EDITORIAL

SUDEP Awareness

A Gulf Neurologists Must Cross

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Epilepsy is one of the most common conditions that neurologists treat, with up to 1 in 26 people experiencing epilepsy within their lives.[1] Epilepsy is notable for its heterogeneity of causes, presentations, and comorbidities. In addition, people with epilepsy have a 2-to-3-fold increased mortality risk compared with the general population. Sudden unexpected death in epilepsy (SUDEP) is the most common cause of death related to epilepsy.[2] Globally, SUDEP is second only to stroke as the leading neurologic cause of lost potential years of life.[3] Despite this fact, SUDEP awareness remains low among clinicians and people with epilepsy.[4] Several groups have published guidelines and expert consensus documents in an attempt to enhance awareness of this condition, yet a gulf remains between current and desired levels of SUDEP awareness among patients and family members.

A paper published by Tokatly Latzer et al.[5] in this issue of *Neurology*® explores the consequences of this persistent gap. The authors examined awareness of SUDEP through a qualitative analysis of semistructured interviews with 51 caregivers of 43 children who had died of SUDEP. Participants were recruited through nonprofit epilepsy advocacy organizations and through the North American SUDEP registry. Participants were interviewed using a series of open-ended questions to explore their experience with their child's death from SUDEP. The responses were varied and complex. The authors used thematic narrative analysis to identify recurring themes in responses, providing qualitative analysis of the interviews. It is recognized some self-selection bias is present because of recruitment methods. Yet the quotations in the paper from parents who were unaware of the risk before they had suffered the death of a child from SUDEP are haunting. They illustrate the grief, confusion, and suffering experienced by these families. In comparing the interviews of caregivers who had not been aware of SUDEP with those who were aware before their child's death, those who had been "unaware" expressed more intense trauma and maladaptive grief.

The quotations in the study by Tokatly Latzer et al. poignantly show how awareness of the risk of SUDEP can mitigate some of the guilt and sadness that follows these tragic deaths. A parent who was not aware of the risk of SUDEP, for example, said that, "I would give everything 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. That type of comment from a doctor is real. It's not creating paranoia. It's just describing facts (P36, M, UA)."[5] This quotation stands in stark contrast to a quotation from a parent who was aware of the phenomena of SUDEP. "… the epileptologist] mentioning it [SUDEP], that saves my sanity even today (11 years after). It soothes my mind knowing that I was told about it because I know there is nothing I can do or have ever that would have prevented it (P1, F, A)."[5]

Losing a child to SUDEP was universally described as life-shattering. However, a lack of prior SUDEP awareness was associated with intensified suffering and prolonged the grieving process. "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)."[5]

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Some parents also describe another negative aspect of the lack of awareness of SUDEP. Some faced difficult encounters with first responders, and they explain that the detectives and EMTs who responded to the death were frequently unaware of SUDEP, making a tragic situation more challenging as caregivers responded to their questions.

There is much yet to discover about the pathophysiology and the mechanisms of SUDEP. The study by Tokatly Latzer et al. reminds us that the first gulf to bridge is the one that exists between our current state and the level of awareness needed by community and families of these patients. We must continue to counsel our families and first responders about SUDEP because it is evident that the failure to do so has long lasting effects on these families and their relationship with the medical community.

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