Epilepsy Care Guidelines in the Developing World:

Improving Access & Quality

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Abstract

In 2011, the World Health Organization’s (WHO) mental health Gap Action Programme (mhGAP) released evidence-based epilepsy care guidelines for use in low and middle income countries (LAMICs). From a geographical, socio-cultural, and political perspective, LAMICs represent a heterogenous group with significant differences in the epidemiology, etiology and perceptions of epilepsy. Successful implementation of the guidelines requires local adaptation for use within individual countries. For effective implementation and sustainability, the sense of ownership and empowerment must be transferred from the global health authorities to the local people. Socio-cultural and financial barriers that impede the implementation of the guidelines should be identified and ameliorated. Impact assessment and program revisions should be planned and budgeted for. If effectively implemented, as intended, at the primary care level, the mhGAP guidelines have the potential to facilitate a substantial reduction in the epilepsy treatment gap and improve the quality of epilepsy care in resource limited settings.

Keywords:
Non-physician healthcare worker, clinical officer, variations in care, treatment gap
**Background**

Epilepsy is a major global healthcare issue. An estimated 70 million people live with epilepsy worldwide [1, 2], most of whom remain untreated [3]. To improve epilepsy care services, most developed countries adopted national guidelines at least a decade ago with these being regularly updated [4, 5] [6]. Whenever possible, such guidelines are evidence-based, relying upon the body of evidence for best care practices in high-income, resource-rich countries with predominantly moderate climates. However, 80% of people with epilepsy (PWE) live in so-called “developing”, low-income, or resource-poor countries in tropical or subtropical regions[1]. For many reasons including resource restrictions, simply adopting healthcare guidelines created for higher-resourced areas for use in the developing world isn’t appropriate or feasible [7]. Unfortunately, developing countries generally lack sufficient neurologic expertise and/or advocacy for the development and implementation of epilepsy care guidelines. The World Health Organization (WHO) has recently released evidence-based, epilepsy care guidelines appropriate for use in resource-limited, tropical settings [8, 9]. Implementation of the WHO’s mental health Gap Action Programme (mhGAP) guidelines will require local adaptation for use within individual countries, but if effectively implemented as intended at the primary care level, the mhGAP guidelines could facilitate a substantial reduction in the epilepsy treatment gap and improve the quality of care received by PWE in resource limited settings. Effective guidelines require local adaptation, implementation, impact assessment and program revision. The challenges to these important processes are substantial.

**mhGAP Guideline Development and Local Adaptation**
Developing vs. developed regions differ substantially in terms of the underlying etiologies of epilepsy, healthcare personnel expertise, diagnostic capacity, treatment options and cultural perception of the disorder (Table 1). Guidelines for use in the resource-poor environments must address factors specific for the clinical and socio-cultural setting (Table 2). Valid guidelines are of paramount importance for developing countries as the mortality associated with epilepsy in such regions may be quite high even with treatment available [10] and the treatment gap remains devastating with <20% of people with active epilepsy in most developing countries receiving treatment [11].

Guidelines developed in high-income countries are likely appropriate for use in LAMICs [7]. In general, the transferability of evidence derived from studies conducted in high-income countries to LAMICS is dubious [7, 12, 13]. Differences in patient populations and healthcare systems are so prominent that the evidence may not be valid [7, 14]. Hence, the development of guidelines specifically crafted for resource-limited settings is the most optimal strategy.

In 1977, the WHO, in collaboration with the International League against Epilepsy and the International Bureau for Epilepsy, launched the Global Campaign Against Epilepsy to improve the care of people with epilepsy in resource-poor countries[15]. In 2008, WHO began development of evidence-based guidelines for epilepsy and seizure care in LAMICs [8, 16]. These guidelines were released in 2011. The clinical care algorithms provided in the mhGAP were developed for use in a broad range of possible low and middle income settings and therefore must be adapted to local resources and needs, especially if the guidelines are to be used by the non-physician healthcare
workers who provide most primary healthcare services in such settings. From the geographical, socio-cultural, and political point of view, developing countries represent a markedly heterogenous group. The epilepsy burden is different in Asia, Latin America and Sub-Saharan Africa [17]. Even within Sub-Saharan Africa, there are significant variations in the epidemiology, etiologies and perceptions of epilepsy in different geographical regions and communities [18]. The process of adaptation also offers the opportunity to further foster a sense of ownership and empowerment among local health authorities [19].

The most feasible and cost-effective way to deliver epilepsy care in LAMICs is through the use of inexpensive antiepileptic drugs (AEDs) delivered by nonphysician health care workers at the primary care level [20]. Clinical case definitions for epileptic seizures and epilepsy used for guideline application must consider the limited neurologic expertise of primary care providers, lack of diagnostic options, and the local syntactic-semantic language used for describing seizure symptoms as well as the time frame of the symptoms [21]. The mhGAP guidelines recognize that in LAMICs, seizures are often due to acute CNS infection or metabolic disorders. Furthermore, epilepsy can be the first presentation of a subacute or chronic CNS condition that might be amenable to treatment in resource-poor environment [20]. Hence, local adaptation of mhGAP guidelines must consider the local epidemiology of potential underlying seizure etiologies [20, 22].

Local adaptation must also address any special circumstances within a specific country. For example, where HIV rates are high, a significant proportion of PWE can be expected
to suffer from co-morbid HIV infection. If the available AEDs are limited to enzyme inducing agents, potential interactions between AEDs and antiretroviral medications must be considered and treatment options appropriate for dual therapy must be made available [23, 24]. Guidelines for epilepsy care in resource limited settings by non-physician healthcare workers must also specifically address injury prevention and, if applicable, contagion fears [10]. The adapted content of such programs must be directed by local practices, injury risk factors and beliefs.

**Implementing Guidelines in the Developing World**

Passive dissemination of guidelines alone is not sufficient to ensure appropriate uptake of recommendations [25]. Socio-cultural and financial barriers impede the implementation of guidelines in all healthcare settings. Within LAMICs, strong advocacy for guideline adoption by health authorities at the national, provincial, district and institutional levels are required [25]. Patient-, healthcare worker- and macro-level barriers threaten the implementation of guidelines [23]. True advocacy requires that local healthcare authorities prioritize epilepsy care highly enough to guarantee that the basic materials and training required to adhere to the guidelines are provided to healthcare workers at every level of care which is intended to utilize them. If care equity is to be achieved, special attention must be focused on the implementation of the guidelines in poorer rural areas since residency in a rural region is an independent risk factors for poor access to treatment [3].

**Impact Assessment**
As guidelines are being implemented, program evaluations to assess their operational performance in clinical practice and their impact on care quality should be concurrently planned and budgeted for[26]. As in developed countries[27], developing regions need valid quality indicators for epilepsy care that can adequately assess the impact of guideline implementation. It may be possible to develop such quality indicators, even with basic health records in some LAMIC institutions[28]. Before initial implementation, plans should be discussed for updating guidelines as needed as well as revising them based upon the findings of the impact assessment. Special consideration should also be given to any potential unintended consequences of the guidelines. For example, if a guideline refers to additional diagnostic studies, could primary care workers delay necessary seizure treatment while waiting for an EEG or neuroimaging when access to such studies are limited and the logistics of study acquisition are challenging?

**Conclusion**

The mhGAP guidelines need to be adapted for country-specific use in LAMICs. These baseline recommendations can facilitate the development of national guidelines as well as the establishment of national epilepsy programs tailored to the existing health care setting. The locally relevant guidelines should then be critically evaluated and amended based on the results of their assessment (Figure 1, Panel 1). Evaluations are needed to ensure that the guidelines are practical, evidence-based and cost effective [29, 30]. Training resources (including sample pathways and video training) adapted for local primary care settings should be expanded to facilitate the acceptance and the successful implementation of the guidelines [9]. The implementation of epilepsy guidelines could result in a decrease in the burden of epilepsy worldwide [16].
Abbreviations

AED antiepileptic drug

CNS central nervous system

LAMIC low- and middle- income countries

mhGAP mental health Gap Action Programme

PWE people with epilepsy

WHO World Health Organization
Competing Interests:

Juri Katchanov declares no conflict of interest or competing interests.

Gretchen Birbeck served as an advisor to the World Health Organization and participated in the development of the mental health gap Action Programme guidelines as well as the National Guidelines for Epilepsy Care adopted by the Neurologic and Psychiatric Society of Zambia. She has received research funds for epilepsy-related work from the US National Institute of Health.

Authors Contributions

Drs. Birbeck and Katchanov co-conceived the idea for this commentary. Dr. Katchanov conducted the literature review for this manuscript and wrote the first draft of the manuscript. Dr. Birbeck provided critically inputs and edits for the final version, which Dr. Katchanov approved.

Authors’ Information

Drs. Birbeck and Katchanov are neurologists who trained in academic centers in the developed world, but they have extensive experience providing epilepsy care in tropical, resource-limited settings.
References


9. WHO: mhGAP Newsletter. In


Table 1. Critical differences in healthcare settings in developed vs. developing countries [19, 23]

<table>
<thead>
<tr>
<th></th>
<th>Developed countries</th>
<th>Developing countries</th>
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<tbody>
<tr>
<td>Gross national income per capita</td>
<td>high-income (≥ US$ 9,386) or upper middle-income (US$ 3,036–9,385)</td>
<td>low (≤ US$ 765) or lower middle (US$ 766–3,035)</td>
</tr>
<tr>
<td>Access to health care</td>
<td>Initial access usually through primary care with established referral networks which may include high indirect costs</td>
<td>Limited to very basic primary care especially in rural areas +/-established referral networks which invariably include high indirect costs</td>
</tr>
<tr>
<td>Healthcare funding</td>
<td>national programmes, private insurance, out-of-pocket</td>
<td>Often ill-funded, may rely on donors/ volunteering services, indirect costs and informal payments can represent major barriers to care</td>
</tr>
<tr>
<td>Common epilepsy etiologies</td>
<td>Neoplastic, cerebrovascular (post)infectious, antenatal, post-traumatic</td>
<td></td>
</tr>
<tr>
<td>HIV prevalence</td>
<td>low</td>
<td>Can be moderate to high</td>
</tr>
<tr>
<td>Cultural perception of</td>
<td>Biomedical model</td>
<td>Traditional medicine,</td>
</tr>
<tr>
<td>Seizures</td>
<td>Spiritual approach, contagion beliefs common</td>
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<tr>
<td>Social-cultural attitude towards epilepsy</td>
<td>Neutral public perception or at least social presentation of neutrality</td>
<td>Overt negative public perception, stigmatization and discrimination common</td>
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Table 2. Realities and requirements for guidelines developing countries

<table>
<thead>
<tr>
<th>Reality</th>
<th>Requirement</th>
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<tr>
<td>Care is largely provided by non-physician healthcare workers with very basic or no neurological training</td>
<td>Clear case definition of epileptic seizures and simple algorithms tailored for the local circumstances</td>
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<td>Limited access to medication</td>
<td>Guidelines that recommend those medications which can be accessed</td>
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<tr>
<td>Indirect costs as a barrier to care seeking and adherence</td>
<td>Priority for inexpensive affordable drugs delivered as close to the patient’s residence as possible</td>
</tr>
<tr>
<td>High prevalence of infectious causes</td>
<td>Incorporate into guidelines testing/ treating of common conditions such as HIV, neuro-tuberculosis, and parasitosis. Refer to existing treatment guidelines whenever possible unless co-morbid conditions require care that differs from national guidelines</td>
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Panel 1

Primary Principals for Developing Guidelines for Epilepsy Care in Low Income Countries

<table>
<thead>
<tr>
<th>Clear case definitions of epileptic seizures and epilepsy, tailored for use by non-physician healthcare workers</th>
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<tbody>
<tr>
<td>User-friendly guidelines adapted for local environment, based on local diagnostic capacity and with input from local experts and stakeholders</td>
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<td>Active dissemination of guidelines with workshops appropriate for resource-low setting</td>
</tr>
<tr>
<td>Implementation of the guidelines within the framework of the existing healthcare delivery system. Should include using the guidelines for testing for treatable causes of epilepsy</td>
</tr>
<tr>
<td>Meticulous evaluation of guidelines which include local researchers and provides feedback to the local stakeholders as well as the WHO</td>
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