EPILEPSY CARE IN DEVELOPING COUNTRIES: PART I OF II

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Although 80% of people with epilepsy reside in resource poor, developing countries, epilepsy care in these regions remains limited and the majority of epilepsy patients go untreated. Cost-effective, sustainable epilepsy care services, delivering first-line antiepileptic drugs through established primary health care facilities, are needed to decrease these treatment gaps. Neurologists with local experience and knowledge of the culture, who are willing to serve as educators, policy advisors, and advocates, can make a difference. This is Part I of a two-part article. Part I reviews the burden of epilepsy and the current state of resources for treatment in developing countries, while Part II (to be published in Epilepsy Currents issue 10.5) will provide an "Overview of Care" in these countries.

The Burden of Epilepsy in the Developing World

Epilepsy affects approximately 50 million people worldwide, with 80% of these individuals residing in developing regions. Epilepsy accounts for about 1% of the global burden of disease (1,2). To understand many of the issues inevitably encountered in providing services for a chronic condition in a developing country, some important realities must be appreciated, some of which will be detailed here in Part I.

Almost universally, developing countries have marked inequalities in the distribution of health care resources (3). Health care in private, settings of these countries may be relatively equivalent to first-world care, but care for the poor is virtually nonexistent. Inequities in the distribution of public services favoring urban regions are also problematic. For example, South Africa has two parallel health care systems—one public and one private. The private health care system serves approximately 15% of the population, but it accounts for 57% of health care dollars spent. The private system employs 65% of all health care workers and an even greater proportion of specialists; for instance, 75% of neurologists are employed entirely within the private sector. Access to technological aspects of care is also extremely unequally distributed, as 73% of EEG machines, 91% of CT scanners, and 94% of MRIs are owned by the private sector (4). In South Africa, epilepsy care within a top-ranked private urban facility differs a great deal from epilepsy care provision in an urban slum or rural village.

Consistent findings from epidemiologic studies of epilepsy in developing countries indicate that both the prevalence and, unfortunately, the treatment gap, defined as the number of individuals with epilepsy who remain untreated with antiepileptic drugs, for epilepsy is typically higher in rural than urban areas of the same country (5–8). For example, reports from Brazil indicate the rural treatment gap is 67% versus 38% in urban areas. The higher treatment gap is understandable since medical infrastructure, resources, and personnel are largely focused in urban regions. Prevalence differentials are less understandable. It is possible that the lack of medical infrastructure results in greater exposure to common risk factors for epilepsy, such as birth injury as a result of suboptimal antenatal care. Alternatively, urban dwellers that develop epilepsy may be sent back to "stay in the village," where lack of formal employment and a broader network of family members may be perceived as being a more optimal environment for caring for someone with recurrent seizures. Thus, it is difficult to assess with certainty the underlying reasons for the higher prevalence rates of epilepsy in rural areas of developing countries.

While the treatment gap is a very useful global measure for assessing epilepsy care in a given setting, it is also important to recognize its limitations, as the measure alone fails to elucidate anything about the etiology of a high treatment gap. Such treatment gaps might be a result of lack of antiepileptic drugs (AEDs) in the system, generally poor health care infrastructure, lack of transport for patients to health care services, and problems in attitude toward or knowledge of how to seek out health care. Determining the appropriate interventions needed to narrow the treatment gap relies critically upon understanding the driving force behind the gap.

Understanding Resources for Epilepsy Care Provision

The impressive disparities in resources for the provision of epilepsy care in developed versus developing countries has been

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clearly delineated in two projects undertaken by the World Health Organization that use global atlases to portray resources for epilepsy care, specifically, and neurologic care, in general (9,10). Review of these atlases, both available online (http://apps.who.int/bookorders/MDIbookPDF/Book/11500643.pdf and http://www.who.int/mental_health/neurology/neurogy_atlas_lr.pdf, respectively), reveal that neurologic expertise is limited or nonexistent in many of the poorest countries and that technological resources for care, including neuroimaging and EEG, are similarly rare. In sub-Saharan Africa, most countries have approximately one neurologist for 10 million people. In 2005, only 61% of African countries had even a single CT scanner. As grim as the figures provided are, in reality it may be worse, as access to the few resources available in low-income regions is unequally distributed in favor of urban dwellers with financial resources, as already discussed. Furthermore, as the atlas depicts, many countries surveyed were unable to provide any data at all about neurologic resources for care. One can surmise that countries, in which virtually no one is capable of answering survey questions about neurological resources, must indeed be wastelands for epilepsy care.

Where there are very few neurology experts, the most effective role for a neurologist to assume (i.e., in terms of having the greatest positive impact on the neurologic health of the population) is almost certainly the role of educator, advisor, and advocate. Many more people will receive epilepsy care through the efforts of a single neurologist if that individual can develop useful algorithms of care that can be applied at the primary health care level, train primary health care workers to use these algorithms (or better yet, train the trainers), and successfully advocate for the adequate provision of AEDs in the essential drug kits of these primary health care centers. Time devoted to provision of neurologic care may be best spent in the training of postgraduate students to appropriately triage individuals who have been referred from within the health care system. Understandably, this role of teacher, policy advisor, and advocate may not be congruent with the career path anticipated by a clinician who spent years in advanced clinical training. It also may not be consistent with the expectations of the employer. Yet, it must be recognized that the role of a neurologist or health care worker in a developing country must, by necessity, also be that of an advocate, who may need to work with local authorities to insure that essential care is available.

Approaches to Health Care Provision

"*In many developing countries the mental hospitals are of lower standard than the jails*" (11).

It is important to note that in many developing countries epilepsy care is relegated to the mental health sector. The mental health sector is noted to be perhaps the most underfunded health sector in most low-income countries. Ideally, health services for epilepsy should be both responsive and financially fair. Responsive health care is patient-oriented care that treats the individual patient and his or her family with respect. Financial fairness refers to the magnitude of the financial burden associated with receiving health care and the distribution of this burden within society (3). The goal should not be to replicate systems and processes of care from developed regions and transplant them into developing countries. Rather, cost-effective care must be provided in a culturally appropriate fashion that reflects the resources and priorities of the community. As such, to some extent, systems and care processes must be individualized. Some general considerations are worth noting, as follows.

Systematic analyses have concluded that the most cost-effective way to deliver epilepsy care in developing countries is through the use of older AEDs (especially phenobarbitone) delivered by health care workers, often nonphysician health care workers, at the primary care level (12). Implementation of such care in a setting with a high baseline treatment gap likely requires better general coordination of health care services, epilepsy care delivery by primary health care staff (with substantial retraining of workers), provision of essential drugs, and better integration of care from primary to secondary levels. Relatively small financial investments can result in functional systems of epilepsy care (13–15). The initial investment in political persuasion, organization, and goodwill may, however, be substantial. For sustainability, the system developed must be integrated into the mainstream health care system, funded through renewable public funds, and not be reliant on individuals, outside experts, or international funds.

The community-based rehabilitation model of care has arisen from grassroots efforts of individuals with disabilities and their families, who have begun to organize and advocate for patient needs. It can offer an alternative approach to epilepsy care and address the reality of most people with disabilities in developing countries: they live in rural areas and are poor (16). These groups not only advocate for basic care provision in the community but also for equal opportunities for people with disabilities through programs that decrease stigma and fight discrimination, aiming to integrate such individuals into the community, school, employment, and so forth. While some may be opposed to categorizing people with epilepsy as having disabilities, the model is advantageous in that it assumes a need for lifetime rehabilitation and is congruent with the reality of many people with epilepsy in developing countries that suffer from comorbid physical or neuropsychiatric disabilities as a consequence of seizure-related injuries or long-standing untreated seizures.

Evaluations

"*Poor sanitation may be the single most important social factor underlying the increased prevalence of epilepsy in tropical and developing countries*" (17).

Brain injuries, neurodevelopmental problems, and genetic predispositions that cause epilepsy in developed settings certainly result in epilepsy in developing countries as well. Traumatic brain injuries, due to poor transport infrastructure, are common, and head injury in regions of conflict are frequent. In addition, unique causes for epilepsy in developing and tropical settings must be considered. In some tropical settings, parasitic infestations are a common cause of epilepsy. Table 1 details parasites that may result in epilepsy. Not included are HIV-related infections, as there is very limited data available regarding the natural history and long-term seizure risk among HIV/AIDS survivors of CNS opportunistic infections. An excellent Internet resource for further reading on CNS parasitosis is available at: http://www.dpd.cdc.gov/dpdx/HTML/Para_Health.htm.

TABLE 1. *Parasitic Infestations Causing Epilepsy*

PARASITE	REGION	DIAGNOSIS/ CHARACTERISTICS	COMMENT
Taenia solium (neurocysticercosis)	Latin America; regions of Africa	May be associated with cysts; appears in muscles and breast	Important to assure seizures represent epilepsy and not acute provoked seizure, which may require a much shorter duration of treatment. No clear consensus: cysticidal treatment does not improve long-term epilepsy outcome and is associated with increased cost. *Reference*: Carpio and Hauser (30)
Echinococcosis granulosum (cerebral hydatid disease)	Middle East, Australia, New Zealand, South America, Turkey, North and East Africa, China, southern and eastern Europe	Lesions can grow slowly and might be quite large before patient present with symptoms.	Caution is needed, as biopsy or excision that ruptures cysts may precipitate anaphylaxis and death.
Trypanosoma brucei gambiense T.b. rhodesiense (human African trypanosomiasis)	Central, southern, and eastern Africa	Acute provoked seizures are common. Anecdotal information indicates later epilepsy is typical in persons surviving to long-term treatment.	Diagnosis requires a high level of suspicion. Formal surveillance is poor.
Trypanosoma Cruzi (South American Tryps)	Latin America	Cardiac disease with arrhythmias and dilated cardiomyopathy is associated with high rates of stroke and thus, secondary epilepsy.	Underlying parasitic infection must be treated to avoid cardiac disease progression.
Paragonimus westermani	Asia regions where raw shellfish (especially drunken crab) are consumed	CNS infection is uncommon but occurs in regions where pulmonary disease is well recognized.	Underlying parasitic infection must be treated. Anecdotally, survivors of CNS lesions may develop epilepsy after full treatment and acute recovery.
Schistosoma japonicum (bilharzia)	Asia	Underlying parasitic infection must be treated.	Other schistosoma species rarely infect brain.
P. falciparum	Primarily Africa, also Asia	History of cerebral malaria, usually with seizures and prolonged coma; remote parasite infection	Usually a localization-related epilepsy, unless patient is neurologically devastated after cerebral malaria recovery.

For additional information on parasites, see Meyer and Birbeck (18).

While Part II will review treatment, evaluating what type of care is needed is also an essential part of effectively treating patients in developing countries. Evaluating a person with epilepsy or who may potentially have epilepsy in these countries requires an approach that is much the same as in developed settings. A good history of the suspicious event(s), as described by the patient as well as a family member or other person who has witnessed it, is critical. When working with a translator, it is important to learn the local terminology for seizures and epilepsy and make special efforts to avoid the use of locally pejorative terms. For instance, rather than labeling the events, solicit descriptions of them. Given the relative dearth of neurodiagnostics (e.g., EEG, neuroimaging) in developing countries, a full history and physical may be the sole data available to determine seizure semiology or epilepsy syndrome and thus, should be used to its maximum potential.

Efforts to investigate the underlying etiology of epilepsy in resource-limited settings may be frustrating. In extreme situations, blood tests for monitoring electrolytes, liver function, and AED levels may not be routinely accessible, and neuroimaging and EEG or both may not be available at all. Where EEG is available, the value of the EEG must be considered in the context of its technical quality. Poor quality recordings may offer little information of significance, especially in the nonacute outpatient setting. EEG interpretations by inexperienced or untrained readers tend to be biased toward overinterpretation. Inaccurate readings are especially problematic in EEGs of pediatric patients in whom the wide range of normal variants can be misinterpreted as epileptiform, leading to misdiagnosis as epilepsy and years of unnecessary and potentially harmful treatment (19,20). When determining what diagnostic evaluation is warranted in a given situation, the physician must consider what is feasible as well as how the findings of the investigation will affect management when treatment options are few.

Knowledge of local diseases and toxins is critical for the optimal provision of clinical care. Isoniazid toxicity, either through attempted suicide or iatrogenic overdose, will present acutely as status epilepticus, and epilepsy develops frequently among survivors of isoniazid toxicity. Annual epidemics of Japanese encephalitis affect some regions of Asia, and long-term neurologic sequelae, including epilepsy, unfortunately are common (21). Despite the reality that most children in very low-income countries are exposed, at least periodically, to malnutrition, the impact of malnutrition on brain development and any associated increased risk of epilepsy is almost entirely unstudied.

Conclusion

Although the clinical principles of epilepsy care provision remain the same in developed and developing regions, for optimal use of local resources, the organization of care, including the personnel who care for epilepsy patients and the first-line AEDs provided, must be adapted to the existing health systems and capacity.

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