

AAN 69th ANNUAL MEETING ABSTRACT

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Abstract Title: To Reveal or Conceal? Adult Patient Perspectives on SUDEP Disclosure

Press Release Title: People with Epilepsy: Tell Us About Rare Risk of Death

Objective: To evaluate adult patient feelings and viewpoints associated with Sudden Unexpected Death in Epilepsy Patients (SUDEP) awareness.

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Background: The decision to discuss SUDEP with patients and families has created much debate. Many HCPs are hesitant to discuss SUDEP due to the perception of imposing unnecessary patient-related fear, while others argue that informing patients about SUDEP may enhance patient compliance, improve seizure control and aide in saving lives. Limited data exist on patients' viewpoints regarding their right to be informed of SUDEP and on the effects of awareness on patient motivation.

Design/Methods: Consenting adult epilepsy patients and caregivers were given a one-page SUDEP information sheet promoted by the National Epilepsy Foundation of America. Participants were then asked if they were interested in completing an eight-item questionnaire assessing their perception of the information. All patients were given the opportunity to clarify SUDEP related concerns with an epilepsy specialist. Study results were analyzed using Chi Square and Mann Whitney U tests.

Results: Forty-two subjects completed the questionnaire. One hundred percent (100%) felt that adult PWE had a right to know about SUDEP and 92% felt that HCPs should be required to inform patients. Respondents agreed that SUDEP awareness motivated them for better medication adherence (81%) and management of their seizure triggers (85%). Thirty percent endorsed increased fear with a trend ($p=0.08$) to be more prevalent in the group with generalized tonic clonic seizures.

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Conclusions: One hundred percent of PWE felt that it is their right to be informed about SUDEP. Most agreed that HCPs should be responsible for disclosing related information. While some participants endorsed fear, most agreed that SUDEP awareness motivated them to better manage factors that trigger seizures. SUDEP awareness may reduce the risk of associated deaths in adult PWE.