

GUEST EDITORIAL

Epilepsy, risks and insurance

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Improvements in the diagnostic and therapeutic approach to patients with epilepsy have substantially changed the outcome, and consequently, the socio-cultural implications of the disease. Up to 90% of patients from different countries have prolonged periods of seizure remission^{1–3} and about 60% of those who have been taken off treatment remain seizure-free at two years⁴. This brings a considerable proportion of cases back to normal life. The everyday life risks (morbidity, accidents, etc.) for the majority of patients with epilepsy are therefore not expected to be different from those of the general population. However, the improvement in the medical approach to epilepsy has not yet been followed by an equal improvement in the management of the social and legal aspects. Patients with epilepsy are still thought to be at higher risk of morbidity and accidents. This belief may influence the attitudes of lay people towards epilepsy and have a significant impact on individual patients' quality of life. Insurance premiums are generally higher for patients with epilepsy, under the belief that the disease interferes with everyday activities through the patient's life.

Available knowledge of the everyday life risks in patients with epilepsy is inadequate because published reports are far from conclusive. This was clearly stated in a recent workshop on epilepsy, risks and insurance⁵. Based on the results of that workshop, the International Bureau for Epilepsy (IBE) set up an ad-hoc Commission on Epilepsy, Risks and Insurance (C. Cornaggia (Chairman) and E.

Beghi, Italy; W.A. Hauser, USA; J.H. Loeber and A.E.H. Sonnen, Holland; R. Thorbecke, Germany) to draft guidelines for the assessment of everyday life risks based on the results in the literature⁶. In brief, patients with epilepsy may be at higher risk of early death, suicide and psychiatric hospital admission, but they do not seem at higher risk of having traffic accidents or, when epilepsy is controlled, of unfitness to work and early retirement. A greater risk of accidents at work among people with epilepsy was occasionally reported, due to motor impediments, not secondary to the disorder *per se*. Data are lacking on the risk of morbidity, days lost from work and treatment in hospital.

The lack of high-quality information about the everyday risks in epilepsy depends on the scarcity of reports and of studies conducted with proper methods. The risks attributable to epilepsy can be precisely calculated by comparing the frequency of each measurable event in patients and in a matched control population. As epilepsy presents fairly similar characteristics in the developed countries, special problems with regard to everyday life risks are likely to be similar within the European Union, and a sizeable sample of patients and matched controls is needed to investigate these points.

The scarcity of the available data prompted a multinational cohort study on everyday life risks in pediatric and adult patients with epilepsy and in matched non-epileptic controls. Firstly, diagnosed patients with idiopathic and

remote symptomatic epilepsies residing in the areas served by the participating centres will be selected and followed up for 24 months. The following variables will be collected and analysed in patients and controls: medical contacts and underlying illnesses, accidents (traffic, domestic, work), hospital admissions and days off work (off school).

Seven European countries (Italy, Germany, France, United Kingdom, Denmark, Holland and Spain) will participate in the study providing a cohort of about 1000 patients and 1000 matched controls. At the end of the study, data from these international sources will be delivered to insurance companies and any other private or governmental agency dealing with patients with epilepsy. The study has been funded by the European Union (Biomed I Program) which has promoted concerted action between members of European countries having common interests and objectives in health care.

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