

Letter to the Editor

## Sudden Unexpected Death in Epilepsy (SUDEP): The Story Must Be Told First to Medical Students

Fulvio A. Scorza<sup>1</sup>, Ana C. Fiorini<sup>2</sup>, Carla A. Scorza<sup>1</sup>, Manoel J.B.C. Girão<sup>3</sup>, Josef Finsterer<sup>4\*</sup>

<sup>1</sup>Disciplina de Neurociência, Escola Paulista de Medicina/Universidade Federal de São Paulo (EPM/UNIFESP) São Paulo, Brasil

<sup>2</sup>Programa de Estudos Pós-Graduado em Fonoaudiologia, Pontifícia Universidade Católica de São Paulo (PUC-SP), Departamento de Fonoaudiologia, Escola Paulista de Medicina/Universidade Federal de São Paulo (EPM/UNIFESP), São Paulo, Brasil

<sup>3</sup>Departamento de Ginecologia, Escola Paulista de Medicina/Universidade Federal de São Paulo (EPM/UNIFESP) São Paulo, Brasil

<sup>4</sup>Krankenanstalt Rudolfstiftung, Messerli Institute, Vienna, Austria

**\*Corresponding Author**

Finsterer J, MD, PhD

**Article History**

Received: 27.01.2020

Accepted: 03.02.2020

Published: 09.02.2020

**Keywords:** Epilepsy, sudden unexpected death, complication, multisystem disease, cerebral involvement, antiepileptic drugs.

### LETTER TO THE EDITOR

Always on the lookout for articles published in *Epilepsy and Behaviour*, one in particular has attracted a lot of attention because relevant discussion and future perspectives are really fascinating. Thomas and colleagues considered the dual viewpoints of the clinician and the scientist and how they consider the family experience of sudden death in epilepsy (SUDEP) to provide advice for all parties [1]. We totally agree with the authors that the effects of SUDEP on families cannot be underestimated, but also its effects on the treating physicians and caregivers should be acknowledged [1]. Considering the conclusions that the protocols for passing on information and education must be reinforced and supported, we applaud the authors for pursuing this topic [1]. Really, we need to educate everyone about SUDEP [2]. Besides that, it is very clear to all professionals involved with any kind of educational dynamics that educating is an arduous and complex task, but it is major path to provide access to human emancipation and social transformation [2].

Following these line of reasoning, our research group started 3 years ago a pilot educational project in our university (Escola Paulista de Medicina/Universidade Federal de São Paulo) on SUDEP with a very specific population, medical students. The medical students are attending the fourth year of the medical course and the SUDEP didactic class is in the Neurology module. Particularly, the experience has been a success. Basically, the class lasts approximately 1h and 30 minutes and begins with the demonstration of a clinical case of SUDEP [3]. After that, the story of SUDEP is told in a simple and elegant way to the students. In this sense, explanations about the definitions, epidemiology, main risk factors, mechanisms and possible biomarkers and preventive measures are discussed with the students [4-6]. In this short period of time, it became clear from our assessment that future clinicians and neuroscientists were able to absorb correct information about SUDEP and will be able to discuss it much more serenely in their daily work. Furthermore, it is important to note that the success of the project was so great that the next steps for this year will be to implement it for the other multidisciplinary courses at our university. We epileptologists and neuroscientists were unaware of the severity of SUDEP until the early 1990s. It is well known at the time that many neurologists are still of the opinion that epilepsy is a benign disease. Unfortunately, this reality has changed. Today epilepsy is a malignant disease with high mortality rates and unfortunately, SUDEP is a leading epilepsy-related cause of death in patients with epilepsy [7]. Finally, all

**Copyright @ 2020:** This is an open-access article distributed under the terms of the Creative Commons Attribution license which permits unrestricted use, distribution, and reproduction in any medium for non commercial use (NonCommercial, or CC-BY-NC) provided the original author and source are credited.

forms and educational cycles are extremely important. Obviously, the sooner we start educating neurologists about SUDEP, the more successful we will be on all fronts.

## ACKNOWLEDGEMENTS

Our studies are supported by the following grants: FAPESP (Fundação de Amparo à Pesquisa do Estado de São Paulo); CNPq (Conselho Nacional de Desenvolvimento Científico e Tecnológico) and Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES).

## REFERENCES

1. Thomas, R. H., Craig, D. P., & Leach, J. P. (2019). The view of the clinician and the scientist on the family experience of sudden epilepsy deaths. *Epilepsy & Behavior*, 106679.
2. Scorza, F. A., Olszewer, E., Fiorini, A. C., Scorza, C. A., & Finsterer, J. (2019). Sudden unexpected death in epilepsy: Rethinking the unthinkable. *Epilepsy & Behavior*, 93, 148-149.
3. Couzin, J. (2008). When Death Strikes Without Warning.
4. Devinsky, O., Hesdorffer, D. C., Thurman, D. J., Lhatoo, S., & Richerson, G. (2016). Sudden unexpected death in epilepsy: epidemiology, mechanisms, and prevention. *The Lancet Neurology*, 15(10), 1075-1088.
5. Watkins, L., Shankar, R., & Sander, J. W. (2018). Identifying and mitigating Sudden Unexpected Death in Epilepsy (SUDEP) risk factors. *Expert review of neurotherapeutics*, 18(4), 265-274.
6. Scorza, F. A., Arida, R. M., Terra, V. C., & Cavalheiro, E. A. (2010). What can be done to reduce the risk of SUDEP?. *Epilepsy & Behavior*, 18(3), 137-138.
7. Scorza, F. A., do Carmo, A. C., Scorza, C. A., & Fiorini, A. C. (2017). SUDEP: A steep increase in publication since its definition. *Epilepsy & Behavior*, 72, 195-197.