THE FRENCH SENTINEL NETWORK ON EPILEPSY-RELATED MORTALITY

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- INTRODUCTION -

It is now generally accepted that **people with epilepsy** are at **increased risk of premature death** compared with the general population, and this has been consistently reported in many studies (1-4). A meta-analysis of mortality studies in people with epilepsy reports a standardized mortality ratio ranging from 1.6 to 9.3 depending from the source population (5). Over the last few years, there has been a growing interest in mortality in epilepsy. Local initiatives have been launched in some countries to study mortality in epilepsy. In France, only two studies have investigated this topic (6, 7). In 2010, the **Ligue Française Contre l'Epilepsie (LFCE)** with and on behalf of bereaved families founded the French sentinel network on epilepsy-related mortality named **Réseau Sentinelle Mortalité Epilepsie (RSME)**.

- OBJECTIVES -

The two main objectives of the network are:

- **To describe causes and circumstances of death related to epilepsy in France,**
- **To evaluate the needs and expectations of bereaved families**, to propose to get in touch with other bereaved families or to have a talk with a neurologist of the network to answer their questions.

Other objectives:

- To evaluate the incidence of mortality linked to epilepsy in regions actively participating to the network
- To help neurologists in coping with the death of their patients (training on grief, exchanges with psychologists…) and providing them with advice as to how they should inform their patients with epilepsy and their family of the mortality risk.

– METHODS –

The network RSME includes 75 physicians of whom **39 epileptologists and 36 neuro-pediatricians located in the different regions of France (Figure 1), 21 of the 22 metropolitan regions and 3 of the 5 overseas districts are represented.** They were designated by the Ligue Française Contre l'Epilepsie in 2009. A national **steering committee,** consisted of physicians, epidemiologists, researchers, representatives of bereaved families, and representatives of LFCE and FFRE, coordinates the network.

The ascertainment of epilepsy-related deaths is prospective, between Jan. 2010 and Jan. 2012. No age limit.

Data Collection :

- A **standardized form** is filled in by neurologists or physicians with the agreement of the family
- **Collected data**: Socio-demographic data, circumstances and causes of deaths, autopsy, characteristics of the epilepsy, medication and compliance, medical history, recent events
- **Validation of the cause of death** by an expert committee (2 neuro-pediatricians, 2 neurologists and 1 epidemiologist)

The study has been approved by the CNIL and the ethics committee of Lyons, France.

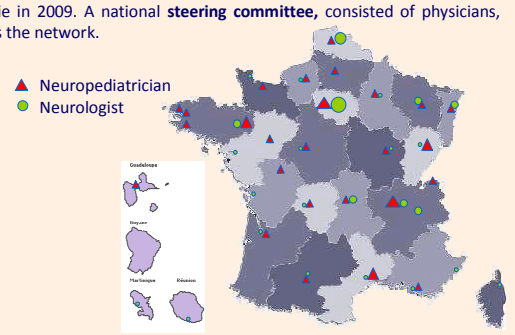

Figure 1 : Location of physicians who represent the network

- FIRST RESULTS (July 2011) -

Overall mortality (n = 34)

Table 1: Demographic data		
Age at death	Mean (years)	30.5
	Median (Interquartiles)	28 (20-40)
	< 15 years old N (%)	4 (12.5)
	≥ 15 years old N (%)	30 (87.5)
Sex	Men N (%)	21 (62%)
	Women N (%)	13 (38%)

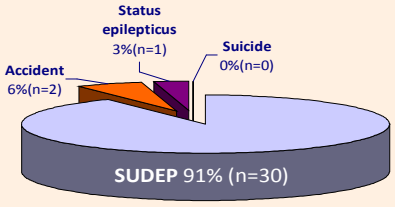

Figure 2 : Causes of death

Autopsy: 8 / 26 SUDEP (31 %) of which 4 for forensic reasons

Sudden Unexpected Death in Epilepsy (SUDEP) cases (n=30)

Table 2: Circumstances of death	N (%)
Place of death:	
-Home	19 (63%)
-Outside (school/work)	2 (7%)
-Hospital	4 (13%)
-Institution	5 (17%)
Death during sleep	22 (76%)
Clinical features suggestive of a recent seizure	11 (42%)

Lying flat on stomach N (%)	14 (67%)
Presence of a third person N (%)	4 (19%)
Particular monitoring N (%)	1 (5%)

- Epileptic syndrom in SUDEP cases -

4 (15%) had an **idiopathic epilepsy, 11 (41%)** a **cryptogenic one** and 10 (37%) a **symptomatic** epilepsy.

- Antiepileptic drugs (AED) in SUDEP cases -

For 83% (n=24) of the SUDEP cases, seizure were not controlled by AED and 42% of the SUDEP cases underwent a treatment modification in the past 3 months (N=11)

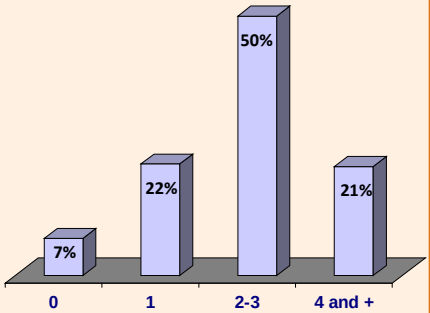

Figure 3 : Number of AEDs in SUDEP cases (N=28)

- DISCUSSION AND PERSPECTIVES -

The participation rate is not equally distributed throughout the country and, even in the regions participating in the network, only SUDEP are correctly reported. In addition, most of the deaths are notified by neurologists working in hospital. To increase the awareness health professionals (in particular private practitioners) and to improve completeness of deaths notification, an information campaign by the specialized medical press and the Website of the French league against Epilepsie were made (www.mortalite-epilepsie.fr) A leaflet presenting RSME's activities have been distributed to all French neurologists concerned by epilepsy. The data collected as part of this network can also carry out research projects related to mortality. Thus,the SUDEP cases recorded in the network are included in a case-control study to identify risk factors for SUDEP.

Founded in 2009, the network has now a national coverage – neurologists and pediatric neurologists - distributed throughout the country. The network is a discussion forum between health professionals involved in the care of patients with epilepsy but it is also a forum and resource for bereaved families. In the near future, the founding of a national psychologists network should permit in providing better support to bereaved families. The information gathered from the bereaved families will help us in providing advice and therapeutic education to patients and their families in order to reduce the risks of death associated with epilepsy. In the case of SUDEP, this point is crucial for physicians for whom there is a real dilemma between the duty to inform about the risk of SUDEP and the need to avoid increasing the anxiety of the patient and his family. Recent advances in the literature (8-15) help identify when the risk of SUDEP should be discussed. Interviews with families provide valuable elements in answering the two key questions: What is it? How should I speak about it?

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