Epilepsy: the care providers
Introduction

- The respondents were asked about the number of specialist medical professionals such as neurologists, neuropaediatricians, psychiatrists and neurosurgeons involved predominantly in providing epilepsy care in the responding countries. A total number of 32 668 neurologists, neuropaediatricians, psychiatrists and neurosurgeons are reported to be involved predominantly in providing epilepsy care in 69.6% of the responding countries. A total of 11 869 psychiatrists involved predominantly in epilepsy care are reported to be available in 80 countries. The median number per 100 000 population is 0.08 (interquartile range 0.03–0.23).
- Neurologists are involved predominantly in providing epilepsy care in 85% of the responding countries. A total of 14 094 neurologists involved predominantly in epilepsy care are reported to be available in 108 countries. In these countries, the median number per 100 000 population is 0.18 (interquartile range 0.05–0.46).
- The median number of neurologists per 100 000 population involved predominantly in epilepsy care varies widely across regions: 0.01 in South-East Asia, 0.06 in Africa and the Eastern Mediterranean, 0.08 in the Western Pacific, 0.30 in the Americas, and 0.33 in Europe.
- Neuropaediatricians are involved predominantly in providing epilepsy care in 77% of the responding countries. A total of 5 283 neuropaediatricians involved predominantly in epilepsy care are reported to be available in 87 countries. The median number per 100 000 population is 0.08 (interquartile range 0.03–0.23).
- The median number of neuropaediatricians involved predominantly in epilepsy care per 100 000 population varies from zero in South-East Asia to 0.14 in Europe.
- Psychiatrists are involved predominantly in providing epilepsy care in 69.6% of the responding countries. A total of 1422 psychiatrists involved predominantly in epilepsy care in 85% of the responding countries. A total number of 11 869 psychiatrists involved predominantly in epilepsy care are reported to be available in 80 countries. The median number per 100 000 population is 0.10 (interquartile range 0.03–0.28).
- Neurosurgeons are involved predominantly in providing epilepsy care in 68.8% of the responding countries. A total of 1422 neurosurgeons involved predominantly in epilepsy care are reported to be available in 75 countries. The median number per 100 000 population is 0.04 (interquartile range 0.01–0.09).
- The percentage of medical professionals involved in epilepsy care varies across income groups of countries. For example, 100% of total number of neurologists are involved predominantly in providing epilepsy care in low-income countries compared with high-income countries (median number per 100 000 population: 0.09 and 0.03, respectively).

Salient findings

- It is difficult to quantify the number of medical professionals involved predominantly in epilepsy care. The figures are based on best estimates by the respondents.
- Information about the distribution of the medical professionals in countries is not available but, as reported by some respondents, the majority are likely to be concentrated in urban areas, thus leading to more inequity than is apparent from the above figures.
- The number of medical professionals is greater in higher middle-income countries than in high-income countries. This could be attributable to different definitions of the specialists, or there could be reporting errors.
- The number of psychiatrists involved in epilepsy care is lower in high-income countries compared with low-income countries. One possible reason for this could be the presence or absence of neurology specialists in these countries.

Conclusions

- Specialist medical professionals are important members of the team providing comprehensive care for people with epilepsy, especially at tertiary level. They are also essential for training and providing support and supervision to primary health-care providers in epilepsy care.

- The inequity in the number of specialist medical professionals observed across countries in different income groups and geographical areas needs to be specifically dealt with.
**15.1 Median number of neurologists per 100,000 population involved predominantly in epilepsy care in WHO regions and the world**

- **World:** 0.18
- **Africa:** 0.33
- **Americas:** 0.03
- **South-East Asia:** 0.06
- **Europe:** 0.06
- **Eastern Mediterranean:** 0.01
- **Western Pacific:** 0.3

*N = 108*

**15.2 Median number of neuropaediatricians per 100,000 population involved predominantly in epilepsy care in WHO regions and the world**

- **World:** 0.14
- **Africa:** 0.02
- **Americas:** 0.08
- **South-East Asia:** 0.03
- **Europe:** 0.06
- **Eastern Mediterranean:** 0.08
- **Western Pacific:** 0.01

*N = 87*

**15.3 Median number of neurosurgeons per 100,000 population involved predominantly in epilepsy care in WHO regions and the world**

- **World:** 0.07
- **Africa:** 0.03
- **Americas:** 0.05
- **South-East Asia:** 0.008
- **Europe:** 0.04
- **Eastern Mediterranean:** 0.08
- **Western Pacific:** 0.04

*N = 75*

**15.4 Median number of psychiatrists per 100,000 population involved predominantly in epilepsy care in different income groups of countries**

- **Low:** 0.17
- **Lower middle:** 0.12
- **Higher middle:** 0.09
- **High:** 0.03

*N = 80*

**15.5 Number of medical professionals providing epilepsy care in WHO regions**

<table>
<thead>
<tr>
<th>Region</th>
<th>Number of Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Americas</strong></td>
<td>5822</td>
</tr>
<tr>
<td><strong>Europe</strong></td>
<td>10,779</td>
</tr>
<tr>
<td><strong>Western Pacific</strong></td>
<td>13,235</td>
</tr>
<tr>
<td><strong>Africa</strong></td>
<td>691</td>
</tr>
<tr>
<td><strong>East Mediterranean</strong></td>
<td>1563</td>
</tr>
<tr>
<td><strong>South-East Asia</strong></td>
<td>575</td>
</tr>
</tbody>
</table>

*For "N", refer to 15.1-15.4*

**Epilepsy Atlas © WHO 2005**
Introduction

◆ The respondents were asked about the number of professionals allied to medicine such as neurological nurses, psychologists and social workers involved for 50% or more of their time in providing epilepsy care. This figure is used as a marker of their predominant involvement in epilepsy care.

Salient findings

◆ A total number of 19,732 neurological nurses, psychologists and social workers are reported to be involved predominantly in providing epilepsy care in the responding countries.

◆ Neurological nurses are involved predominantly in providing epilepsy care in 56.5% of the responding countries (N=92). A total of 2036 neurological nurses involved predominantly in epilepsy care are reported to be available in 52 countries. In these countries, the median number per 100,000 population is 0.11 (interquartile range 0.06–0.36).

◆ While the median number of neurological nurses per 100,000 population in Europe is 0.19, it is 0.03 in South-East Asia.

◆ The median number of neurological nurses per 100,000 population involved predominantly in epilepsy care is 0.07 for low-income countries; it is 0.17 and 0.11, respectively, for higher middle-income and high-income countries.

Limitations

◆ Some countries were unable to provide data regarding various professionals allied to medicine as they do not have a separate register.

◆ Information about the distribution within countries of professionals allied to medicine is not available but, like all other specialist human resources, the majority are likely to be concentrated in urban areas.

◆ The number of professionals allied to medicine is greater in higher middle-income countries than in high-income countries. This could be attributable to different definitions of the specialists, or there could be reporting errors.

◆ In significant number of countries where no formal training programme exists for neurological nursing, many nurses are informally trained in aspects of neurological care. This is not reflected in the data.

◆ It is possible that the job description of social workers differs among the countries, making comparison of numbers difficult.

Conclusions

◆ For many chronic disorders such as epilepsy, nurses can be important providers of primary care and liaison services at community level. Emphasis is needed to give them appropriate training and facilities for providing care to people with epilepsy.

◆ In spite of the limitations of the data set, it is clear that the number of social workers working in the field of epilepsy is grossly inadequate. Efforts need to be made to improve the situation.

◆ Psychologists are important members of the multidisciplinary team providing comprehensive care to people with epilepsy. They have an important role in the diagnosis, treatment, presurgical evaluation and rehabilitation of people with epilepsy.
16.1 Median number of neurological nurses per 100,000 population involved predominantly in epilepsy care in WHO regions and the world

N=67

16.2 Median number of psychologists per 100,000 population involved predominantly in epilepsy care in WHO regions and the world

N=67

16.3 Median number of social workers per 100,000 population involved predominantly in epilepsy care in WHO regions and the world

N=62

16.4 Number of professionals allied to medicine in WHO regions

- **Americas**: 7548
- **Europe**: 11109
- **Western Pacific**: 611
- **South-East Asia**: 18
- **Eastern Mediterranean**: 119

* For "N", refer to 16.1-16.3
Introduction

◆ This theme refers to specialist training in the diagnosis, prevention, care, rehabilitation and research in epilepsy for medical graduates and professionals allied to medicine.

Salient findings

◆ Training facilities in epileptology are available in only 15.8% of the responding countries.

◆ No facility for training in epileptology exists in countries in South-East Asia, whereas such facilities exist in only 2.6% of the countries in Africa, 6.7% in the Eastern Mediterranean, 17.4% in the Western Pacific, 20.8% in the Americas, and 31.8% in Europe.

◆ While only 2.1% of the low-income countries have a training programme in epileptology, 28% and 23.5% of the higher middle-income and high-income countries, respectively, offer training in epileptology.

◆ The median duration of training in epileptology is 12 months (interquartile range 5–12). A median number of 10 (interquartile range 5–20) students obtain a specialist degree in epileptology every year in the responding countries.

Limitations

◆ Information was not obtained regarding the prerequisite qualification required to train in epileptology.

◆ As mentioned by some respondents, informal training in epileptology is carried out without licensing. The data do not include this information; e.g. in several countries that do not provide a formal diploma or degree in epileptology academic chairs have been instituted, usually in the department of neurology and often in combination with the chair for electroencephalography and clinical neurophysiology.

◆ Data regarding the structure of training or the training curriculum are not available.

Conclusions

◆ Education in the field of epileptology plays a key role in reducing the burden of epilepsy and facilitating the rehabilitation of people with epilepsy.

◆ Specialist training in epileptology is needed on multiple levels to reach all those concerned in epilepsy management.

◆ There is a need to establish eligibility criteria for entry to training programmes, accreditation of training centres and criteria for epileptologists based on local needs. The epilepsy organizations are playing a significant role in organizing epilepsy education.

◆ Educational materials, including standard guidelines for diagnosis and care of people with epilepsy, ought to be produced and distributed in resource-poor countries where training facilities cannot be established because of the high costs involved. Opportunities for the training of professionals involved in epilepsy care from low-income countries should also be encouraged.
Training in epileptology in WHO regions and the world

N=158

17.1 Availability of training in epileptology in the world

N=158

17.2 Training in epileptology in different income groups of countries

N=155

17.3

- Africa: 2.6%
- Americas: 20.8%
- South East Asia: 31.8%
- Europe: 6.7%
- Eastern Mediterranean: 17.4%
- Western Pacific: 18.8%
- World: 15.8%
- Low: 2.1%
- Lower middle: 18.8%
- Higher middle: 23.5%
- High: 28%

Information not available
Good training and continuous education of the professionals involved in epilepsy treatment are the key to any improvements in the care of people with epilepsy. Epilepsy care needs to be comprehensive, including medical, social and psychological aspects, and multiple professions are therefore involved. Dependent on the complexity of the individual case, care is provided at the primary, secondary and tertiary levels of health care. ILAE gives professional education the highest priority. Traditionally, epileptological training is obtained on-site in well-known epilepsy centres, and updates of knowledge are offered in courses and other meetings organized by ILAE Chapters, epilepsy centres, pharmaceutical companies and others. Since the early 1990s, a master course in epilepsy is offered for a fee by King’s College, London, United Kingdom, and the French ILAE Chapter has organized a diploma course in epileptology in cooperation with several universities (diplôme inter-universitaire).

Organized, structured educational activity on a larger scale started in ILAE in 1996, with the establishment of a regional academy in the European Region – the European Epilepsy Academy (EUREPA) – which has since been given global responsibility. The Academy set out by establishing a modular curriculum for the education and certification of epilepsy specialists to ensure the availability of a three-level system of care in all European countries. Many epilepsy centres and other institutions that provide on-site training in epileptology joined the Academy. Existing educational courses and meetings in the various countries were included in the curriculum on the basis of indicators of quality, and with systematic evaluations. These courses which receive EUREPA acknowledgement were supplemented with new courses in previously neglected fields. Educational seminars of EUREPA became a regular part of the international and regional epilepsy congresses of ILAE and IBE and other major meetings, including the annual meetings of several national ILAE Chapters.

Train-the-trainer courses established a multinational and multilingual group of certified EUREPA trainers who take responsibility for these educational activities at the national and regional levels. It turned out that the Academy courses were attended by doctors working at the secondary healthcare level even more than by aspiring epilepsy specialists, so the trainers adjusted the focus of their teaching accordingly to neurologists, paediatricians and psychiatrists.

In addition, EUREPA’s system of medical education is now being supplemented by a similar programme for other health professionals involved in epilepsy care – professions allied to medicine such as neurological nurses, psychologists, social workers and EEG technicians. This extension is being developed as a joint endeavour of ILAE and IBE.

The globalization of ILAE’s educational activity is taking place in various ways. Other regional commissions in cooperation with EUREPA are organizing similar academies in their regions. The most advanced of these is the Asian and Oceanian Epilepsy Academy (ASEPA), whose activities include epilepsy meetings for the primary and secondary sector in the least developed countries of the region, educational sessions at the biennial regional epilepsy congresses, and an offer of scholarships for training selected individuals in epilepsy centres. An Eastern Mediterranean Epilepsy Academy is also under development.

Advanced courses and summer schools are offered to groups of postgraduate students for 1–2 weeks with a distinguished faculty of international epileptologists. Since 2002, ILAE has been organizing annual summer courses in Venice, Italy, at the International University on San Servolo. Students from all over the world are selected on the basis of their qualifications, experience, affiliation and publications, with grants to candidates from less affluent countries. The courses are partially research-oriented (e.g. Bridging basic with clinical epileptology) and partly theme-centred (e.g. Paediatric epileptology). In September 2005, a new summer school on clinical pharmacology of antiepileptic drugs was organized for the first time, in Eilat, Israel, on behalf of the ILAE Commission on European Affairs, also with grants to allow the participation of non-Europeans.

More needed to be done, however, to reach out to regions where distances are larger than in Europe, travel is expensive, and fewer possibilities exist to receive on-site education in centres or to attend quality courses. In 2004, EUREPA therefore started a programme of distance education with a pilot module about genetics in epilepsy. This e-learning programme uses the Internet with a special learning platform. The advantages are:

- participation on an equal basis is possible for anyone with a computer and Internet access in any part of the world;
- a tutorial system gives every participant individual access to interaction with an expert in the specific field;
- apart from an initial meeting, no displacements are necessary;
- costs are much lower than for meetings or on-site education; for students who cannot pay even the modest course fee, grants are made available.

There are also some disadvantages:

- the course has a tight time schedule which may cause problems for students who have many professional or personal commitments;
◆ a ratio of 20 students to one tutor seems to be the reasonable maximum, which means that either many tutors are needed or only a few students can participate;
◆ the students have different levels of epileptological knowledge when they enter the course;
◆ computers with Internet access are often not available in some of the countries most in need;
◆ a relatively high standard of fluency is required in the language in which the course takes place (at present tuition is available only in English).

Because there is a high interest in these distance learning courses, ILAE will need to recruit many tutors in several languages from its membership. This seems to be possible, however, because the need for education is widely understood. Other modules need to be developed so that distance training in as many aspects of epileptology as possible can be provided. For some fields more sophisticated technologies will be required, to enable the exchange of EEG and imaging data or of videos.

The linguistic aspect of education that becomes evident with respect to e-learning has in fact been recognized by EUREPA from the outset. On the principle that a high standard education in epilepsy should be available to everybody in his or her own language, the certified EUREPA trainers already cover more than 35 languages. More specifically, as Africa remains a region where epileptology is difficult to develop, EUREPA and members of the French ILAE Chapter took an initiative for French-speaking Africa of establishing a francophone section of EUREPA in 2002. Special sessions took place during annual meetings of the French League, and a series of train-the-trainer courses in French for participants from North and West Africa was started in autumn 2004. These activities are already beginning to make a visible difference in Africa.

At its last strategic planning meeting, ILAE decided to pursue, intensify and broaden these initiatives, and to make education the first priority for the coming years. Special attention will be paid to regions that until now have been only marginally involved in ILAE’s educational programmes. For some regions, this will require the education of the primary health-care sector including professions allied to medicine. Additional language Academy sections are planned, the next being a Portuguese-speaking section as a joint effort of the Portuguese and Brazilian ILAE Chapters and EUREPA. The modular system of provision of education, comprising the three components of on-site training in centres, summer schools and advanced courses, and e-learning will be further developed and streamlined. It is ILAE’s ambition to establish an exemplary global educational system, and in this way take epilepsy care worldwide a large step further.