

# Epilepsy kills

## Epilepsia mata

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### ABSTRACT

People with epilepsy are more likely to die prematurely, and the most common epilepsy-related category of death is sudden unexpected death in epilepsy (SUDEP). Thus, the purpose of this article was to alert the scientific community about SUDEP.

**Key words:** epilepsy, SUDEP, heart, seizures.

### RESUMO

Pessoas com epilepsia têm maior chance de morrer prematuramente e a principal causa de morte relacionada à epilepsia é a morte súbita em epilepsia (SUDEP). Assim, o objetivo deste artigo foi alertar a comunidade científica sobre a SUDEP.

**Palavras-Chave:** epilepsia, SUDEP, coração, crises epilépticas.

Epilepsy is one of the most common serious brain disorders; it knows no age, racial, social class, geographic, or national boundaries<sup>1</sup>. Often epilepsy is still seen as a benign condition in which individuals only have seizures. Unfortunately, the story is not as simple as it seems. Epilepsy is a malignant condition, which has a high rate of premature death compared to the general population<sup>2-4</sup>. Most of the excess death is due to the underlying disease causing epilepsy, and some is epilepsy-related, including trauma, suicide, aspiration pneumonia, *status epilepticus*, but mostly due to sudden unexpected death in epilepsy (SUDEP) that is a leading cause of mortality in epileptics<sup>2-4</sup>. The lack of findings in autopsy and the fact that most cases of SUDEP are not witnessed cause difficulties with regard to the definitions of SUDEP. It is generally defined as a sudden, unexpected, witnessed or not witnessed, nontraumatic and non-drowning death in patients with epilepsy, with or without evidence of a seizure and excluding documented *status epilepticus*, in which postmortem examination does not reveal a toxicological or anatomical cause of death<sup>5</sup>.

The reported incidence of SUDEP is quite variable, and this is largely due to differences in patient populations, study design, and the criteria for defining SUDEP<sup>4</sup>. In fact, results from a US population-based study indicate that the risk of sudden death in people with epilepsy is estimated to be at least 20 times higher than the one of the general population<sup>6</sup>. In general terms, SUDEP is responsible for 7.5 to 17% of all deaths in people with epilepsy and it has an incidence among

adults between 1:500 and 1:1,000 patient-years<sup>7</sup>. Concerning risk factors, several studies have tried for more than ten years to find factors predisposing to SUDEP in order to identify individuals with particularly high risks. To date, several risk factors have been identified such as refractoriness of the epileptic condition, presence of convulsive seizures, early onset of epilepsy, antiepileptic medication (polytherapy with antiepileptic drugs), young age, and duration of the seizure disorder<sup>4,8,9</sup>. The cause(s) of SUDEP is(are) still unknown, however research consistently suggests that the main mechanism for SUDEP is autonomic deregulation, i.e., cardiac and respiratory abnormalities during and after seizures<sup>4,8-10</sup>.

It is clear that SUDEP is mainly, yet not exclusively, a problem for people with uncontrolled epilepsy<sup>9</sup>, but our understanding of the best way to prevent it is still incomplete. Strict evidence for their effectiveness is still lacking, but epidemiological and observational data seem to suggest some measures to minimize the risk of SUDEP, including good seizure control, stress reduction, participation in physical activity and sports (with appropriate professional supervision), dietary management (omega-three supplementation), night supervision, family members' knowledge of cardiopulmonary resuscitation techniques, and the basics of defibrillator use<sup>9,11,12</sup>.

Despite the great scientific advances of SUDEP over the past two decades, the discussion of potential death related to seizures is still a topic under discussion between epileptologists. Due to the high sensitivity of the issue, some clinicians

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believe that a policy of informing all patients will cause stress and anxiety<sup>13</sup>. Thus, two questions have generated more passionate discussion than any other aspect of SUDEP: should all people diagnosed with epilepsy be told about the possibility of SUDEP? Or should only those who are at higher risk be told?<sup>14,15</sup>. In general, it has been proposed that people should be fully informed about the risks of any condition or its treatment, although there is debate about the quality and timing of information on SUDEP to patients and relatives<sup>13</sup>. Following this line of reasoning, as neuroscientists in Latin America we do not have a formal opinion on this matter; therefore we enjoyed the presence of experts on this condition in the last Latin American Summer School on Epilepsy (LASSE) to start clarifying this issue in our region<sup>16</sup>. The main question was designed as a multiple choice meant to cover any position towards SUDEP counseling<sup>16</sup>: under which conditions would you tell a person with epilepsy the risks of SUDEP?

- a) I would never tell;
- b) I would tell only if the person approached the subject;
- c) I would tell to all people with epilepsy;
- d) I would tell to people with higher risk factors;
- e) I have never thought of this possibility.

After careful analysis, some important conclusions and future prospects could be established: as SUDEP is not a rare event, caution remains prudent and necessary; patients with high risk factors for epilepsy should be told about SUDEP; a SUDEP practice guideline via the all Leagues of Epilepsy in Latin America should be developed; a SUDEP task force

should be created in Latin America to disseminate consistent information regarding it for all health professionals; a research agenda in Latin America (experimental and clinical level) should be developed, and research agencies of the governments of each Latin American country should be encouraged to release funds for this purpose; from these preliminary data, SUDEP will be deeply discussed in all subsequent editions of LASSE<sup>16</sup>.

People with refractory epilepsy may appear healthy during their lives, but they are more likely to die suddenly. Various mechanisms have been hypothesized or already proven to play a role in the etiology of SUDEP; however, more research is required to further elucidate its pathophysiology. Besides, if there is reason to suspect a patient's risk, we are certain that a point of convergence between physicians (family physician, cardiologist, and specialist center) is really important, in order that together they can establish diagnosis, treatment options, risk determination, and counseling of the family members or caregivers.

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