EPILEPSY PATIENTS AND THEIR FAMILIES SHOULD ROUTINELY BE TOLD ABOUT THE RISK OF SUDEP

Jera Kruja
UHC Mother Theresa, Tirana, Albania

SUDEP is a “Sudden, unexpected, witnessed or unwitnessed, no traumatic and no drowning death in patients with epilepsy, with or without evidence for a seizure and excluding documented status epilepticus, in which postmortem examination does not reveal a toxicological or anatomic cause for death.” (Nashef 1997)

The incidence is reported to be between 0.1 and 2 per 1000 patient years. The cause of SUDEP is unknown. Various mechanisms have been proposed: central apnea, cardiac arrhythmia, autonomic dysfunction, seizure-induced metabolic changes, and alterations in cerebral autoregulation. Risk factors are, history of and number of GTCS, frequent seizures, sub therapeutic AED levels, long epilepsy duration, early epilepsy onset, young adults, AED polytherapy, frequent AED changes, IQ <70 (Tomson 2005).

Evidence that poor adherence to AED regimens is a risk factor for SUDEP is contradictory. Because the cause of death is unclear, prevention remains a challenge. The abolition of generalized tonic clonic seizures, wherever possible, should be a priority as the majority of witnessed cases of SUDEP occur during or shortly after seizures (Duncan & Brodie 2011).

The question of informing patients and their families about the risk of SUDEP, and whether and when SUDEP should be discussed remain a problematic issue.

The need for SUDEP risk disclosure is supported by the 2009 report of the American Epilepsy Society/Epilepsy Foundation Joint SUDEP Task Force (So 2009), which recommends that the “increased risk of death associated with epilepsy should be disclosed in the context of a comprehensive education program provided to all patients and their families and caregivers”. This is also supported by a recent NIH/HINDS workshop report (Hirsch 2011). A 2010 questionnaire survey (Gayatri 2010) found that 91% of parents of children with epilepsy expected their pediatric neurologist to provide SUDEP risk information and that provision of this information did not have a significant immediate or longer term negative impact.

The potential benefits of health care providers discussing SUDEP with people with epilepsy and their families include the following: helps health care providers and people with epilepsy share in treatment goals, helps to establish a “truth-telling” relationship, allows people with epilepsy to organize their lives with reasonable expectations, allows people with epilepsy and their families to help reduce possible risk factors for SUDEP, e.g., by ensuring medical compliance and minimizing behavior that can exacerbate seizures. The ethics value is the right to know vs. the right not to know.

On the other hand, telling the risk of SUDEP to every epilepsy patient or their relatives has potential risks: may precipitate anxiety, depression, or posttraumatic stress disorder in individuals with a predisposed psychological type, in certain cultures, the discussion could be interpreted as predisposing the individual to the event. Furthermore it is believed to be not necessary to stress the possibility of SUDEP at the beginning of the follow up of a patient opposite to the possibility to be seizure free in about 60%. A personalized behavior according to the clinical form and course of disease is more convincing.