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Letter to the Editor in response to Professor Josef Finsterer

The authors thank Prof Josef Finsterer for his concerns and comments expressed in his letter to the editor on the article of mortality and sudden unexpected death in epilepsy (SUDEP) [1]. The authors considered all deaths identified in a cohort of 235 persons living with epilepsy (PWE) and administered the World Health Organization verbal autopsy age-specific questionnaire (WHO-VAQ) [2].

The concern expressed on the absence of a post-mortem examination is valid. Nevertheless, post-mortem examination are very rarely performed in low- and middle-income countries (LMIC). Community-based (social and verbal) autopsies are often used for an evaluation of the cause of death in countries with limited resources and unregistered population, and are a proxy for an in-depth macroscopic and histopathological post-mortem examination [3,4]. Verbal autopsy is an increasingly important methodology for assigning causes to otherwise uncertified deaths, based on the assumption that a standardised interview of family members or community yields a detailed knowledge of the circumstances, signs and symptoms leading to the death [5]. Even in high income countries (HIC), specifically designed registries miss full autopsies and clinical information and data analysis requires additional data collection through interviews, illustrated by a recent report of the North American SUDEP Registry [6]. Conducting a structured interview of family members by a questionnaire-trained physician offers, in our opinion, the best opportunity to increase the understanding of deaths, including SUDEP, in LMIC.

The WHO-VAQ may not include epilepsy or SUDEP-specific information. Hence, medical records were reviewed, when available. Within the limitations of our manuscript, relevant data on each patient, based on WHO-VAQ and review of the medical records, were summarised in a comprehensive clinical description with details on the technical investigations, concomitant condition, and organ specific data. In addition, whereas serum levels of the antiseizure drugs are important, access to the appropriate testing in LMIC is equally very limited, and even in HIC serum levels are not always available [6].

In addition to our stated limitations and recommendations, we appreciate this feedback as it invites reflection on future directions, such as, (*i*) appropriate education of persons living with epilepsy (PWE) (and family) and healthcare professionals (HCPs) on risks and reporting of SUDEP; (*ii*) training of HCPs on SUDEP classification; (*iii*) training of HCPs on the administration of the WHO-VAQ; and, (*iv*) creating a country-specific SUDEP registry. Finally, it would be worthwhile to complement the WHO-VAQ with SUDEP-specific questions in case of death in PwE, such as provided in the Canadian Paediatric Surveillance Programme SUDEP questionnaire [7].

A better understanding of the cause of death in PWE in LMIC is necessary to ultimately update healthcare policy relative to epilepsy.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: D. Teuwen is an employee of UCB Pharma. P. Dedeken received consultancy fees from UCB Pharma and Novartis. P. Boon received speaker and consultancy fees from UCB Pharma, LivaNova, and Medtronic, and research grants from the same companies through his institution. Dr. Sebera no interests to declare.

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