Epilepsy in Action

The current climate and intervention proposals for improving the lives of people who live with epilepsy

Executive summary - EY Spain
Epilepsy is one of the most common chronic neurological disorders. Approximately 50 million people of all ages throughout the world suffer from it. It is a highly complex pathology characterised by excessive uncontrolled neuronal discharges, called epileptic seizures. This disorder is also closely linked to neurobiological, cognitive and social consequences, which vary according to the severity of the clinical status of each patient.

Although the majority of people have heard of epilepsy, only those who suffer from it, their family members and experts in the field understand it and are well informed about the physical, psychological and social burden the disorder entails. The great majority of society lacks information and is conditioned by social stigma, stemming from ancient beliefs about the human being which still have negative effects on the social integration of these patients today.

Epilepsy affects approximately 345,000 people in Spain, of whom around 29,000 are children, although these figures are inaccurate, since there are no national epidemiological studies or patient registers. Although the condition affects patients of all ages, the incidence is particularly high in children. According to the experts, this disorder is the primary cause of paediatric neurological consultations. Its prevalence is also high in the elderly and is expected to increase at a considerable rate in upcoming years.

The prognosis of the disorder is highly variable, 70% of patients who receive pharmacological treatment are able to successfully eliminate the seizures. However, the remaining 30% suffer from seizures which cannot be controlled by drugs and require alternative treatments. Furthermore, between 25% and 40% have cognitive problems of diverse severity, which may simply entail learning difficulties or reduced cognitive and psychomotor skills. The experts highlight that 14% of paediatric patients suffer from severe epilepsy, associated with delayed development.
The complexity of epilepsy requires specialist, comprehensive and coordinated care from all the healthcare levels involved. Although in recent years specialist care has evolved, there are still many regional health services without the resources or professionals who specialise in epileptology. As a result, in Spain, only 25% of patients are attended by a neurologist who specialises in epilepsy. The diagnosis of the disorder is relatively simple, although there is still limited access to certain tests and resources, which often delays the process. Experts in the field emphasize the need to promote actions and initiatives to promote standardized, multidisciplinary and comprehensive care.

With regard to the financial impact, epilepsy currently accounts for almost 3% of annual health service expenses, costing the system 2.76 thousand million euros annually. This includes healthcare costs and non healthcare costs, sick leave losses and other expenses paid by the patient. It is of note that in recent years the management of epilepsy has evolved considerably in terms of social involvement and the struggle to ensure good quality of life for the patient. Despite this, epilepsy still has a high social and emotional impact for the patient. In this regard, one of the most important aspects to address is the promotion of complementary services and assistance for all patients so as to reduce as far as possible the negative impact of the disorder on their quality of life and relationships, and to foster their integration into society.

Below are some of the goals to improve healthcare in Spain:

- Creation of a clinical guide for a generalised approach throughout the national health system that empowers and accommodates innovation to improve the quality of life of the patients
- Higher specialisation and training of multidisciplinary teams to care for the epileptic patient at all levels of healthcare
- Creation of new medical epilepsy units in the different regional health services, and the enhancement of existing medical-surgical units
- Investment in key diagnostic systems, such as the prolonged EEG video
- Promotion of complementary services and psychological support for the patient
- Creation of a nationwide patient register
- Higher awareness and education at all levels of society

In the light of this situation, coordinated work by the different agents involved in epilepsy healthcare, at both a clinical and a social level is essential to promote and drive the provision of professional training, raise consciousness and educate society and to offer the patient the complete, personalised care they require.
Epilepsy is a neurological pathology which is characterised by suffering from epileptic seizures of diverse symptoms, caused by abnormal and uncontrolled neuronal activity

The experts indicate that epilepsy is one of the main central nervous system disorders. It is also a chronic and complex condition which combines a broad variety of conditions of varying aetiology, prognosis and levels of severity. Its clinical, social and financial impact is high worldwide. Although the triggers for the condition are often unknown, epilepsy may be due to structural causes, such as trauma, or genetic or congenital metabolic diseases.

In Spain initiatives need to be generated for the creation of specialist medical units, for enhancing the existing medical-surgical units and for training healthcare professionals in epileptology

In Spain, three out of every four patients attend neurology departments, where they are seen by a non-specialist neurologist or paediatric neurologist, due to the lack of medical units for epilepsy and the lack of epileptologists, particularly in paediatrics. Furthermore, in the existing medical units, access to the main diagnostic tests is limited and the waiting lists are long. In this context, one of the challenges of epilepsy is to promote initiatives aimed at training clinical experts in the disorder, and to drive actions to promote the creation of new medical units equipped with the right diagnostic systems, and actions to enhance state-of-the-art medical-surgical units. This would ensure that all patients had access to the diagnosis and treatment they need, regardless of geographical location.

Conclusions
Seventy percent of patients treated with antiepileptic drugs successfully control their seizures; the remaining 30% are refractory

Epilepsy is mostly treated with drugs. The objective is to successfully achieve complete remission of the seizures with the fewest adverse effects possible. However, many patients do not control their seizures with drugs and require other treatments. Five percent to 10% of patients with epilepsy are candidates for surgical treatment, although the success rate largely depends on the type of intervention and the clinical situation of the patient. Stimulation of the vagus nerve or a ketogenic diet are also treatments designed to reduce the frequency and severity of seizures and have a higher success rate in paediatric patients.

The costs associated with epilepsy in Spain amount to 2.76 thousand million euros each year, which is equivalent to almost 3% of public health spending

Epilepsy has a high financial impact as it includes healthcare costs from diagnosis, treatment and patient follow-up, as well as other costs associated with the disease. As a result, the specialisation and training of professionals in the main disciplines, and the creation of adequately equipped medical units for epilepsy are key to achieving a healthcare system more efficient in epilepsy management which would reduce public spending and improve the system’s sustainability.

Actions are needed to drive research in epilepsy in all areas and thus contribute to long-term improvement in healthcare quality

Despite the efforts made in recent years to improve healthcare for patients with epilepsy, the experts accentuate the need to promote and invest in researching all areas of the disorder and thus increase epidemiological studies, research into new drug regimes with higher tolerability, innovation into systems of diagnosis, monitoring and patient follow-up, and also the development of less invasive surgical techniques.

Even today, discrimination against epilepsy continues to greatly impact the patient socially and emotionally

Patients with epilepsy not only have to cope with the clinical conditions of the disorder throughout their lives, but are also subjected to its social and psychological consequences. The fear generated by lack of knowledge, stigma and low social awareness result in making these patients feel misunderstood, rejected or marginal to society and this affects their educational and professional performance. One of the major challenges of epilepsy is therefore to educate and raise the social awareness of patients, family members and society in general. Furthermore, the experts consider that it is crucial to drive initiatives to boost complementary services, including those of psychologists, to help patients cope with their condition and thus help them to improve the quality of their lives.
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