

Educational needs of epileptologists regarding psychiatric comorbidities of the epilepsies: a descriptive quantitative survey

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ABSTRACT – *Aim.* Psychiatric disorders are relatively frequent comorbidities in epilepsy and they have an impact on morbidity, mortality, and quality of life. This is a report from the Task Force on Education of the ILAE Commission on Neuropsychiatry based on a survey about educational needs of epileptologists regarding management of the psychiatric comorbidities of epilepsy.

Methods. The Task Force designed a quantitative questionnaire to survey the self-perceived confidence of child and adult epileptologists and psychiatrists in managing major psychiatric comorbidities of epilepsy to identify: (1) critical areas of improvement from a list of skills that are usually considered necessary for effective management of these conditions, and (2) the preferred educational format for improving these skills.

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Results. A total of 211 respondents from 35 different countries participated in the survey. Confidence and usefulness scores suggest that responders would most value education and training in the management of specific clinical scenarios. Child neurologists identified major Axis I disorders, such as mood and anxiety disorders, while adult neurologists identified attention deficit hyperactivity disorder, intellectual disabilities, and autistic spectrum disorder as key areas. Both adult and child neurologists identified screening skills as the priority. Psychiatrists mainly valued specific training in the management of psychiatric complications of epilepsy surgery or psychiatric adverse events of antiepileptic drugs. Sessions during congresses and face-to-face meetings represent the preferred educational format, while e-learning modules and review papers were chosen by a minority of respondents.

Conclusions. Results of this survey identify key areas for improvement in managing the psychiatric comorbidities of epilepsy and suggest specific strategies to develop better training for clinicians involved in epilepsy care.

Key words: epilepsy, education, survey, psychiatric disorders, autism, depression, intellectual disability, surgery

Epilepsy is now recognized as a disorder of the brain characterized not only by an enduring predisposition to generate epileptic seizures, but explicitly also by the neurobiological, cognitive, psychological, and social comorbidities of this condition (Fisher *et al.*, 2014). Whilst seizure freedom should represent the ultimate goal when possible, it is now becoming evident that numerous factors determine the quality of life (QoL) of people with epilepsy, with comorbid depression or the adverse effects of medications often constituting stronger predictors of poorer QoL than seizure frequency itself (Birbeck *et al.*, 2002). Even in those in whom remission is achievable, QoL remains poor if psychiatric comorbidities are untreated. Successful integration of people with epilepsy into society is another important goal of epilepsy care. Educational level, intellectual ability, psychological stability, family and social support, and employment opportunities, as well as the ability to overcome stigma, transportation, and mobility issues are important determinants of successful integration (Hermann and Jacoby, 2009). The combination of these factors influences the life of people with epilepsy and what they consider meaningful (Bautista *et al.*, 2014).

A lifetime history of psychiatric disorders can be identified in one in three people with epilepsy (Lin *et al.*, 2012). Mood and anxiety disorders are the most frequently reported (Tellez-Zenteno *et al.*, 2007) for both biological and psychosocial reasons. In May 2015, the World Health Assembly approved the WHO Resolution on the Global Burden of Epilepsy which provides a powerful tool for engaging national governments in :

- implementing effective actions to improve medical and social services for people with epilepsy;
- promoting public awareness about epilepsy;

– and allocating resources to epilepsy research (Covanis *et al.*, 2015).

This provides a wonderful opportunity to improve epilepsy care and address the global burden of epilepsy so that people with epilepsy can receive timely treatment and benefit from educational and occupational opportunities, free from stigma and discrimination. It is, therefore, evident that epileptologists need to develop multiple clinical skills and be able to organise care plans involving a range of experts and health care professionals in order to address the multiple needs of people with epilepsy.

In 2004, Gilliam *et al.* reported that only 7% of US neurologists routinely screen epilepsy patients for depression in their outpatient clinics (Gilliam *et al.*, 2004). Since then, the International League Against Epilepsy (ILAE) has developed a number of documents and initiatives in order to increase the awareness of epileptologists of the importance of identifying and managing psychiatric problems in epilepsy, and to provide training and clinical instruments to accomplish this goal. Over time, the ILAE Commissions on Neuropsychiatry have developed consensus guidance documents (Kerr *et al.*, 2011), supported the dissemination of validated screening instruments for depression, such as the Neurological Disorders Depression Inventory for Epilepsy (NDDIE) (Di Capua *et al.*, 2012; Metternich *et al.*, 2012; Mula *et al.*, 2012; Tadokoro *et al.*, 2012; Brandt *et al.*, 2014; Thomson *et al.*, 2014), and, in conjunction with the Virtual Epilepsy Academy (VIREPA), offered the on-line course on “Neuropsychiatric aspects of epilepsy” that has been run twice.

The Task Force on Education of the ILAE Commission on Neuropsychiatry was appointed to formulate proposals to address the educational needs of epileptologists about the psychiatric comorbidities

of epilepsy. This Task Force report is based on the results of a purpose-developed survey circulated among epileptologists and other healthcare professionals working with people with epilepsy.

Methods

The Task Force on Education of the ILAE Commission on Neuropsychiatry designed a quantitative questionnaire to survey the educational needs of epileptologists about managing the major psychiatric comorbidities of epilepsy. First, respondents were asked to provide demographic information including gender, age, and job role. Second, respondents were asked questions about their routine practice (*i.e.* whether they routinely screen for psychiatric comorbidities; reluctance about prescribing psychotropic drugs in patients with epilepsy; whether psychiatrists or clinical psychologists are available in their treatment setting). Respondents were then asked to rate their knowledge/confidence in managing the major psychiatric comorbidities of epilepsy using a 5-point Likert-type scale (1=very good and 5=very poor) and to assess the importance of a list of skills that are usually considered necessary for effective management of psychiatric comorbidities (*i.e.* how to screen, how to diagnose, how to treat, how to use behavioural interventions, how to deal with specific situations such as post-surgical complications or psychiatric adverse events of antiepileptic drugs). Finally, the questionnaire was designed to ask respondents about their preferred educational format for improving their clinical skills (*i.e.* books/textbooks; review papers/peer review material; face-to-face meetings, such as congresses or symposia; and e-learning modules). The questionnaire remained online for eight months between October 2015 and May 2016. It was freely available and easily accessible. The survey was circulated via the ILAE Regional Chairs, who were asked to send the questionnaire to individual ILAE Chapters for distribution. Completion of the questionnaire was entirely anonymous.

Results

A total of 211 respondents from 36 different countries participated in the survey (*table 1*). Demographic data are presented in *table 2*. The majority of respondents comprise adult neurologists/epileptologists, 14.7% are child neurologists/epileptologists, 22.4% psychiatrists/neuropsychiatrists, and 5.7% are other healthcare professionals especially epilepsy nurses and some neuropsychologists. In almost 40% of cases, neither psychiatrists nor clinical psychologists form part of the epilepsy team, while one third of respondents

Table 1. List of countries that participated in the survey (in alphabetical order).

Albania
Argentina
Australia
Azerbaijan
Belgium
Brazil
Bulgaria
Canada
Denmark
France
Georgia
Germany
Greece
Italy
Japan
Lithuania
Mexico
Montenegro
New Zealand
Norway
Poland
Republic of Korea
Russia
Serbia
Slovenia
South Africa
Spain
Sweden
Switzerland
Thailand
The former Yugoslav Republic of Macedonia
Turkey
Ukraine
United Kingdom of Great Britain and Northern Ireland
United States of America
Zimbabwe

work in tertiary epilepsy centres with easy access to both. About 50% of respondents stated that they routinely screen for psychiatric comorbidities and feel at ease with the prescription of psychotropic medications (*e.g.* antidepressants or antipsychotics), but one out of four remain reluctant to use these medications for patients with epilepsy (*table 2*).

In general terms, management of psychoses, attention deficit hyperactivity disorder (ADHD), psychiatric complications of epilepsy surgery, and autistic spectrum disorder (ASD) are perceived as critical by a large number of clinicians, with almost one out of two rating individual knowledge/confidence as 'poor' or 'very poor' (*figure 1A*). However, looking at individual group ratings, adult neurologists, child neurologists, and

Table 2. Profile of respondents.

n=211	
Gender	
Male	52.4%
Female	47.6%
Age	
25-34	10.5%
35-44	24.4%
45-54	34.9%
55-64	20.6%
65-74	9.1%
>75	0.5%
Clinical role	
Adult neurologist/Epileptologist	51%
Child neurologist/Epileptologist	14.7%
Psychiatrist	16.7%
Child psychiatrist	6.2%
Neuropsychiatrist	5.7%
Others (<i>i.e.</i> neuropsychologist, epilepsy nurse, mental health nurse, neuropathologist)	5.7%
Is there a psychiatrist or a psychologist dedicated to patients with epilepsy in your centre?	
Yes both	33.8%
Only a psychologist	11.4%
Only a psychiatrist	15.7%
None of them	39.1%
Do you routinely screen for psychiatric problems at your epilepsy clinic?	
Yes (Adult neurologist)	56.6%
Yes (Child neurologists)	54.8%
Are you reluctant about prescribing antidepressants/antipsychotics to patients with epilepsy?	
Yes always	25.5%
Only for antidepressants	4.8%
Only for antipsychotics	19.7%
I have no problems	50.0%

psychiatrists show some clear differences (*figure 1B, 1C, 1D*). Child neurologists mainly perceive Axis I disorders as critical, such as mood and anxiety disorders and psychoses, with more than 50% rating their knowledge/confidence as 'poor' or 'very poor', followed by complications of epilepsy surgery (*figure 1B*). Conversely, more than 60% of adult neurologists feel that their knowledge about ADHD and ASD is 'poor' or 'very poor', and one out three rated their competence in managing intellectual disabilities (IDs) and psychiatric complications of epilepsy surgery as 'poor' or 'very poor' (*figure 1C*). Among

psychiatrists, psychiatric complications of epilepsy surgery constitute the only area rated as 'poor' or 'very poor' in terms of knowledge/confidence, by only one in five clinicians (*figure 1D*).

Regarding specific skills rated as the most important by respondents (*figure 2*), both adult and child neurologists identified screening for major psychiatric comorbidities in outpatient clinics as the priority (40% of child neurologists and one third of adult neurologists). Diagnostic issues and developing clinical skills for specific situations, such as psychiatric complications of epilepsy surgery, are considered a priority by one third of psychiatrists.

Data relating to the preferred educational format indicate that the majority of respondents consider congresses (plenary sessions or symposia) to be most valuable (*figure 3*). More than half of adult epileptologists and one third of child neurologists and psychiatrists have chosen this as the preferred format.

Discussion

This survey identified key areas of improvement in terms of knowledge and development of specific skills for epileptologists regarding management of the psychiatric comorbidities of epilepsy. For the first time, psychiatrists were involved in the process and it was possible to identify specific needs for adult and child neurologists treating patients with epilepsy.

Epileptologists are keen to improve their clinical skills and screening during routine clinical practice seems to be the priority. Most adult neurologists feel inadequate or not skilled enough when dealing with patients with epilepsy and ASD, ADHD, or IDs in general. Child neurologists are historically better trained in these conditions and thus, usually more adept in their management. A prospective community-based study of children and adolescents with active epilepsy showed that up to 40% of patients have IDs, one third have ADHD, and around 20% have ASD (Reilly *et al.*, 2014). In addition, a community-based survey of more than 1,000 adults with epilepsy reported that ADHD-like symptoms are present in one out of five patients and are associated with depression, anxiety, drug-resistance, and poor QoL (Ettinger *et al.*, 2015). It is clear that adult neurologists need to be trained in these specific areas in order to maintain good clinical skills in the management of complex patients with epilepsy and IDs. The development of Transition Clinics dedicated to transition from paediatric to adult epilepsy service may also favour this process.

Child neurologists identified screening and managing Axis I disorders as the most critical area for their clinical skill development. Mood and anxiety disorders in children are still underestimated and poorly recognised

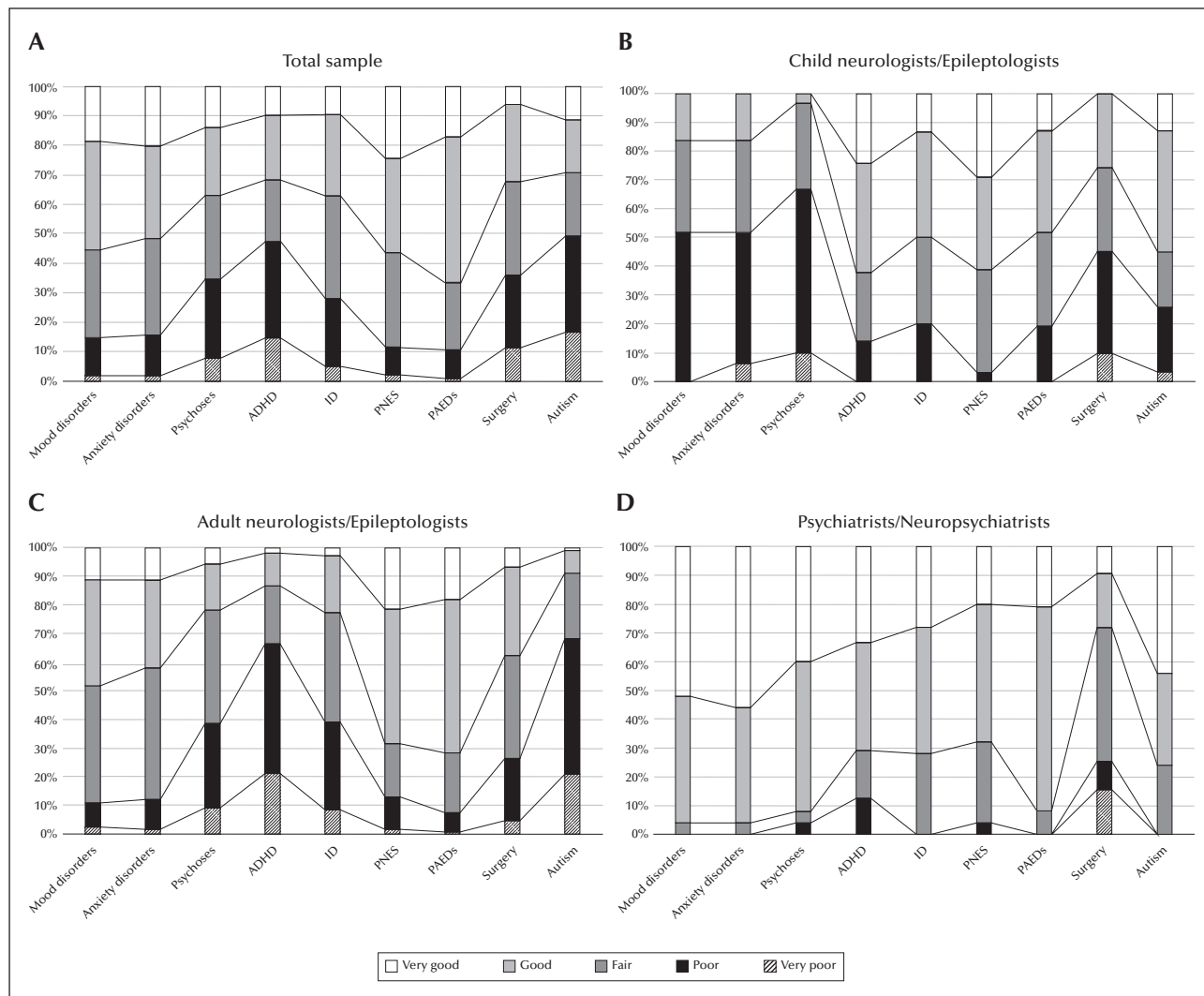


Figure 1. Self-perceived knowledge and level of confidence in managing psychiatric comorbidities of epilepsy in the total sample (A), among child neurologists (B), adult neurologists (C), and psychiatrists/neuropsychiatrists (D). ADHD: attention deficit hyperactivity disorder; ID: intellectual disability; PNES: psychogenic non-epileptic seizures; PAEDs: psychiatric adverse events of antiepileptic drugs.

(Jones, 2014). This is often due to the atypical phenomenology of depression and anxiety in children as compared to adults. It is estimated that up to 50% of adult patients with a mood or anxiety disorder (not restricted to persons with epilepsy) had an anxiety disorder during childhood (Kim-Cohen *et al.*, 2003), making routine screening crucial for the development of preventative strategies. This is further supported by the American Academy of Child and Adolescent Psychiatry that recommends that children and adolescents should be routinely screened for symptoms of anxiety (Connolly and Bernstein, 2007). In children, the rate of self-reported as compared to parent-reported anxiety is higher, suggesting that it is important to rely on children’s self-assessment wherever possible,

but also to develop specific guidelines of treatment in order not to over-medicate children with non-specific symptoms.

Finally, this report identified congresses as the preferred educational format for the majority of respondents. However, it has to be acknowledged that this may be inflated by the high number of adult neurologists who participated in the survey. In fact, looking at the preferred format by individual categories, more than 50% of adult neurologists chose congresses while the same format was chosen by only one third of child neurologists and psychiatrists. Review papers and e-learning modules were chosen by one out of three. This may be explained by the opportunity to discuss personal cases, ask specific

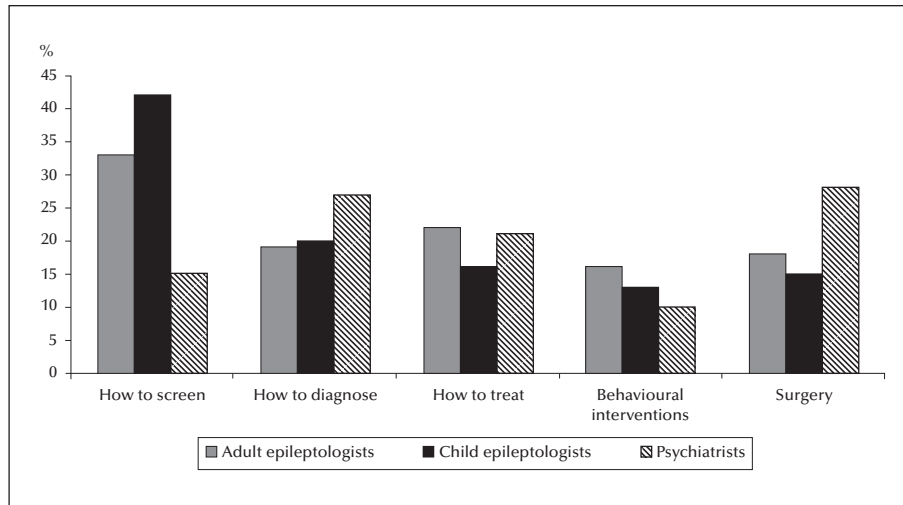


Figure 2. Clinical skills perceived as most important in managing the psychiatric comorbidities of epilepsy.

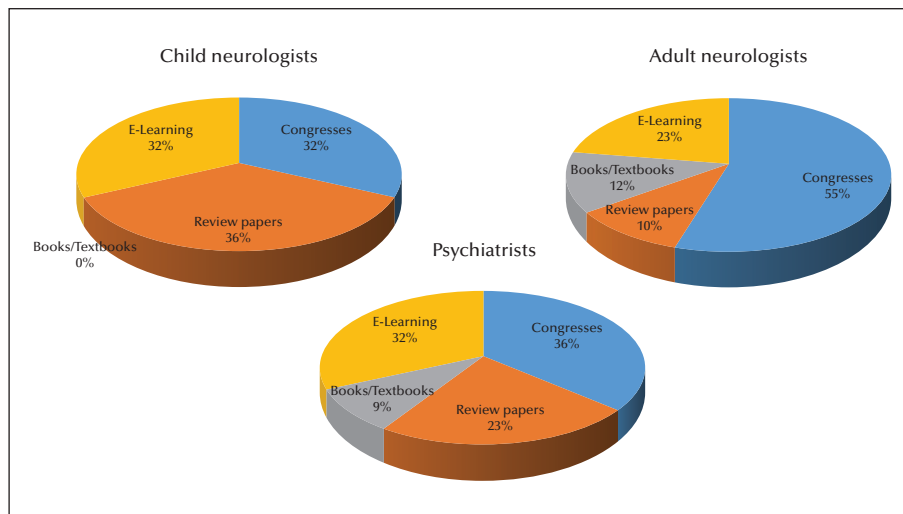


Figure 3. Educational formats perceived as the best way to improve knowledge and confidence in managing the psychiatric comorbidities of epilepsy.

questions, or discuss specific clinical scenarios with colleagues.

Results of this survey should be considered bearing in mind the following limitations. On line surveys are practical, cost-efficient, and fast. However, there may be accessibility issues in some areas of the world. In addition, as for any survey, respondents are more likely to have a special interest in the subject. In this regard, the limited number of respondents reflects the still limited interest of epileptologists in psychiatric comorbidities of epilepsy and thus, these results may be representative of a small subgroup of clinicians who are already interested in this subject. This is further

suggested by the high rate of clinicians stating that they routinely screen for psychiatric disorders in the clinic, namely more than half. Since the initial report of Gilliam *et al.* (2004), showing that only 7% of neurologists routinely screen for depression, the ILAE has been strenuously working on a number of educational initiatives. These include two series of the VIREPA course on the psychiatric aspects of epilepsy, the dissemination of easy-to-use screening instruments for epileptologists (*i.e.* the NDDIE), and the Latin American Summer School for Epilepsy that dedicated one edition just to comorbidities. However, relying only on the results of this survey to state that now half of neurologists

screen for psychiatric comorbidities is probably overly optimistic, although it is definitely encouraging. Furthermore, the present survey was mainly circulated through the ILAE network, thus reflecting the opinion of health professionals working in epilepsy centres. Further studies among general neurologists would be of great value.

Second, the majority of respondents are located in Europe, North America, and Australia. Although this may be due to language barriers, it is also representative of the still low interest of clinicians in other continents regarding psychiatric comorbidities of epilepsy. Epilepsy is still a highly stigmatised condition, and stigma greatly affects the QoL of people with epilepsy, leading to increased anxiety and depression and poor adherence to medication (Buck *et al.*, 1997). Unfortunately, even currently, stigma is present in both high-income and resource-poor countries (de Boer *et al.*, 2008). Stigma is not only responsible for poor QoL but also seems to play a role in mood and anxiety problems in both people with epilepsy and their caregivers. Perceived stigma is also responsible for increased rates of aggressive behaviour associated with depression and anxiety (Seo *et al.*, 2015). In low and middle-income countries, 20% of mothers of children with epilepsy feel stigmatized because of their child's neurological condition (Elafros *et al.*, 2015), and the caregiver's perception of burden, together with the level of family function, are indirectly correlated with depressive symptoms in people with epilepsy via the mediating effect of caregiver depression (Han *et al.*, 2015). It seems evident, therefore, that one of the future missions of the ILAE Commission of Neuropsychiatry will be to increase the awareness of clinicians in low-income countries of the psychiatric comorbidities of epilepsy, and to explore the consequences of this double stigma.

Supplementary data.

Summary didactic slides are available on the www.epilepticdisorders.com website.

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None of the authors have any conflict of interest to declare. This report was written by experts selected by the International League Against Epilepsy (ILAE) and was approved for publication by the ILAE. Opinions expressed by the authors, however, do not necessarily represent the policy or position of the ILAE.

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TEST YOURSELF



(1) Among the different psychiatric comorbidities of epilepsy, which one is perceived as critical by the majority of clinicians?

- A. Mood and anxiety disorders
- B. Psychogenic non-epileptic attacks
- C. Psychoses, ADHD, and autism
- D. All of them

(2) Which educational format is preferred by the majority of adult epileptologists regarding psychiatric comorbidities of epilepsy?

- A. Textbooks
- B. Symposia during congresses
- C. On line courses
- D. None of them

Note: Reading the manuscript provides an answer to all questions. Correct answers may be accessed on the website, www.epilepticdisorders.com, under the section "The EpiCentre".