57.5 (52.4–70.2)	0.10

Characteristic	Deceased children of the entire study group (N = 43 [100%])	Deceased children of "aware" parents[a] (n = 22 [100%])	Deceased children of "unaware" parents[a] (n = 21 [100%])	*p* Value[b]
Age at death, y, mean ± SD	19.1 (11.5–23.8)	17.0 (11.5–22.4)	19.5 (14.1–25.8)	0.40
≥18 y, n (%)	25 (58)	10 (45)	15 (71)	0.07
<18 y, n (%)	18 (42)	12 (55)	6 (29)	
Sex (male/female), n (%)	25 (58)/18 (42)	13 (59)/19 (41)	12 (57)/9 (43)	0.57
Order within siblings, n (%)				
Single child	5 (12)	4 (18)	1 (5)	0.18
Has siblings	38 (88)	18 (82)	20 (95)	
Developmental delay/intellectual disability, n (%)	11 (36)	6 (27)	5 (24)	0.53
Age of epilepsy onset, y, median (IQR)	9.0 (2.1–15.0)	7.0 (1.7–13.5)	9.0 (3.0–17.4)	0.47
Epilepsy type, n (%)				
Generalized[c]	28 (65)	13 (59)	15 (71)	0.93
Focal[d]	5 (12)	2 (9)	3 (14)	
Mixed generalized and focal	10 (23)	5 (23)	5 (24)	
Nocturnal seizures, n (%)	31 (72)	16 (73)	15 (71)	0.59
ASM number at the time of SUDEP, n (%)[e]				

Continued

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Table 1 Demographic and Clinical Characteristics of the Study Participants and Their Children Who Died From SUDEP *(continued)*

Characteristic	Deceased children of the entire study group (N = 43 [100%])	Deceased children of "aware" parents[a] (n = 22 [100%])	Deceased children of "unaware" parents[a] (n = 21 [100%])	*p* Value[b]
0	3 (7)	0 (0)	3 (14)	0.05
1–2	21 (49)	9 (41)	12 (57)	
>2	19 (44)	13 (59)	6 (29)	
Family history of epilepsy, n (%)	9 (21)	4 (18)	5 (24)	0.46
Treated in a specialized epilepsy center, n (%)	33 (77)	17 (77)	16 (59)	0.07
Time from epilepsy onset to SUDEP, median (IQR)	10.2 (5.3–14.8)	9.8 (5.6–12.6)	10.6 (2.8–15.4)	0.89
SUDEP classification, n (%)[f]				0.60
Probable	10 (23)	5 (23)	5 (24)	
Definite	33 (77)	17 (77)	16 (76)	

Abbreviations: ASM = antiseizure medication; IQR = interquartile range; SUDEP = sudden unexpected death in epilepsy.

[a] "Unaware" and "aware" denote parents' reported previous awareness of SUDEP.

[b] Pertains to the comparison between the subgroups of "aware" and "unaware" parents or their deceased children.

[c] Includes 3 participants with juvenile myoclonic epilepsy.

[d] Includes 2 participants with self-limited epilepsy with centrotemporal spikes.

[e] >2 ASMs (noting that other ASMs were discontinued for their inefficacy) indicate the epilepsy was drug resistant.

[f] As reported by parents, "definite" was determined based on an autopsy, which did not reveal a structural or toxicological cause of death and "probable" was determined when an autopsy was not performed.

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> When we spoke, the neurologist was strictly professional about the case, telling me there were no signs suggesting this would happen. Then, pulling again the genetic tests to show me they were negative. But nothing to do with emotions or, you know, getting help, or resources, or caring after me. That's it. My daughter was a patient, and she's not a patient anymore. That's it. (P25, F, UA).

Empathetic responses and those in which information was provided were found to be beneficial: "He (the physician) listened to me cry and try to get through everything, and he just said, we have a long way to go, in terms of the medical industry feeling comfortable about something they don't know. That helped with some of the anger I had" (P23, M, UA).

Theme 2: Grief Following SUDEP

Sustained Guilt or Absolution, Linked to Perceived Prevention

Losing a child to SUDEP was universally described as life-shattering. However, a lack of previous SUDEP awareness intensified parental suffering: "No parent should ever lose their child. Secondly, no parent should ever lose their child to something they had no earthly idea about. That's the critical one" (P26, F, UA). Unaware parents experienced profound and widespread guilt, driven by the belief their child's death could have been prevented through precautionary measures:

> When it's a child or a person in their prime that dies, it impacts so many people and in such a catastrophic way that saying it's rare and we don't want to scare families is not the way to go. In fact, I think the opposite is true. If you think you might die, guess what? Your medication compliance is going to be way higher and you might actually have neurosurgery instead of thinking it's okay to have seizures (P28, F, UA).

They frequently ruminated on actions they would have taken in their child's epilepsy care or on the day of their death had they known about SUDEP, convinced that previous knowledge would have fundamentally altered their approach to epilepsy management and adherence to seizure prevention recommendations:

> …if we knew SUDEP could be a part of it, obviously we would get monitors and things of that nature. And on that day, in hindsight, I wouldn't have left her. Yeah. I would call my wife and say, "Hey, you got to catch an Uber home. We have to call our family and cancel our dinner out." We'd have ordered food. I would not have left her that day. She would have slept right beside me. When you don't have all the information it puts you at a disadvantage. You start questioning, Man, if I'd have known that what would I have done differently? (P23, M, UA).

Parents often sought a sense of control and expressed regret over actions they did not take, or might have taken had they known, even when these involved interventions lacking established medical evidence, such as seizure monitoring devices. Crucially, although acknowledging SUDEP can be unpreventable, previous awareness was empowering, alleviating guilt by enabling parents to feel they had done everything possible: "If you take all the precautions, it could still happen, but I think it would give the power back to the parents at that point in time. So like having that piece of knowledge, like you know, a Monday night quarterback thing" (P15, F, UA).

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Table 2 Additional Representative Quotations of the Theme "Immediate Upheaval"

Theme: Immediate upheaval

Subtheme	Quotation	Insights from the quotation
Shock and trauma	"My husband is having a hard time just because of the way we found her. He says: That's going to haunt me for the rest of my life" (P25, F, UA) "I could not turn the doorknob to go in his room. Two years. Two years, I could not turn that doorknob because I had the worst vision in my head. We all feel the same. In the SUDEP support groups, we all have the same pain. A lot of us found our children" (P6, F, UA)	Witnessing the SUDEP event can lead to a haunting trauma
Police and procedures	"…a police officer stood at the bottom of the stairs, preventing anyone from going up, but my husband repeatedly insisted he had to see Brian (their son), to which the officer repeatedly said no. Defying the officer, my husband lifted him and ran upstairs, saying he had to see my son with his own eyes to confirm he was no longer alive" (P10, F, UA)	Escalating difficulties with law enforcement personnel can compound the already challenging post-SUDEP situation
	"We had 2 angels in blue, the 2 police officers who responded to the call. They were explaining the whole legal aspect of a young person found dead unexpectedly. About the coroner, the funeral home, that someone would have to come and remove the body. It was obvious there was no foul play involved, but they said, you know, we'll have to wait for the coroner, and they were supposed to go off shift at 6 AM but stayed with us till 1 PM that day" (P34, F, UA)	Immediate and clear communication about the circumstances results in more positive recollections of the event
	"…we were under investigation, we were allowed to be in the room, but not to touch him, and we were supervised the whole time. It was horrible. It was cruel. And we fought the medical examiner. We talked to lawyers to see if we could figure it out. Whereas if somebody had just come up to me and said: Look, we're making an effort to understand these deaths better and there's a chance this is SUDEP" (P10, F, UA)	Insensitive management of emergency room personnel, linked with their SUDEP unawareness, can intensify parents' emotional turmoil
	"They did not do an autopsy. They told me that in order to have an autopsy, it would be $5,000" (P30, F, UA)	There are frustrating legal battles to obtain an autopsy after SUDEP
	"I would have really liked a little bit more of a layman's term explanation of what happened. Just something like, this is what happened, sometimes it happens, and we can't explain it. There's not much you could have done about it. These are the resources for therapy and groups, etc. We had to find… pretty much all of our resources. We didn't know what direction to go. You don't know that there is a whole community of people who have been through this. Let me know I'm not alone" (P43, M, UA)	A designated point person should help to simplify the overwhelming experience and connect parents to appropriate support services
	"At that moment (right after SUDEP), there's so much shock involved. It's very difficult to string 2 thoughts together. So being offered something that is going to help you when you don't know what help you need is helpful. You've got more decisions when you can't make decisions. So trained professionals should be assigned for this. That takes the guesswork out of this. Guiding through the autopsy and the research and all those things we don't know" (P26, F, UA)	
Interaction with the treating physician	"The neurologist never called me after she died. I got a letter from her ENT doctor, a handwritten letter saying, you know, I'll miss you, she was an amazing little girl. A handwritten, beautiful letter, but nothing from her neurologist. Zero" (P30, F, UA)	Challenges are experienced in cases of dismissive or absent interactions with the child's treating physician
	"I had notified his epilepsy doctor that he had passed away, and she expressed her condolences and stuff like that. She asked what ended up happening. I said, you know, he had a seizure, and she just kind of went silent and didn't mention SUDEP. It still wasn't mentioned at that point in time, so I felt very betrayed. It hurt because even after losing him, there still wasn't like, hey, like you know that there's X amount of patients that this happens to. I'm so sorry that your son was one of them, like something to kind of confirm, like, hey, it happens, you know" (P15, F, UA)	After it happens, SUDEP should be mentioned and discussed by the treating physician

Abbreviations: ENT = ear, nose, and throat; SUDEP = sudden unexpected death in epilepsy.

Aware parents, whose children died despite perceived maximal efforts, reported immense sorrow but significantly less guilt, finding long-term absolution and closure,

> …him (the epileptologist) mentioning it, that saves my sanity even today (11 years after). It soothes my mind knowing that I was told about it because I know that there is nothing I can do or have ever done that would have prevented it (P1, F, A).

Awareness-Dependent Prolonged Anger and Depression

Parents unaware of SUDEP experienced a longer duration of intensified grief, particularly anger and depression: "I just felt like I needed to know she might die. It's been 12 years now. The anger persists and I just didn't get any closure" (P19, F, UA). This lack of previous knowledge significantly hindered their ability to find resolution, even when SUDEP was acknowledged as unpreventable:

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> We should have known. I don't know if it would have changed the outcome. It might not have. I don't know. This, I will tell you though, has been the worst thing to live with. Ever, I mean, I have lost people, but this is a different animal (P40, F, UA).

Conversely, parents with previous SUDEP awareness expressed milder anger, often channeled at the situation's unfairness rather than the medical system: "I was angry at the totally unfair part of it, you know, he was just like this young man that was living a good life. I wasn't really angry at the medical system or anything" (P45, F, A). Their adherence to clinical recommendations and the sense of preparation that came with knowing about SUDEP's possibility, even with low risk, helped them avert remorse and cope with the loss. Elimination of the mystery surrounding the death reduced the intensity of their grief symptoms (Table 3).

Alienation and Isolation

Alienation was recounted by all subsets of parents (aware and unaware). For some parents, it stemmed from the crude emergent circumstances: "We're no longer in school and in scouts, we're no longer part of the community in a sense" (P12, F, UA), and for others from deeper underlying causes: "I feel kind of invisible, like, I'm a pariah. People are like, oh my god, there's that woman who lost her kid, because it's your worst nightmare" (P2, F, A).

Theme 3: Coping With SUDEP Loss

SUDEP Support Groups

SUDEP-specific support groups served as a vital support system for "unaware" parents, providing a unique understanding of SUDEP's nuances:

> …finding people as small of a group as we are, who understood what it was like having a child with epilepsy, but 99% had no clue that SUDEP was even a possibility. So it made me feel at home in a weird way. Finding people who lost their child in the same very strange way" (P15, F, UA).

Parents also conveyed a need for therapists familiar with SUDEP and emphasized the importance of authenticity and directness from their support network. A minority also noted that witnessing the prolonged suffering of other parents in these groups deterred their participation. In contrast to the main narratives conveyed by "unaware" parents, those who were "aware" expressed reservations about these groups, finding them overly focused on issues related to previous awareness: "I don't do the SUDEP support groups because people get really caught up in 'my doctor didn't tell me' and my knowing what SUDEP was, I don't know that it really helped that much" (P51, F, A).

Altruism

Mostly "unaware" parents channeled their grief into advocacy and research, hoping to spare other families similar hardships, viewing these altruistic actions crucial for their own healing and reconciliation. A key motivation was their belief that limited awareness of SUDEP among medical examiners leads to its under reporting, inaccurately portraying the condition as rarer than it truly is (Table 4). This perceived rarity, they recognized, created a significant obstacle in their campaigns for greater awareness (Table 4).

Relationship Circles and Marriage

The quality and proximity of relationships with relatives influenced their ability to support parents coping with SUDEP. Friendships were often redefined, with some offering unexpected comfort whereas others proved unsupportive (Table 4). The need for continuous, long-term support from friends was emphasized throughout the prolonged grief journey: "The cards, the sympathies, the texts, the calls, the meals, they quit coming after a few months. So, this help given down the road might be more helpful than if given right away" (P19, F, UA). Spousal relationships were often reported as strengthening after SUDEP, and marital challenges were more common for "unaware" parents, attributed to their intensified trauma, anger, and sadness (Table 4).

Religious Beliefs

For most religious participants, their beliefs and communities provided significant coping support. However, SUDEP awareness influenced this: "unaware" religious parents often expressed anger towards God: "Where was God? Where were his hands when everything happened? I used to be able to reconcile everything through my faith, knowing that God knows what he's doing" (P22, F, UA), whereas "aware" religious parents commonly found God to be a source of consolation: "We know God's got a plan. I mean, it sucks that we don't know it. Um, but…We know there is a plan" (P49, M, A).

The SUDEP and Epilepsy Dialog

SUDEP Discussions

Most participants strongly advocated for open and honest discussions about SUDEP, consistently arguing for the right to know and often comparing SUDEP counseling with that for other medical conditions with life-threatening risks: "After I gave birth, we had to sit in the hospital, watch a video or 2 videos, read through this stuff, sign off that we understand safe sleeping and SIDS and preventative things. And it's like, why isn't there that for epilepsy?" (P12, F, A). Participants, including those with other living children with epilepsy, stressed the importance of facts and accessible information (including on official websites) and felt that disclosure would be constructive and empowering:

> I would give everything that I own to go back in time and have the doctor give that discussion to us. I would give my life. Just let us try, you know, as opposed to just letting him (the doctor) make the decision for us. That type of comment from a doctor is real. It's not creating paranoia. It's just describing facts (P36, M, UA).

Only 1 parent expressed uncertainty about wanting previous SUDEP knowledge (Table 5).

Epilepsy Education

Many parents, beyond their lack of SUDEP knowledge, also reported significant challenges because of not understanding their

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Table 3 Additional Representative Quotations of the Theme "Grief Following SUDEP"

Theme: Grief following SUDEP

Subtheme	Quotation	Insights from the quotation
Sustained guilt or absolution, linked to perceived prevention	"Losing a child is the worst thing that can happen to a parent… your whole life just shatters" (P45, F, A)	Losing a child is universally devastating
	"Blaming yourself…You know, you didn't have a hand in that, but when you have a child who relies specifically on you and you're the protector, right? You blame yourself for not being able to save your child" (P14, F, A) "Grief from SUDEP is complicated because… there is so much guilt around it, the unknowing around it, um, I think it's just it's very different" (P7, F, UA)	Intense guilt is linked to failure to protect your child
	"Nothing would prepare me for losing my child, but knowing that there was a possibility I could have prevented it? You know, I wouldn't have the guilt that I have thinking that I didn't know this. I didn't do enough. Like, he was 10 feet away from me in his room and I had no clue about it, you know, so there was a lot of guilt and a lot of anger towards the medical field at that point, you don't want to think that your child could die, but if you told me that it was a possibility, I would have taken measures that maybe I would be able to feel better about knowing that I did everything in my possibility to save him. And it's something that I have to live with for the rest of my life, and it's hard (crying)" (P15, F, UA)	The roots of the experienced guilt are linked to an overwhelming despair that the death could have been prevented by implementing precautionary measures
	"I never agreed to a taper of his meds, no matter how stable he was, if they ended up screwing his, uh, you know, kidneys or whatever, we did another med. And I kept the timing really consistent. He needed Valtoco once in his life, but still, I put it everywhere, and in every place he went regularly, somebody had it all over" (P20, M, A)	Strict adherence to epilepsy management recommendations results from having prior SUDEP awareness
	"At least I know we tried everything. He hated the ketogenic diet. The medications made him so tired… but we were afraid of the risks" (P13, F, A)	When SUDEP occurs despite maximal efforts to prevent it, the experience is described with sorrow, but much less guilt
Awareness-dependent prolonged anger and depression	"Now I want to die. I want to die because there's no fixing it. I can't fix this. I didn't even get a chance to try" (P5, F, UA)	Anger and depression are more prolonged and expressed more intensely by parents with no prior awareness of SUDEP
	"I died along with my son. I also, essentially died. I feel like I just take up oxygen at this point. I've been told to go on antidepressants, and I don't want to because I don't deserve to feel better" (P28, F, UA)	There were expressions of unresolved feelings and a diminished sense of identity and purpose
	"It's kind of like… almost preparing yourself, you know, it's in the back of your mind. Always knowing that there is a chance of this happening. And when it does happen, it's not that… big shock. Like, when someone has cancer vs a heart attack. You have time to prepare for their 3-month sickness, and then death, vs they just drop dead" (P48, F, A)	Adherence to clinical management recommendations averts feelings of remorse about what could have been done
	"So we were made aware of this thing called SUDEP. But it was always with this kind of asterisk that it is extremely rare. You really don't need to worry about it. It always had this caveat. We have to say this, but don't worry about it. So, I mean…grief is still grief. It sucks. But I do think that had this been a complete mystery, I would have struggled even more" (P37, F, A)	Even when the risk of SUDEP is registered as low, there are benefits to being aware of its possibility
	"You learn to stop talking about yourself because people don't want to hear it. You put on this facade. You know, when you lose a child, it's like you have this disease that people start running away from you. You're no longer the person that they can have fun with. Your life does change hugely. Any of the girlfriends I had many years, they don't contact me anymore. I was difficult to be around. I won't deny that" (P21, F, UA)	The grief from SUDEP is linked to masking of pain, social distancing, and friendship loss

Abbreviation: SUDEP = sudden unexpected death in epilepsy.

child's epilepsy details, or in extreme cases, being unaware of the diagnosis entirely. They consistently emphasized the critical need for better education on epilepsy diagnosis, management, and its progression, a sentiment that remained strong regardless of their child's seizure control or their own SUDEP awareness (Table 5). Concerns were also raised that current epilepsy management practices misleadingly normalize the condition, extending to issues with comorbidities and lifestyle effects (Table 5).

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Table 4 Additional Representative Quotations of the Theme "Coping With SUDEP Loss"

Theme: Coping with SUDEP loss

Subtheme	Quotation	Insights from the quotation
SUDEP support groups	"…it's like, you're from Mars and you have to go find the other Martians" (P34, F, UA)	SUDEP-specific support groups are especially helpful to "unaware" parents, as they offer an understanding of SUDEP's unique nuances
	"I found more support in the support groups than I did with a general grief counselor, because it was parents who understood the loss of a child, or it was somebody who understood the loss of SUDEP, vs a counselor who didn't have that understanding of that deep grief. Yes, they went through the training. Yes, they may have somebody who they love died, but they didn't truly understand that particular loss" (P30, F, UA)	Parents bereaved by SUDEP prefer a therapist familiar with SUDEP
	"I couldn't turn to my parents, family or friends. I couldn't burden them. I needed to talk to somebody who had experienced exactly what I experienced and who had the same questions and was angry" (P7, F, UA)	Family and friends are also relied on for support; however, at times, SUDEP support groups are more beneficial
	"…just knowing that you're around a group of people going through the same thing at various different stages. You've just got a shared experience that you can bond from and learn from. This is a group of people that are not going to treat you with kid gloves and don't want you to treat them that way either" (P43, M, UA)	There is a need for authenticity and nondelicate handling by supporting people
	"In the SUDEP group I met a mom and a dad and they talk as if it's been like, I don't know, 2 weeks ago or 2 months ago, and when they say, like, 7 years, I say, How long? It's brutal. I wish I would have been dead you know. Just watching them and I'm like, I'm 6 months into this, how will I be able to do this? This (the group) is not helpful" (P35, F, A)	The grief complexities raised in the SUDEP support groups can also be deterring
Altruism	"I just want to make sure that other children don't fall through the crack like he (my son) did" (P17, F, UA) "I am very involved in SUDEP awareness and epilepsy awareness with the local epilepsy unit because to be able to help others is how I can best help myself. It helps me feel there was some purpose in what happened. And I will do this forever" (P35, F, A)	"Unaware" parents are driven to save others from the hardships they endure. These behaviors serve as a support system for coping and reconciliation
	"We had to fight the medical examiner to list his (son's) death as SUDEP. It was clear that attention wasn't given to the fact that he (his son) had epilepsy. I can just imagine how many times SUDEP goes unnoticed. And then they tell everyone it's rare" (P31, M, UA)	Parents' altruistic actions often stem from their belief that SUDEP's rarity is misperceived. This belief is also acknowledged as hindering the ability to campaign for its awareness
	"I do want to be part of what changes this, but it seems like a Herculean effort because you have the statistics showing it's rare. How do we keep going with trying to get some actual results here?" (P5, F, UA)	The misperceived rarity of SUDEP, as recognized by parents, created challenges in campaigning for its awareness
Relationship circles and marriage	"We are very close to our family, my parents and my wife's parents and her sister live near us. They cared for us so much and were our biggest support system. Emotionally and with practical stuff" (P24, M, A) "We already had a strained relationship with my in-laws. And I think that further amplified it" (P30, F, UA)	The quality of participants' relationships with relatives, along with their geographical proximity, determines the benefit of these relationships for coping
	"The one thing that a death like this will do-you find out really fast who is here and who is not. And believe me, I have had to reprioritize the people in my orbit. And some of that has been my own sisters who have been unhelpful" (P40, F, UA)	Friendships were redefined following SUDEP
	"The cards, the sympathies, the texts, the calls, the meals, they quit coming after a few months. So, this help given down the road might be more helpful than if given right away" (P19, F, UA)	It is important to provide continuous, long-term support to parents bereaved by SUDEP
	"We had each other's backs, and in a way, it made us really close" (P45, F, A)	Spousal relationships (independent if the spouse is the biological parent of the deceased child) are often strengthening
	"It's very hard in a marriage because you're both grieving, and so it was hard enough to take care of yourself, let alone another person, right? And grief exaggerates a bit of who you are. My husband and I are different people, and it exaggerated who we were in very different ways. And he needed to do what he needed to do, and I needed to do what I needed to do. But, you know, it sends you down very different paths for a while. We're still married, but it hasn't always been easy" (P7, F, UA)	SUDEP can lead to a reappraisal of the spousal relationship
	"We grieve differently. And the grief drove a wedge between us. And we were separated for a year. And our marriage is not the same. We both had anger. We both were sad. We both have a certain level of trauma. I found her. He was doing CPR. He shoved his feelings down and didn't know how to deal with them, and didn't want to. I wanted to face mine" (P26, F, UA)	Prior SUDEP unawareness may lead to marriage challenges, linked to the partner's intensified trauma and grief symptoms

Continued

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Table 4 Additional Representative Quotations of the Theme "Coping With SUDEP Loss" *(continued)*

Theme: Coping with SUDEP loss

Subtheme	Quotation	Insights from the quotation
Religious beliefs	"Going to church, doing that same routine, and being surrounded by the faithful community was helpful in overcoming the overflowing emotions we had. Especially in the first few months" (P48, F, A)	Religious beliefs and their associated communities serve as a valuable support system for coping
	"We don't understand. We do because we are people of faith, and we know that when it's someone's time, it's someone's time. But we don't understand. Why weren't we told this information?" (P33, F, UA)	Prior SUDEP unawareness can coincide with anger towards God and confusion about faith (in religious individuals)

Abbreviations: CPR = cardiopulmonary resuscitation; SUDEP = sudden unexpected death in epilepsy.

Discussion

Our in-depth interviews with parents whose children died from SUDEP revealed both universal aspects of child loss and SUDEP-specific themes. A prevailing narrative reflected parents' reported grief symptoms characteristic of prolonged grief disorder,[19] or persistent complex bereavement disorder,[10] including intense sorrow, anger, isolation, and difficulty engaging in activities. This aligns with research on grief after sudden child loss from any cause.[20] Moreover, a sudden and unexpected death of a child has been shown to intensify parental grief manifestations.[21] Although initial shock and trauma were consistent across all participants, regardless of demographics, certain factors shaped grief and coping. Grief intensity was higher in women, unmarried individuals, and those with more recent SUDEP experiences. Women more frequently sought therapy, and spousal relationships and continued employment aided coping. Notably, the child's age at death, epilepsy type, seizure control, and epilepsy duration did not significantly influence initial shock, trauma, grief, or coping. These factors influence on parents' experiences after SUDEP have been alluded to elsewhere[22] but not specifically reported.

A central finding of this study, woven through many themes, was the profound effect of previous SUDEP awareness on perceived trauma, grieving, and coping. Despite demographic and clinical similarities between "aware" and "unaware" groups, "unaware" parents reported exacerbated trauma, greater difficulties with post event procedural issues, and prolonged maladaptive grief fraught by guilt, extreme anger, medical distrust, and preoccupation with their child's manner of death. By contrast, "aware" parents, although still experiencing grief symptoms associated with sudden death (i.e., their experience did not resemble that of "anticipatory grief"[23]), described mitigated trauma, less guilt, anger directed elsewhere than the medical system, acceptance, and closure. Moreover, although "aware" parents detailed various coping strategies, "unaware" parents frequently cited SUDEP-specific support groups as a primary coping mechanism, emphasizing the unique understanding found within shared experiences. These findings partly corroborate evidence that grief can be prolonged or complicated by lack of preparedness or unresolved issues.[24] However, a particular factor that may augment the negative grief symptoms in SUDEP relates to the haunting notion of preventability if disclosure had occurred. As guilt and rumination are closely tied to the traumatic event,[25] it is plausible that the lack of SUDEP foreknowledge may exacerbate the perception of the trauma,[26] and further add to parental burden. Within this context, "unaware" parents also primarily expressed altruistic desires to change SUDEP-related practices stemming from a realization that their nondisclosure of SUDEP might have resulted from a vicious cycle of misinformation, under-reported occurrences, and subsequent under-acknowledgment by health care providers.

Our findings strongly underscore the critical importance of SUDEP counseling, aligning with recommendations from organizations like the American Academy of Neurology and American Epilepsy Society,[7,27] and the UK's National Institute for Clinical Excellence.[28] Although some reluctance to discuss SUDEP stems from fears of causing stress, interfering with normalcy, or perceived ineffectiveness because of lack of clear prevention strategies,[9,29] global evidence refutes these concerns. SUDEP disclosure does not cause persistent stress[5,30] and it may increase management practices potentially preventing it, such as adherence to anti-seizure medications,[5,30,31] reduction of seizure triggers,[32,33] use of seizure-detection devices, and cosleeping.[34] Moreover, beyond their "right to know,"[35] and the nearly unambiguous willingness of PWE and their caregivers to be informed[36,37] (corroborated by our findings), discussing SUDEP has been shown to improve wellbeing and perception of epilepsy stigma,[6,30] reduce the fear of death, and empower PWE and their caregivers.[38] Despite these guidelines and consistent expert advice, SUDEP remains under discussed.[9] Determining the true "absolute risk reduction" and "number needed to treat" for SUDEP counseling on its incidence is difficult due to its rarity. Indeed, the "intervention" (a meaningful SUDEP discussion), requires precious clinical encounter time within a care model that is increasingly constrained by time and driven by reimbursement metrics, may elicit some physician discomfort, and has minimal side effects (some short-term stress is possible). Nonetheless, considering the severity of the outcome (death), even a high "number needed to treat" should be

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Table 5 Additional Representative Quotations of the Theme "The SUDEP and Epilepsy Dialog"

Theme: The SUDEP and epilepsy dialogue

Subtheme	Quotation	Insights from the quotation
SUDEP discussions	"There's no easy way to do it, and, you know, doctors aren't counselors or therapists or any of that stuff. So you just kind of leave us to figure it out, and it's fine. I just wish that doctors could be okay saying: I know it's scary, I want you to know that I'm totally devoted to every single possible thing we can do to protect your child and be able to just sit with parents that are scared" (P2, F, A)	Physicians should be able to deal with situations in which people with epilepsy or their caregivers are scared or stressed (after discussing SUDEP)
	"The whole conversation was very light. It was very informative. The segue into SUDEP didn't feel jarring. It just felt like a natural part of the conversation. It just felt like more information that he was arming us with" (P1, F, A)	SUDEP disclosure is constructive and informative
	"That's the secret. This is the SUDEP secret. Even on the Epilepsy Foundation page, it's buried in the back" (P5, F, UA)	There is an inaccessibility of SUDEP information in official web-based resources
	"I feel very afraid having another child with epilepsy who could die from SUDEP. But you could also die in a car crash, right? The world is filled with risks. And so we just have to talk about them" (P41, F, A)	SUDEP disclosure is also desired by parents bereaved by SUDEP who have remaining living children with epilepsy
	"If you had informed me there was even like a 0.01% chance that this might cause him serious harm, I could not ever go back to work. I would have been sitting like, you know, behind his door. Yeah, I don't know" (P18, F, UA)	A minority of parents (one in our study) are uncertain whether they would have wanted prior awareness of SUDEP
Epilepsy education	"This isn't a one-dimensional experience. Epilepsy is really… complex, mentally, physically, emotionally, you know, medically" (P2, F, A)	Management of epilepsy is challenging for many reasons
	"The word epilepsy was never mentioned to us by the doctor and only later (after her child died from SUDEP) I saw he (the doctor) mentioned possible epilepsy through his notes several times and I understood that if you have 2 or more seizures, that is considered epilepsy, and it makes you feel like you failed as a parent" (P39, F, UA)	Parents sometimes do not even understand that their child has epilepsy
	"It doesn't start with SUDEP, it goes back to the information we receive about the actual disease, epilepsy. I get it that it's complicated and doctors can't explain everything, but I wish someone had explained to us the basics of this disease in layman's terms" (P38, M, A)	Basic education of parents on the diagnosis and management of epilepsy and its course is important
	"Epilepsy carries a risk of dying after a seizure or dying in an accident, and there are certain things you can do to mitigate these risks. And so, epilepsy should be presented as a life-altering diagnosis, and the doctor would do their best to help you to be as normal as possible, as opposed to nonstop reassurance that everything is normal. Nothing is freaking normal anymore" (P3, M, UA)	The apparent normalcy of epilepsy can be misleading
	"Normalizing epilepsy is hugely problematic, and risky. Any person diagnosed with epilepsy and their family should have access to some kind of support and mental health services because stress is a huge trigger. And there's a 'huge behavioral component" (P41, F, A)	

Abbreviation: SUDEP = sudden unexpected death in epilepsy.

acceptable.[39] Therefore, SUDEP counseling guidelines should be revised to be more directive; however, the best methods for establishing SUDEP counseling practice standards remain undetermined. Challenges in discussing diagnoses and risks, although common in health care,[40,41] highlight the critical importance of effective communication. Established frameworks like the Setting, Perception, Warning call, Information, Clarification, Emotions, and Strategy model[42] and the processes for teaching them[43] can be readily adapted for epilepsy and SUDEP discussions. Training health care professionals in these conversations is crucial. In addition, patient and family support groups, as well as epilepsy organizations, should advocate for changes in clinical practice that address the challenge of providing meaningful SUDEP counseling within the time-constrained and reimbursement-driven environment of clinical medicine, which often fails to account for the time, skills, and emotional labor required to conduct these sensitive conversations effectively.

This study also emphasizes the urgent need for greater SUDEP awareness among emergency responders, law enforcement, and medical examiners—a concern that has been previously underscored.[44] With respect to increasing law enforcement personnel's familiarity with epilepsy and SUDEP, we advocate they participate in initiatives such as the Epilepsy Foundation of America's Law Enforcement Training Program,[45] which aims to educate officers on recognizing and responding to seizures, and also addresses issues specific to

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SUDEP. As suggested by a subset of parents in this study, their guidance through the obstacles faced after SUDEP could be facilitated by hospital-appointed trained case managers and referral to programs such as the Epilepsy Foundation's Bereavement & SUDEP Family Resource Guide,[46] North American SUDEP Registry,[47] and the Sudden Unexplained Death in Childhood Foundation.[48] Given the exceptionally prolonged parental grief after SUDEP, as echoed by our findings, long-term follow-up guidance and resources, especially SUDEP support groups, should be offered. This is corroborated with recommendations for continuous, long-term support to parents bereaved by sudden causes, focusing on their readjusting to a new reality, and aligning to individual needs.[49]

Finally, the quality of interaction with the child's treating physician post-death significantly afected parents' emotions. Honest condolences, empathy, and providing known details about the event softened negative feelings. Conversely, dismissive or evasive interactions led to persistent bitterness. Evidence suggests parents' desire detailed information about their child's death.[50] Health care professionals should therefore ascertain parents' informational needs, tailor conversations accordingly, and offer ongoing opportunities for discussion and emotional support in follow-up appointments.

Our study's generalizability is limited by its recruitment method, which relied on self-selection due to ethical considerations. This may have introduced self-selection bias. Although participants were heterogeneous in time since SUDEP, employment, family setting, marital status, and their children's demographics and clinical details, they were predominantly women, White individuals, and located in the United States. Underrepresentation of other groups may have influenced responses, as grief and coping may be shaped by cultural factors, underscoring the need for broader inclusion in future studies. Nonetheless, these demographic skews were similar across the study's 2 main groups of parents with and without previous SUDEP awareness and did not hinder our ability to draw conclusions stemming from their diverse narratives. Another limitation is our reliance on self-reported SUDEP awareness. However, this accurately captured participants' current understanding, regardless of whether they had been made aware of SUDEP but did not recall or process the information.

By exploring the perspectives, feelings, and experiences of parents who lost children to SUDEP, we report that beyond the immediate loss, SUDEP inflicts a profound and lasting wound in parents who are plunged into an agonizing and protracted grief. This devastating ripple effect demands our attention. Through our analysis, we identified that previous SUDEP counseling offers parents of PWE a degree of emotional preparation that buffers the devastating reality and provides a sense of agency and a foundation for acceptance. Conversely, a lack of previous SUDEP awareness may exacerbate parents' perceived trauma and the post-SUDEP administrative challenges, prolong and complicate their grief, and alter their coping strategies. Not only is the death of their child preceded by a lack of preparedness and followed by unresolved issues concerning its cause but it is also accompanied by a perceived notion that it could have been prevented by them, simply by being aware of its possibility and risk factors.

Our study's findings also reveal a gap in the immediate post-SUDEP management across health care and law enforcement, and the importance of the treating physician's role post facto. As a whole, these observations strongly emphasize the need for a paradigm shift in SUDEP-related practices across multiple disciplines, including legislative efforts. They should be focused on the importance of SUDEP counseling and offer working models to implement it, aiming at both maximizing its prevention efforts and also empowering PWE and their caregivers, and ameliorating their traumatic effect and subsequent grieving processes.

Author Contributions

I. Tokatly Latzer: drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; study concept or design; analysis or interpretation of data. D. Friedman: drafting/revision of the manuscript for content, including medical writing for content; study concept or design; analysis or interpretation of data. D.N. Williams: drafting/revision of the manuscript for content, including medical writing for content; study concept or design; analysis or interpretation of data. G. Lapham: drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; study concept or design. A. Kukla: drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; study concept or design. O. Karnieli-Miller: drafting/revision of the manuscript for content, including medical writing for content; study concept or design; analysis or interpretation of data. P.L. Pearl: drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; study concept or design; analysis or interpretation of data.

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