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## Challenges of epidemiological research on epilepsy in resource poor countries

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Epilepsy is one of the most common neurological disorders. Today, an estimated 50 million people live with epilepsy (PWE), 80% of whom in developing countries. The public health significance is particularly high in these settings because of its high prevalence, its seizure acuteness and frequency, and the sociological, psychosocial, and financial consequences for the households it affects.

The difficulties encountered managing seizures and implementing epilepsy prevention and control programmes are numerous. The recently published Atlas of Epilepsy care [1] describes the public health dimensions and highlights underlying global features. It shows that epilepsy is a disorder of internationally recognised importance in resource-poor countries; but, substantial local obstacles hinder control, which often requires comprehensive investigations. Hence, there is a need to conduct epidemiological studies particularly in these settings.

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Resource poor countries share demographic, sociological and economic features. They are particularly marked by ethnic, linguistic and religious richness, and their populations are frequently threatened by political instability and economic uncertainties. As a consequence health systems are typically weak and lack efficiency in addressing health needs. The purpose of this text is to highlight some of the methodological challenges faced when conducting epidemiological research on epilepsy in resource poor settings.

An acute resource constraint is a dominant underlying feature of health services in developing countries. The treatment gap is huge (reaching more than 90%) in most places. As only a small fraction of PWE benefit from treatment, health services are of limited value to conduct epidemiological research on this condition. Typically, beneficiaries of treatment originate from urban areas and belong to the economically advantaged section of the population which does not represent the majority in need. Therefore, community based studies are inevitable to correctly assess the living conditions and needs of PWE.

However, community-based epidemiological studies are challenging. Exact and reliable census data are rarely available, and denominators needed to calculate population prevalence or incidence rates are often crude estimations because they are too resource-consuming to be determined properly. Door-to-door surveys produce an accurate account of denominators; however, migratory effects and other population dynamic elements cannot be easily captured by this technique.

Passive case finding of PWE underestimates the actual number. Those most affected often do not come forward. Stigma, misconceptions and beliefs attached to this condition influence the open presentation of affected individuals in public meetings. Hence, active case detection is

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necessary. Door-to-door surveys in a delimited area are frequently conducted [2]. Normally, they are performed in two steps. In a first step, a screening questionnaire is used to identify suspected cases. Subsequently, a confirmatory examination is performed by a specialist, preferably a neurologist.

A number of rapid and low-cost screening tools have been developed [3, 4]; some of which report sensitivity and specificity of up to 98% and 92%, respectively. In order to increase validity, door-to-door survey approaches are complemented by key-informant methods or information from other sources such as medical registries. By combining the information of several independent sources, a capture-recapture method can be used. Estimates using this technique were shown to better appreciate the burden [5].

The diagnosis of epilepsy relies on reported rather than observed seizures. The questioning of the patient and his close relatives is of underlying importance. Sensitivity and specificity of specific questions depend on the social and cultural background of the investigated population. Local adaptation and validation of the research tools are thus required to capture the different types of seizures and to reach cross-culturally comparable results.

When comparing epilepsy studies over time, difficulties arise from changing definitions. A single (standardized) definition allows a valid comparison between studies across sites and continents [6]. In 1993, an international commission has defined epilepsy as: the recurrence of at least two seizures, unprovoked by any immediate identified cause, occurring in more than 24 hours, precluding febrile seizures and neonatal seizures (in this definition, multiple seizure occurring in 24 hours period and status epilepticus are considered as a single event) [7]. In 2005, a new definition has been put forward by the ILAE and IBE [8]: epilepsy is a disorder

of the brain characterized by an enduring predisposition to generate epileptic seizures and by neurobiological, cognitive, psychological, and social consequences of this condition.

Although this definition takes into account some weaknesses of the earlier, it poses a particular problem for clinical and epidemiological practice as it does not clearly spell out how “enduring predisposition” should be measured. In the previous definition of epilepsy the predisposition was accounted for by the need of a second seizure episode. [9, 10]: This broader and less operational definition of epilepsy is most likely to reduce comparability of epilepsy studies. Recent reviews on epilepsy in Latin America [11], sub-Saharan Africa [12], Europe [13] and Asia [14] show the wealth of information which has been collected over the past decade. In the light of the changed definition, a critical revisiting of the comparable information will be required; particularly for poor-settings where the burden of disease is highest.

Mortality data of PWE in developing countries are scarce. A recent effort in China to address this gap revealed that PWE had 3-4 times higher mortality than the general population [15].

Most probably is the epilepsy-associated mortality also elsewhere considerably elevated.

Accurate mortality information is essential to place epilepsy correctly within the burden of disease context. Prospective cohort studies are recommended to investigate this issue [16].

They rely in turn on a comprehensive demographic database updated over time. Sites with a continuous demographic surveillance system can provide this information. Another possibility is to integrate surveillance of epilepsy in cohort surveys in progress for other purposes. There is a need to follow-up on the possibilities to include epilepsy surveys during data collection rounds of such research platforms.

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The World Health Report 2006 is dedicated to the actual chronic shortage of adequately trained staff at all levels of the health system [17]. This is of particular importance for developing countries, and an acute issue in neurology e.g. in Africa, the median number of neurologists is 0.3 per million people and 11 countries do not have any [18]. This penury of qualified health staff has immediate implications. In most countries, it is difficult to find adequately trained researchers and assistants for field research activities. Application of screening tools, case ascertainment, classifications of seizures and case management are particularly dependent on qualified professionals. In addition, qualitative research techniques are essential in understanding the socio-cultural environment which PWE have to face. Aspects of perception of epilepsy, stigmatisation, or associated conditions (such as depression) need these additional research tools. Most frequently, these research competences are simply absent in developing nations. Hence, external personnel are essential to meet the demand, and training of local health staff is an integral part in research activities.

The classification of epileptic seizures depends on the availability of electroencephalogram (EEG), which is a helpful tool for differentiation between generalized and focal seizures. Portable digital EEG devices, which can be brought to remote communities, are viable alternatives to health facility based investigations. The efforts to record EEG in field studies are sometimes excessive and costly when compared to the benefits: rarely seizure types need reclassification after EEG examination [19]. In absence of EEG, emphasis must be placed on a comprehensive clinical assessment and a follow-up. Consistently performed, it can provide fundamental information for seizure management options, e.g. diaries of PWE logging essential information, such as moment and circumstances of seizures, provide useful information on underlying causes and risk factors, as well as information on the consequences of seizures on patient and family. A well designed and followed-up diary, e.g. accompanied

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by in-depth interviews, therefore becomes a valuable research tool in most remote and underprivileged areas.

Patients diagnosed with epilepsy in the course of the investigation must be provided with treatment. In case of epilepsy, this is a long-term commitment. A working approach combining research and intervention must be achieved. Such programs require an established partnership of research and service oriented institutions and a solid financial assistance.

In the majority of the patients epilepsy is a controllable condition. In the essential drug lists of most countries cheap anti-epileptic drugs are included, but tremendous treatment gaps persist. The performance of the health system is challenged: quick solutions are unlikely to exist. Rather, there is a need of committed work to improve thoughtfully step by step the local health delivery system supported by epidemiological evidence.

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