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RESEARCH LETTER

A question prompt list for sudden unexpected death in epilepsy

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Introduction

Sudden unexpected death in epilepsy (SUDEP) is a common cause of premature mortality in people with epilepsy.[1] Professional guidelines and existing data from caregivers of children with epilepsy support SUDEP risk disclosure in the clinical setting. [1] Yet SUDEP risk disclosure remains a challenge for both clinicians and caregivers.[2] Barriers to clinician risk disclosure may include fear of exacerbating caregiver anxiety, discomfort navigating complex communication, lack of knowledge, and limitations in SUDEP prevention strategies.[2] Caregivers may be unsure of which questions to ask or feel hesitant voicing their questions.[2] Question prompt lists (QPLs) have the potential to empower caregiver question-asking and decrease unmet informational needs about SUDEP.[3]

Methods

In a prospective cross-sectional study, we consulted existing literature on SUDEP communication preferences to design a 24-question survey for caregivers of children with epilepsy.[4] A stakeholder advisory committee comprised of caregivers, epileptologists, and advocates provided guidance on study design and survey content. Of the survey questions, 14 asked for caregiver demographic information and child epilepsy history, while 10 centered on caregivers' knowledge of SUDEP and communication preferences for SUDEP risk disclosure.[5] To collect responses from caregivers, we partnered with advocacy organizations, who posted a link to the survey in their general membership groups. An open-ended survey question prompted caregivers to list any questions they recommend that other patients and families ask their clinicians about SUDEP. Caregiver responses were collated, collapsed, and refined for clarity and reading level. We used Canva (Canva Pty Ltd.) to generate a QPL to complement conversations about SUDEP risk.

Results

One hundred nineteen of the 212 caregivers who participated in the survey submitted a total of 251 questions. Respondents had a median age of 42 years

Table 1. Child and Caregiver Characteristics

Characteristic	All Caregivers (*N* = 212) Median (Range) or *n* (%)	Caregivers Who Submitted Questions (*n* = 119) Median (Range) or *n* (%)
Caregiver Characteristics		
Age, y	42 (18-72)	42 (18-69)
Race		
White	194 (91.5)	112 (94.1)
Mixed	4 (1.9)	3 (2.5)
Asian	2 (0.9)	0
Black or African American	1 (0.5)	1 (0.8)
Prefer not to answer	5 (2.4)	2 (1.7)
Not reported	6 (2.8)	1 (0.8)
Ethnicity		
Non-Hispanic	186 (87.7)	108 (90.8)
Hispanic	13 (6.1)	6 (5.0)
Not reported	13 (6.1)	5 (4.2)
Bereaved	12 (5.7)	9 (7.6)
U.S. Resident	174 (82.1)	104 (87.4)
Region of residence in U.S.		
Midwest	50/174 (28.7)	29/104 (27.9)
South	50/174 (28.7)	31/104 (29.8)
West	37/174 (21.3)	25/104 (24.0)
Northeast	25/174 (14.4)	14/104 (13.5)
Not reported	12/174 (6.9)	5/104 (4.8)
Child Characteristics	*n* = 181*	*n* = 101*
Age, y	10.5 (0-45)	12.0 (0-34)
Number of seizures		
Per month	3 (1-100)	2 (1-100)
Per year	24 (1-100)	15 (1-100)
Presence of > 1 seizure per month	96 (53.0)	49 (48.5)
Presence of tonic clonic seizures	106 (58.6)	65 (64.4)
Number per year	4 (1-100)	4 (1-100)
Presence of nocturnal seizures	123 (68.0)	71 (70.3)
Tonic clonic	73 (40.3)	42 (41.6)
Number of prescribed seizure medications	2 (0-6)	2 (0-5)

*Caregivers whose child died were not shown child demographic questions due to skip logic.

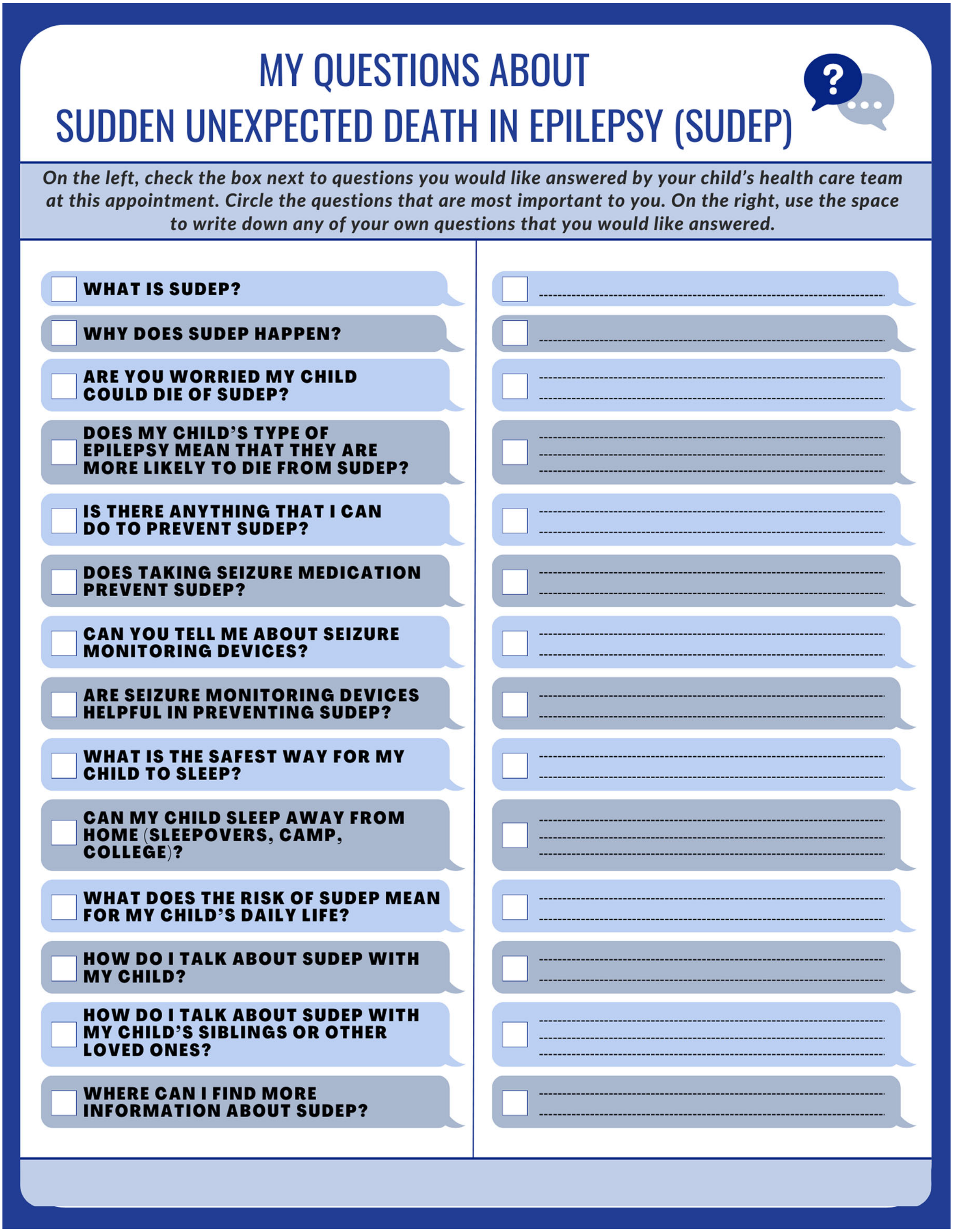
(range: 18–69 years), had children with a median of 15 seizures per year (range: 4–≥100), and primarily identified as White (*n* = 112/119, 94.1%). Twelve respondents identified as bereaved (Table 1).

Collation and categorization of caregiver responses resulted in the identification of 14 questions endorsed by caregivers (Figure 1). Suggested questions included content about ways to mitigate risk, such as “Is there anything that I can do to prevent SUDEP?” and “What is the safest way for my child to sleep?” Other questions, such as “How do I talk about SUDEP with my child's siblings?” focused on addressing SUDEP with loved ones. Caregivers also sought to know how SUDEP risk would impact the quality of life and activities of daily living, submitting questions such as “What does the risk of SUDEP mean for my child's daily life?” A prior publication from this cohort summarizes caregivers' self-reported preferences for SUDEP risk disclosure.[4]

Discussion

We present a novel caregiver-informed tool to support discussions about SUDEP. By empowering caregivers to think about important topics and disclose their concerns to clinicians, this SUDEP-specific QPL may enhance bidirectional communication, decrease parental anxiety, and promote treatment adherence.[3,6,7]

To date, few QPLs have targeted pediatric populations, and none have been developed for people living with epilepsy or their caregivers.[3,6,7] A QPL designed for parents of children with attention-deficit/hyperactivity disorder



MY QUESTIONS ABOUT SUDDEN UNEXPECTED DEATH IN EPILEPSY (SUDEP)

On the left, check the box next to questions you would like answered by your child's health care team at this appointment. Circle the questions that are most important to you. On the right, use the space to write down any of your own questions that you would like answered.

- ☐ **WHAT IS SUDEP?**
- ☐ **WHY DOES SUDEP HAPPEN?**
- ☐ **ARE YOU WORRIED MY CHILD COULD DIE OF SUDEP?**
- ☐ **DOES MY CHILD'S TYPE OF EPILEPSY MEAN THAT THEY ARE MORE LIKELY TO DIE FROM SUDEP?**
- ☐ **IS THERE ANYTHING THAT I CAN DO TO PREVENT SUDEP?**
- ☐ **DOES TAKING SEIZURE MEDICATION PREVENT SUDEP?**
- ☐ **CAN YOU TELL ME ABOUT SEIZURE MONITORING DEVICES?**
- ☐ **ARE SEIZURE MONITORING DEVICES HELPFUL IN PREVENTING SUDEP?**
- ☐ **WHAT IS THE SAFEST WAY FOR MY CHILD TO SLEEP?**
- ☐ **CAN MY CHILD SLEEP AWAY FROM HOME (SLEEPOVERS, CAMP, COLLEGE)?**
- ☐ **WHAT DOES THE RISK OF SUDEP MEAN FOR MY CHILD'S DAILY LIFE?**
- ☐ **HOW DO I TALK ABOUT SUDEP WITH MY CHILD?**
- ☐ **HOW DO I TALK ABOUT SUDEP WITH MY CHILD'S SIBLINGS OR OTHER LOVED ONES?**
- ☐ **WHERE CAN I FIND MORE INFORMATION ABOUT SUDEP?**

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Figure 1. **Asking Questions About SUDEP.** This caregiver-informed question prompt list serves as a tool to facilitate communication about SUDEP. It includes 14 questions that reflect common concerns among caregivers of children living with epilepsy, as well as space for caregivers to write down additional questions they would like clinicians to address.

was endorsed by parents and clinicians alike for prompting discussion and question-asking.[6] A QPL has been developed for parents of infants with neurologic impairment; parents valued the tool for giving them a sense of permission to ask about challenging topics.[3] Future work should test the impact of the QPL presented here on unmet information needs, question-asking, and self-efficacy.

Strengths of this study include our engagement with stakeholders who hold shared interests in improving the landscape of epilepsy care and research, including families of children with epilepsy. Existing cohorts demonstrate that patient-centered partnerships strengthen research and can help ensure that research efforts better reflect the needs of the epilepsy community.[8] The study's strengths should be viewed in light of its limitations, such as the homogeneous demographic profile of the respondents. The recruitment strategy may have resulted in selection bias toward caregivers with the highest level of engagement in advocacy organizations on social media, limiting generalizability to broader populations. Diverse recruitment methods are needed to ensure that communication tools capture concerns held by all caregiver groups. Future work should consider cultural adaptation, translation to other languages, and exploration of cultural barriers that may influence question-asking.

The questions commonly recommended by this cohort of caregivers affirm existing data and guidelines suggesting that clinicians should engage epilepsy patients and caregivers in conversations about SUDEP risk.[4,5] To meet the informational needs expressed by caregivers, these conversations should include basic details on SUDEP, risk reduction efforts, considerations for the future, and strategies to maintain psychosocial well-being alongside physical health. Communication tools like this QPL can serve as a strategy to facilitate comprehensive conversations about SUDEP risk disclosure.[3] Future work will involve user testing to assess the acceptability and efficacy of this tool in clinical practice.

Author Contributions

Simran Bansal: Conceptualization; formal analysis; writing—original draft. **Isabella K. Pallotto**: Data curation; formal analysis; writing—review and editing. **Renée A. Shellhaas**: Conceptualization; writing—review and editing. **Gardiner Lapham**: Conceptualization; writing—review and editing. **Thomas Stanton**: Conceptualization; writing—review and editing. **Zachary Grinspan**: Conceptualization; writing—review and editing. **Jeffrey Buchhalter**: Conceptualization; writing—review and editing. **Elizabeth J. Donner**: Conceptualization; writing—review and editing. **J. Kelly Davis**: Formal analysis; project administration; writing—review and editing. **Shital H. Patel**: Conceptualization; writing—review and editing. **Monica E. Lemmon**: Conceptualization; formal analysis; funding acquisition; investigation; methodology; supervision.

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Conflicts of Interest

Dr. Shellhaas is a consultant for the Epilepsy Study Consortium and receives royalties from UpToDate for authorship of topics related to neonatal seizures. Further, she is a member of the Board of Directors for the Pediatric Epilepsy Research Foundation. Her research is supported by grants from the NIH. Ms. Lapham is affiliated with the BAND Foundation. Dr. Buchhalter receives compensation for serving as a consultant to the Epilepsy Foundation, Epilepsy Study Consortium, Epilog, Neurocrine Inc., and UCB. He provides consultation services without compensation to the American Academy of Neurology and Partners Against Mortality in Epilepsy. Dr. Lemmon's research is funded by the NIH. The remaining authors declare no conflicts of interest.

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