Short Note

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Safeguarding Lives: SUDEP Awareness and Empathetic Discussions in Epilepsy Management

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Abstract: SUDEP is a sudden death in a person with epilepsy, without evidence of a seizure before death. While its cause is still unclear, various factors have been linked to seizure onset and cardiopulmonary function. Studies have shown that although 91.3% of epilepsy patients want information on premature death, only 31% of them receive it. The numbers emphasize the need for open and sensitive communication by medical professionals. It is important to choose the appropriate moment for the conversation, avoiding periods of stress and ensuring emotional stability in the patient, as well as clear, appropriate and easy to comprehend information about SUDEP. To facilitate this, knowing the patient's level of knowledge is essential. Education on the warning signs of seizures and SUDEP can help take precautions and can decrease the incidence of the phenomenon itself. Effective epilepsy care requires a comprehensive plan, including medication adherence and lifestyle changes. Regular communication and collaboration between the patient, caregiver and health professionals are essential for the effective management of epilepsy, so just as epilepsy has a fluid, changeable course of disease and follow-up appointments are very important, the topic of SUDEP is not a one-time conversation either.

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Introduction

International League Against Epilepsy defines Sudden Unexpected Death in Epilepsy (SUDEP) as a "sudden, unexpected death in a person with epilepsy, with or without evidence for a seizure preceding the death, in which there is no evidence of other disease, injury, or drowning that caused the death"[1]. SUDEP incidence in people suffering from epilepsy is ~1/1000 patient-years, varying from numerous factors related to respiratory and cardiac function of the patient as well as epilepsy itself [2].

Despite being a phenomenon whose cause is not well understood, over the years, epileptologists have managed to identify some risk factors based on their observations, such as: poorly controlled epilepsy characterized by uncontrolled or frequent seizures, certain seizure types like generalized tonic-clonic seizures, medication non-adherence, sleeping in a prone position, accompanying respiratory and cardiac dysfunction, sudden seizure onset, lack of seizure monitoring and young age [3,4]. The latter raises the question of discussing the matter with the patient. So why, when and how should a medical professional approach their patient over this topic?

The question of informing patients about the chances of Sudden Unexpected Death in Epilepsy involves a delicate balance between providing crucial information and considering the potential emotional impact on the individual [5]. Many things are to be considered before moving forwards to this conversation. One important point that medical professionals should be aware of is that, based on statistical studies [6], 91.3% of epilepsy patients and 89.6% of family members/caregivers do want information on premature death, but sadly only 31% of the first group and 28% of the second actually receive it [7].

First step is knowing when to have the conversation. Surely the diagnosis of epilepsy is life changing. Whether it's a young or old patient, there are lots of lifestyle changes they have to deal

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with, hence is it not the best idea to have the topic of SUDEP covered immediately after the confirmation of diagnosis. Choosing a time when the patient is emotionally stable and ready to receive information and avoiding discussing SUDEP during periods of heightened stress, immediate post-seizure events, or other challenging circumstances is the key to laying a strong foundation for future good cooperation [8].

As with all medical conditions, it all comes down to informed decision making and open communication between the healthcare provider and the patient. Patients have the right to be informed about potential risks associated with their medical condition. This allows them to make informed decisions about their treatment, lifestyle choices, and overall management of epilepsy. This approach allows patients to express their preferences and concerns while working together to develop a comprehensive care plan that aligns with their values and goals. Before initiating the conversation, the medical professional firstly has to assess the level of knowledge on the topic and then tailor the conversation based on their existing knowledge [9].

It is crucial to present clear and accurate information about SUDEP, including what is known and what remains uncertain. This should be done in combination with addressing individual risk factors, as every patient is unique and this is not a one-time conversation. For example, risk is different for newly diagnosed patients vs refractory patients, so regular appointments need to be made according to the need of the patient. Failing to do so will only complicate the process and put the patient at a higher risk of SUDEP, as confusion and uncertainty bring higher levels of anxiety and stress and reduce the chances of adhering to medication and following doctor's advice on lifestyle changes [10].

While knowing the risk factors of Sudden Unexpected Death in Epilepsy doesn't guarantee prevention, it can guide individuals with epilepsy, their caregivers, and healthcare professionals in taking proactive measures to reduce the risk [11]. Education about the potential warning signs of seizures and SUDEP can empower individuals and their caregivers to seek timely medical attention. Recognizing and responding immediately to changes in seizure patterns or new symptoms can be crucial [12].

Aside from the above mentioned concerns, another thing that should be emphasized is the importance of adherence to anti-seizure medication, in spite of the patient's actual risk of SUDEP [13]. In patients with high risk, the conversation should go further, and more serious lifestyle changes need to be made such as nocturnal supervision or using seizure monitoring devices which can provide an additional layer of safety by alerting caregivers or emergency services in the event of a seizure [14].

Conclusion

It's essential to recognize that while these measures may contribute to risk reduction, SUDEP remains a complex and not fully understood phenomenon which unfortunately is fatal. Individuals with epilepsy should work closely with their healthcare team to develop a comprehensive care plan including medication adherence and lifestyle changes tailored to their specific needs and circumstances. Regular communication, open dialogue about concerns, and a collaborative approach between individuals, caregivers, and healthcare professionals are key components of effective epilepsy management

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References

1. L. Nashef, E. L. So, P. Ryvlin, and T. Tomson, "Unifying the definitions of sudden unexpected death in epilepsy," *Epilepsia*, vol. 53, no. 2. 2012. doi: 10.1111/j.1528-1167.2011.03358.x.
2. T. Tomson, T. Walczak, M. Sillanpaa, and J. W. A. S. Sander, "Sudden unexpected death in epilepsy: A review of incidence and risk factors," *Epilepsia*, vol. 46, no. SUPPL. 11. 2005. doi: 10.1111/j.1528-1167.2005.00411.x.
3. X. Sun, Y. Lv, and J. Lin, "The mechanism of sudden unexpected death in epilepsy: A mini review," *Frontiers in Neurology*, vol. 14. 2023. doi: 10.3389/fneur.2023.1137182.
4. D. J. Thurman, D. C. Hesdorffer, and J. A. French, "Sudden unexpected death in epilepsy: Assessing the public health burden," *Epilepsia*, vol. 55, no. 10, 2014, doi: 10.1111/epi.12666.
5. K. Cooper, P. Kirkpatrick, C. Brand, A. Rolfe, and S. Florida-James, "Discussing sudden unexpected death in epilepsy with children and young people with epilepsy and their parents/carers: A mixed methods systematic review," *Seizure*, vol. 78, 2020, doi: 10.1016/j.seizure.2019.10.002.
6. O. Henning, K. O. Nakken, and M. I. Lossius, "People with epilepsy and their relatives want more information about risks of injuries and premature death," *Epilepsy and Behavior*, vol. 82, 2018, doi: 10.1016/j.yebeh.2018.02.023.
7. B. Mesraoua, T. Tomson, M. Brodie, and A. A. Asadi-Pooya, "Sudden unexpected death in epilepsy (SUDEP): Definition, epidemiology, and significance of education," *Epilepsy and Behavior*, vol. 132. 2022. doi: 10.1016/j.yebeh.2022.108742.
8. C. Kerr, A. Nixon, and M. Angalakuditi, "The impact of epilepsy on children and adult patients' lives: Development of a conceptual model from qualitative literature," *Seizure*, vol. 20, no. 10, 2011, doi: 10.1016/j.seizure.2011.07.007.
9. J. M. Buelow, "Epilepsy management issues and techniques.," *J Neurosci Nurs*, vol. 33, no. 5, 2001, doi: 10.1097/01376517-200110000-00006.
10. M. J. Brodie and G. L. Holmes, "Should all patients be told about sudden unexpected death in epilepsy (SUDEP)? Pros and Cons," *Epilepsia*, vol. 49, no. SUPPL. 9. 2008. doi: 10.1111/j.1528-1167.2008.01933.x.
11. M. A. Alfonso, Y. E. Mastrapa, and L. M. M. Chacón, "Prevention of sudden death in drug-resistant epilepsy: Nursing research," *Revista Habanera de Ciencias Medicas*, vol. 20, no. 2. 2021.
12. G. S. Bell and J. W. Sander, "Sudden unexpected death in epilepsy. Risk factors, possible mechanisms and prevention: A reappraisal," *Acta Neurologica Taiwanica*, vol. 15, no. 2. 2006.
13. A. A. Asadi-Pooya *et al.*, "Counseling about sudden unexpected death in epilepsy (SUDEP): A global survey of neurologists' opinions," *Epilepsy and Behavior*, vol. 128, 2022, doi: 10.1016/j.yebeh.2022.108570.
14. E. K. St. Louis, "SUDEP Risk Counseling: What We Don't Do in the Shadows," *Epilepsy Curr*, vol. 23, no. 1, 2023, doi: 10.1177/15357597221134390.