

The impact and burden of epilepsy and its treatment in children and adolescents in Taiwan

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Background and Objective: Epilepsy is one of the most common neurological conditions in children and young people. Furthermore, children with epilepsy have been known to have more problems with academic studies, making and sustaining relationships, emotional development and behaviour when compared with others. These social consequences can impact a child's development and future opportunities. Despite this, very few studies have been performed in Taiwan to investigate this problem. The purpose of this survey was to investigate, better understand and raise awareness of the impact and burden of epilepsy and its treatment in children and adolescents.

Methods: The International Bureau for Epilepsy (IBE) Survey of Children and Teenagers with Epilepsy was designed to assess the perception of people directly involved with childhood epilepsy worldwide. Survey questionnaires were developed by the IBE in collaboration with a medical and scientific panel for 3 specific groups: 1) Children and young people; 2) Parents and carers; 3) Healthcare professionals. The results of questionnaires distributed via physicians who see children with epilepsy to 10 major hospitals throughout Taiwan are presented here.

Results and Discussion: A total of 14 physicians (36% paediatric neurologists), 21 patients and 118 carers responded. The majority of patients and children of carers were on medications and still experiencing seizures. Routine follow up and increased seizure frequency were the most common reasons for review (93% and 86% of physician respondents respectively). Over 40% of parents and carers expect epilepsy to impair the future lives of their children, particularly in relation to living independently, education and employment. This concern is shared by the patients. On average, the children with epilepsy in this survey miss over a week of school each year. Epilepsy also can have an impact on the child's carer with nearly 50% of the respondents having had to give up their job to care for a child with epilepsy. The stigma of epilepsy appears to be still prevalent with 48% of patients and 34% of carers concealing their epilepsy. Sixty percent of carers believe that others would treat their children differently. The most frequently asked questions by patients and their carers are related to side effects of the medications they were taking. Of these side effects, cognitive complaints were amongst the most common and were considered the most important to avoid by physicians. Most of the physicians (79%) and around a third of both carers and patients surveyed thought that these cognitive complaints were related to their epilepsy medications. Eighty percent of physicians felt that cognitive side effects were the most important to avoid in children. Physicians most frequently referred their patients to patient support groups for further source of information. However, patients and carers still turned to their physicians or nurses as their first choice for information about epilepsy.

Conclusion: Epilepsy and its drug treatments have a significant impact on the lives of patients through the perspective of the patients, their carers and physicians in this Taiwan study. It is hoped that the better appreciation of psychosocial impact will help improve management of children and adolescents with epilepsy.

Reference

1. Future in Mind Report. IBE Survey of Children and Teenagers with Epilepsy, 2006.