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Commentary

Prioritizing Seizure Safety and SUDEP Counseling in People With Epilepsy and Their Caregivers During the COVID-19 Pandemic

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The COVID-19 pandemic has seriously affected the care of people with epilepsy (PWE) and their caregivers. Increased seizure frequency, difficulties in obtaining antiseizure medications, cancelled appointments and investigations, alterations in sleep patterns, mood changes, mental health difficulties, and caregiver stress and anxiety have all been reported.^{1–3} For PWE who are newly diagnosed and their caregivers, the pandemic has been especially challenging, with limited and/or reduced access to in-person support services and agencies, isolation from family members and friends, and the stress of coping with the uncertainty of a new diagnosis.

The care of PWE has been revolutionized during the pandemic as well, with the need to establish alternative care delivery models such as telemedicine and telephone consult services and home-based management options such as ambulatory electroencephalograms and home medication delivery.² In a recent international survey, most PWE (74.2%) reported satisfaction with either a phone or video consult with their neurologist as an alternative to in-person appointments.⁴ Similarly, in a survey of PWE and their clinicians, tele-medicine was found to be both effective and satisfactory in the delivery of chronic outpatient care to PWE.⁵ However,

the suitability/appropriateness of telemedicine practice for newly diagnosed PWE has been questioned by some clinicians.⁵

Counseling regarding a new diagnosis of epilepsy, seizure precautions and safety, as well as sudden unexpected death in epilepsy (SUDEP) may be perceived as difficult when completed via telemedicine or telephone consultation. Discussions around SUDEP and seizure precautions may also be perceived as challenging, especially when the encounter may not be face to face, there is observed heightened anxiety among the patient and/or caregiver (i.e., due to the pandemic), or there is a perceived lack of adequate time/and appropriate medium to have such sensitive discussions. Although counseling regarding seizure safety and precautions are part of a standard seizure evaluation, documentation of such discussions is often lacking, even with in-person visits.⁶ In a recent study of 152 children, only 19% of referring providers and 60% of neurologists documented seizure safety discussions during clinic visits.⁶ Moreover, although, counseling regarding SUDEP is recommended by both the American Academy of Neurology and American Epilepsy Society in PWE and their caregivers, many child neurologists do not follow the current guidelines in their clinical practice.^{7,8} In a recent cross-sectional survey, 36% of child neurologists discussed SUDEP with at least half of PWE and their caregivers and 12% discussed with all or almost all PWE and their caregivers.⁸

It is not currently known how the COVID-19 pandemic has affected the discussion rates of SUDEP and seizure safety among PWE and their caregivers. However, it is evident from a number of publications on SUDEP communication that most PWE and their

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caregivers want to be informed about SUDEP at diagnosis during a face-to-face interaction and discussion.⁹ The COVID-19 and Epilepsy study aims to determine the impacts of COVID-19 on the health and well-being of PWE.¹⁰ Preliminary results as of September 2020 of the ongoing survey from the COVID-19 and Epilepsy study found that only a small number of PWE had discussions regarding epilepsy risks such as safety precautions (16%), sleep (30%), and SUDEP (15%) in the preceding 12 months.¹⁰ Although these findings are preliminary, they are alarming and suggest that in times even before the pandemic started communication regarding seizure safety and SUDEP were lacking.¹⁰ Telemedicine brings about new communication challenges, and we hypothesize that rates of seizure safety and SUDEP discussion during the remainder of the pandemic will be similarly decreased with longer-term results from this survey and future studies to follow.

Discussion of SUDEP and seizure safety with PWE and their caregivers is important because it provides the necessary knowledge and empowerment to understand the risks associated with living with epilepsy. It also provides the opportunity to make changes to lifestyle such as reducing seizure triggers and improving medication compliance, as well as the opportunity to optimize medical therapy or introduce protective measures such as nocturnal supervision or listening devices.⁷ The effect of diminished seizure safety counseling and SUDEP discussion during the pandemic with PWE and their caregivers remains unknown, but it has the potential to increase the risk of seizure-related injury, accidents, and death in PWE. Furthermore, sleep disturbances, lack of adherence to antiseizure medications, increased seizure frequency, and lack of access to health care, all of which have been cited during the COVID pandemic, may have the potential to impact mortality in PWE.^{1–3,10} Failure to discuss SUDEP among PWE and their caregivers may also lead to feelings of anger, frustration, and distrust of health care professionals.

Whether telemedicine or telephone-based practices will affect SUDEP disclosure preferences among PWE and their caregivers is unknown. However, it is the authors' opinion that PWE and their caregivers still want to be informed of SUDEP risk irrespective of

the medium by which the information is delivered and despite the current constraints of health care delivery. Nevertheless, it is important that, as health care professionals, we better understand the preferences of PWE and their caregivers when it comes to disclosure of SUDEP so that we can deliver such information in a sensitive, thoughtful, and patient-centered manner. Telemedicine may become an integral part of health care delivery for PWE and their caregivers, especially for those who live in remote or rural areas or lack access to neurology care. Future studies aimed at exploring the experiences and perspectives of PWE and their caregivers who learn about SUDEP through alternative forms of care delivery such as telemedicine or telephone consultation should be explored.

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