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An epilepsy curriculum for primary health care providers: a report from the Education Council of the International League Against Epilepsy

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ABSTRACT

Objective. Primary health care providers are directly responsible for the care of people with epilepsy. However, their education about epilepsy might be inadequate or lacking. Our objective was to develop an evidence-based and consensus-driven educational curriculum for the management of epilepsy within the primary healthcare setting.

Methods. The International League Against Epilepsy (ILAE) Education Council commissioned a task force of international experts, who met virtually at monthly intervals in 2020/2021 to develop the curriculum. The task force adopted and added to five domains from the ILAE Epileptology Curriculum after discussions on context, structure and wording of associated competencies and learning objectives. The consensus-approved curriculum was disseminated to the ILAE leadership and constituency in six different languages. An online survey was used to collate structured feedback which further refined the curriculum.

Results. Feedback was obtained from 785 voluntary respondents who were inclusive of epilepsy specialists and primary healthcare providers. Nearly two thirds of the respondents approved the use of the curriculum to advance the competency of primary health care providers in epilepsy. The final educational curriculum comprised six domains, 26 competencies and 85 learning objectives. The six domains were: (1) ability to diagnose epilepsy and its broad subtypes; (2) ability to provide counselling to people with epilepsy over a range of issues; (3) ability to introduce treatment and follow-up to people with epilepsy; (4) competency to appropriately refer people to higher centres of care; (5) ability to manage epilepsy emergencies including status epilepticus; and (6) ability to recognize and provide basic care for psychiatric and somatic comorbidities.

Conclusions. The curriculum represents an advance in providing inclusive care for epilepsy within the primary health care setting and ideally should be used to facilitate future primary health care epilepsy education packages.

Key words: epilepsy, seizures, competencies, learning objectives, education

Epilepsy is defined as a tendency of recurrent seizures, has profound social, cognitive and psychological consequences, and affects approximately 50 million people worldwide [1, 2]. It is the fifth leading cause, and in some regions of the world, the second leading cause of disability-adjusted life years [DALYs] associated with neurological disorders [3]. The majority of DALYs are comprised of years lived with disability [4]. However, DALYs are also accounted for by premature mortality in people with epilepsy, estimated to be three times more common than in the general population [2, 3]. A substantial number of deaths and years lived with disability could be averted with cost-effective antiseizure medications prescribed by health care providers with adequate skills, proficiency and knowledge [5, 6]. In many high-income countries (HICs), epilepsy is diagnosed and managed by epilepsy specialists as part of standard practice [7]. This model of care draws support from evidence for better disease outcomes associated with specialist care [8]. In most low- and low-middle income countries (L&LMICs), however, there are few or no epilepsy specialists [7, 9]. In these countries, the diagnosis and treatment of epilepsy often depends on primary health care providers. Further, in many HICs, primary care physicians are the first point of contact for people with seizures and epilepsy. The need for primary health care proficiency in epilepsy in L&LMICs is driven by a dearth of specialists. Some highly successful endeavors, steered jointly by the World Health Organization (WHO) and International League Against Epilepsy (ILAE), in Brazil, China, Myanmar, Senegal and Mozambique have been largely underpinned by engagement of non-specialists in care of epilepsy [5, 6, 10]. These have relied mainly on task shifting (or sharing) and knowledge transfer and translation. Encouraged by the success of these campaigns, the WHO advocates engagement with primary health care providers in the diagnosis and treatment of people with epilepsy [10]. This position is promoted in Resolutions 68.20 and 70.20 of the World Health Assembly endorsed by 194 member countries in 2015 and 2021, respectively [11, 12].

One of the challenges in scaling-up epilepsy care within primary health care is the lack of resources to equip care providers with appropriate training. Expanding skills and knowledge is further challenged by the high burden and diversity of health conditions in their practice. Any educational enterprise for primary health care workers should follow the principles of adult learning rather than being purely pedagogical and should be clear, concise, relevant and practical [13]. Based on these requirements, an ILAE task force formulated an epilepsy educational curriculum, specifically orientated to primary health

care providers. We report the current version of the ILAE primary health care epilepsy educational curriculum and discuss ways forward in its implementation.

Methods

The Education Council of the ILAE reported earlier the development of a competency-based educational curriculum for epileptologists which was endorsed and adopted by its constituency [14]. Following this, ILAE-supported teaching activities are largely formulated based on competencies and learning objectives in this curriculum.

Primary care task force: constitution and activities

In 2019, the Education Council commissioned a task force with the objective of designing an educational curriculum for seizures and epilepsy in adults and children, specifically for primary health care providers.

Task force members were from the six ILAE regions, with representation across HIC and L&LMICs, based on World Bank categories [15]. Members had experience in epilepsy education, especially in settings likely to promote opportunities for primary health care provider engagement in epilepsy care.

The task force met virtually every month between March 2020 and January 2021. Initially, the members reviewed existing tools for basic level epilepsy education suitable for primary health care providers. Next, a five-step approach was undertaken in designing the competencies and learning objectives of the curriculum [16]. These were adapted from the theory of adult learning and consisted of: (a) a needs assessment based on review of the literature; (b) identification of core competencies through expert inputs; (c) assessment of epilepsy-related learning needs of target populations, again based on expert input; (d) establishment of learning objectives; and (e) feedback and refinement [13].

Development of competencies and learning objectives

The previously published ILAE Epileptology Curriculum, with a total of 42 competencies with 124 learning objectives, was organized into seven domains: Diagnosis, Counselling, Pharmacological treatment, Emergencies, Co-morbidities, Epilepsy surgery and Biology of epilepsies [14]. The Primary Care Task Force retained the first five domains as they were considered highly relevant to primary care practice and a sixth domain of "Referral" was added by consensus. Each of the competencies and learning objectives were carefully formulated with discussion around

semantics, syntax, style and appropriateness, as well as relevance for primary care practice. Elements of the educational curriculum were agreed upon by consensus.

Feedback, refinement and finalization

The first draft of the curriculum was completed by June 2020. This was then circulated to the ILAE Executive Committee and to the six worldwide ILAE regional boards. Feedback was obtained through a structured questionnaire and *via* open comments and suggestions. This feedback guided further refinement of the curriculum facilitated by discussions among task force members. The revised version was then translated from English by bilingual experienced young epileptologists from the ILAE membership to five languages: Spanish, French, Russian, Arabic and Chinese. A separate set of bilingual experts verified the linguistic comprehensibility and technical appropriateness of translated versions. All language versions of the educational curriculum as well as feedback questionnaires were circulated to the broad membership of the ILAE, including member country representatives, as well as the International Bureau for Epilepsy with an appeal to further dissemination within each country. The survey questionnaire consisted of 26 items asking respondents to rate the degree of importance of each competency on a five-point scale that ranged from “extremely important” to “not at all important”, in addition to free-text comments. It utilized the SurveyMonkey platform and remained open from March 9th, 2021 to July 14th, 2021. The task force reviewed feedback from the survey and incorporated the key changes to create the final version of the educational curriculum [15].

Results

The final version of the primary care curriculum comprised six domains, 26 competencies and 80 learning objectives (*table 1*).

Survey responses ($n = 785$) were from a broad range of countries ranked according to World Bank income status (L&LMICs: 390 [51%], upper-middle-income countries [UMICs]: 203 [26%], and HICs: 173 [23%]) and vocational status, including 497 (63%) specialists, 105 (13%) primary health care providers, and 183 (24%) others. The in-depth analysis of responses forms a separate study in parallel to this report. The following competencies were rated as “extremely important” by >60% from across all country income groups: definitions of epilepsy, including provoked and unprovoked seizures; ability to counsel women of childbearing age about implications of epilepsy

during pregnancy, childbirth and after delivery; and appropriate management of epilepsy-related emergencies including status epilepticus. Competencies that were rated as “extremely important” by 60% or more specialists and primary health care providers included: knowledge about definitions of epilepsy and seizures, and including provoked unprovoked seizures; common causes of seizures in adults and children; ability to counsel women of childbearing age about implications of epilepsy during pregnancy, childbirth and after delivery; appropriate referral to higher levels of care; and appropriate management of epilepsy-related emergencies including status epilepticus (*table 2*). Conversely, less than 40% of both specialists and primary care providers rated abilities to recognize and manage psychiatric and somatic comorbidities or epilepsy as “extremely important”.

The majority (456/766 [60%]) of respondents agreed that the curriculum should be used to endorse competency of primary health care providers to care for people with epilepsy, and 594 (78%) supported establishment of an exam leading to certification in one or more competency(ies) in primary health care for epilepsy in their respective countries.

Many free-text suggestions in the leadership and community feedback surveys were verified, to be incorporated in the curriculum. Others were added to appropriate sections of the curriculum, for instance, knowledge of and appropriate referral pathways to epilepsy support groups and non-governmental agencies, and community education and awareness (*supplementary table 1*). Lastly, some suggested elements were deemed by consensus to be beyond the scope of primary care practice, for instance: the interpretation of EEG reports, the use and interpretation of therapeutic antiseizure medication monitoring, competency in managing drug-resistant epilepsy and post-epilepsy surgery, and knowledge about rare adverse events. These were not included in the curriculum.

Discussion

Review of existing educational resources

The mandate of the task force was to reach a consensus on the core competencies for diagnosis and treatment of epilepsy in primary health care settings and to systematically develop a corresponding educational curriculum. In addition, the task force also deliberated on existing tools for education of primary health care providers in epilepsy. The WHO mental health gap action program (mhGAP) covers epilepsy with six other mental health conditions and is widely used in resource-limited settings [17, 18].

▼ **Table 1.** Domains, competencies and learning objectives of the ILAE primary health care epilepsy curriculum (six domains, 26 competencies and 85 learning objectives).

1.0 Diagnosis
1.1 Define what are seizures and epilepsies?
1.1.1 Demonstrate working knowledge of what is an epileptic seizure.
1.1.2 Demonstrate working knowledge of what is an acute symptomatic (provoked) and unprovoked seizure.
1.1.3 Demonstrate working knowledge of what is epilepsy.
1.1.4 Demonstrate working knowledge of what is status epilepticus and life-threatening seizure clusters.
1.2 Demonstrate working knowledge of the main causes of acute symptomatic (provoked) seizures in children and adults.
1.2.1 Recognize febrile seizures in children and distinguish between simple and complex febrile seizures.
1.2.2 Recognize the main causes of acute seizures in children and adults (e.g., stroke, trauma, infections, toxins, drugs, metabolic and electrolyte derangements).
1.3 Demonstrate working knowledge of the main causes of focal and generalized epilepsies in children and adults.
1.3.1 Demonstrate working knowledge of infectious (e.g., parasitic, bacterial, viral), structural (e.g., birth insults, trauma, stroke, tumors), and metabolic (e.g., hypoglycemia) causes of epilepsy.
1.3.2 Demonstrate working knowledge of when to suspect a genetic cause of epilepsy (e.g., absence, myoclonic, generalized tonic clonic seizures).
1.4 Identify and describe the semiology (clinical features) of epileptic seizures using standardized ILAE terminology and classification systems.
1.4.1 Extract semiology information from patient history.
1.4.2 Extract semiology information from home-video recordings.
1.4.3 Recognize clinical features which suggest focal vs. generalized onset.
1.4.4 Recognize clinical features of motor seizures (e.g., tonic-clonic, myoclonic, tonic, etc.) and non-motor seizures (e.g., absence, focal with impaired awareness, etc.).
1.4.5 Recognize clinical features of focal and generalized convulsive status epilepticus.
1.5 Recognize common seizure mimics.
1.5.1. Recognize common seizure mimics that do not require active intervention (e.g., night terrors, breath-holding spells, day dreaming, sleep myoclonus).
1.5.2 Recognize common seizure mimics that may require active intervention but do not require antiseizure medication/s (e.g., psychogenic non-epileptic seizures (PNES), syncope, migraine).
1.5.3 Recognize clinical features of seizure mimics that pose a high risk and may be treatable (e.g., irregular pulse, cardiac arrhythmias, blood pressure abnormalities, sweating, chest pain).
1.6 Demonstrate working knowledge of relevant aspects of the clinical examination in newly diagnosed seizures and epilepsy.
1.6.1 Identify neurological abnormalities (e.g., focal deficits, impaired awareness, abnormal head circumference, etc.).
1.6.2 Identify systemic abnormalities (e.g., skin lesions, organomegaly, hypertension, cardiovascular abnormalities, etc.).
1.6.3 Describe common activating maneuvers to trigger seizures (e.g., hyperventilation, visual stimuli, startle, etc.).
1.7 Decide which initial laboratory tests should be ordered in patients with epilepsy or recurrent seizures.
1.7.1 Demonstrate working knowledge of when to obtain blood tests (e.g., blood glucose, calcium, electrolytes).
1.7.2 Demonstrate working knowledge of when to obtain brain imaging, e.g., CT or MRI.
1.7.3 Demonstrate working knowledge of when to obtain an electrocardiogram.
1.7.4 Demonstrate working knowledge of when to obtain an electroencephalogram (EEG).
1.8 Demonstrate working knowledge of implications of test results and pathways to care according to the regional setting.
1.8.2 Recognize when brain imaging results will support management decisions.
1.8.3 Recognize when electrocardiogram results will support management decisions.
1.8.4 Recognize when EEG results will support management decisions.

2.0 Counselling

2.1 Understand and address the culturally appropriate aspects and consequences of the diagnosis of epilepsy, including stigma.

2.1.1. Provide culturally appropriate examples of the experience of stigma.

2.1.2. Recognize and address the impact of epilepsy on quality of life in the appropriate cultural context.

2.2 Provide guidance on specific issues related to epilepsy.

2.2.1 Provide a guide on social issues, including school integration, work, marriage, legal, and related matters.

2.2.2 Provide a guide regarding lifestyle matters, such as driving, sports, alcohol, stress, sleep, recreational drug use, antiseizure medication non-adherence, avoiding burn injuries, falls (from heights), and drowning.

2.2.3 Provide a guide regarding first aid during a seizure such as positioning, breathing, timing, avoiding injuries, and crowding.

2.2.4 Provide a guide regarding the need for emergency medical care (e.g., prolonged seizures, seizure clusters, lack of recovery, breathing difficulties).

2.2.5 Provide a guide to people with epilepsy regarding self-management (e.g., knowing about their disease, understanding disease treatment, laboratory tests, reliable sources of information, and other available resources such as community services, non-governmental organizations, etc.).

2.3 Communicate information about the causes and consequences of the specific type of epilepsy.

2.3.1 Provide guidance regarding culturally-determined misconceptions regarding epilepsy (e.g., spiritual or religious origins and witchcraft, contagiousness, insanity).

2.3.2 Provide guidance to avoiding harmful practices (e.g., exposure to fire, blood-letting, scarification, exposure to hazardous substances).

2.3.3 Educate people with epilepsy, their families and the public about the causes and frequency of epilepsy.

2.3.4 Demonstrate working knowledge and provide guidance regarding common measures to prevent epilepsy (e.g., latrines, pig farming, fences and handwashing to prevent neurocysticercosis, safety belt or helmet to prevent traumatic brain injury, prenatal care to prevent birth injuries, etc.).

2.3.5 Educate people with epilepsy and their families about the disease specifics (e.g. prognosis, risk factors for seizure worsening, risk of death etc.).

2.3.6 Educate people with epilepsy and their families on serious consequences of epilepsy (e.g. accidents, injury and death, including sudden unexpected death in epilepsy (SUDEP)) and measures to decrease these risks.

2.4 Counsel women with epilepsy of childbearing age about the implications and management of epilepsy.

2.4.1 Provide guidance regarding contraception and interaction with antiseizure medications.

2.4.2 Provide guidance regarding pregnancy, including teratogenicity of the various antiseizure medications (e.g., valproate).

2.4.3 Provide guidance regarding post-partum activities e.g. breastfeeding and child care.

2.5 Demonstrate working knowledge regarding issues related to elderly people with epilepsy (e.g., comorbidities and drug interactions).

2.6 Provide counselling specific to children with epilepsy and their parents (e.g. lifestyle, cognitive function, parenting).

2.7 Communicate to patients and carers the diagnosis of non-epileptic events and the need for different treatment.

3.0 Pharmacological treatment

3.1 Demonstrate working knowledge about common antiseizure medications.

3.1.1 Demonstrate working knowledge regarding benefits and risks of antiseizure medication (e.g., common and serious adverse effects).

3.1.2 Identify indications for common antiseizure medications according to seizure type.

3.1.3 Demonstrate working knowledge about common interactions between antiseizure medications and other drugs (e.g., oral contraceptives, antibiotics, treatment of tuberculosis, human immunodeficiency virus, etc.).

3.1.4. Demonstrate working knowledge about the role and limitations of antiseizure medication level monitoring.

3.2 Recommend appropriate therapy based on epilepsy presentation.

3.2.1 Recommend appropriate therapy according to seizure type.

3.2.2 Choose the appropriate antiseizure medication and dosage in elderly patients.

▼ **Table 1.** Domains, competencies and learning objectives of the ILAE primary health care epilepsy curriculum (six domains, 26 competencies and 85 learning objectives) (*continued*).

3.0 Pharmacological treatment
3.2.3 Choose appropriate antiseizure medications and dosage in children.
3.2.4 Choose appropriate antiseizure medication and dosage in women who are of childbearing age or pregnant.
3.2.5 Recommend individualized titrations for optimal dosing for patients including starting and discontinuing medication
3.2.6 Communicate information regarding the antiseizure drug regimen (e.g., long-term treatment, what to do with missed dosages, what to do in the setting of diarrhea and vomiting).
3.2.7 Implement good practices in pharmacological treatment (e.g., monitoring adherence, scheduling, dosing).
3.3 Implement appropriate management strategies for the main causes of epilepsy according to local/regional settings (e.g., infective causes, metabolic, toxins, etc.).
3.4 Identify patients who are drug-resistant according to the current ILAE definition.
3.5 Demonstrate knowledge of when patients are in remission.
3.5.1 Advise patients about lifestyle issues and need for continued medication when they achieve remission.
3.6 Demonstrate the ability to provide initial management of patients with uncontrolled seizures.
3.6.1 Know how to manage common causes of breakthrough seizures.
3.6.2 Recognize when to reassess the diagnosis.
3.6.3 Know when revision of antiseizure medication regimen is needed, following the first trial (choice of medication, dosage, adherence, etc.).
4.0 Referral
4.1 Demonstrate working knowledge about patient referral management to a higher level of care.
4.1.1 Recognize when to refer (e.g., failure to control seizures, epilepsy with significant neurological abnormality, psychiatric or somatic comorbidity, genetic counselling, intellectual disability, etc.).
4.1.2 Know how to access information about referral options within the health care system.
4.1.3 Know how to triage the referral (e.g., urgency, type of service, level of care) within the available health care system.
4.1.4 Communicate appropriate referral information to a higher level of care.
4.1.5 Communicate to the patient and caregivers the rationale for referral and the actions required.
5.0 Emergencies
5.1 Demonstrate the ability to implement emergency treatment plans for children and adults in and outside the hospital setting.
5.1.1 Recognize the conditions or elements that constitute an emergency.
5.1.2 Implement emergency management for prolonged or sequential / clustered seizures.
5.1.3 Recognize that altered level of consciousness may be related to seizures and take appropriate action.
5.1.4 Appropriately manage or advise regarding risk of, or actual injuries.
5.1.5 Appropriately manage or advise regarding drug intoxication or adverse reactions.
5.1.6 Implement initial management for psychiatric emergencies (e.g., psychosis, self-harm, harm to others, agitation, suicidal ideation, etc.).
5.1.7 Demonstrate working knowledge of local guidelines and resources for the management of emergencies.
5.2 Demonstrate the ability to manage focal and generalized convulsive status epilepticus in children and adults.
5.2.1 Implement emergency management (e.g., airway breathing circulation, emergency first-line drugs, laboratory workup, cardio-respiratory monitoring).
5.2.2 Recognize when to refer to a higher level of care.
5.2.3 Recognize and manage common causes or precipitants of status epilepticus (e.g., non-adherence to medication, intoxication, metabolic and electrolyte disturbances, infection, etc.).
6.0 Comorbidities
6.1 Demonstrate the ability to recognize and provide initial management of common psychiatric comorbidities.

▼ **Table 1.** Domains, competencies and learning objectives of the ILAE primary health care epilepsy curriculum (six domains, 26 competencies and 85 learning objectives) (*continued*).

6.0 Comorbidities	
6.1.1	Recognize psychiatric comorbidities, such as depression, anxiety, psychosis, alcohol and substance abuse, suicidality, behavioral disorders.
6.1.2	Institute initial management in accordance with WHO mhGAP, including referral when appropriate.
6.2	Demonstrate the ability to recognize and provide initial management of common somatic multi-morbidities.
6.2.1	Recognize somatic multi-morbidities that are important in the management of people with epilepsy (e.g., diabetes, hypertension etc.).
6.2.2	Institute appropriate initial management of multi-morbidities in individuals with epilepsy.
6.2.3	Institute appropriate management of epilepsy in the presence of multi-morbidities.

▼ **Table 2.** ILAE primary health care competencies, which were rated as extremely important by 60% or more of the respondents from among epilepsy specialists and primary health care providers.

S. No.	Domain	Competency	Learning objectives
1	Diagnosis	Define what are seizures and epilepsies (including acute symptomatic [provoked] and unprovoked seizures; status epilepticus).	1.1.1 Demonstrate working knowledge of what is an epileptic seizure. 1.1.2 Demonstrate working knowledge of what is an acute symptomatic (provoked) and unprovoked seizure. 1.1.3 Demonstrate working knowledge of what is epilepsy. 1.1.4 Demonstrate working knowledge of what is status epilepticus and life-threatening seizure clusters.
2	Counselling	Counsel women with epilepsy of childbearing age about the implications and management of epilepsy (e.g., pregnancy, breast feeding and use of contraception).	2.4.1 Provide guidance regarding contraception and interaction with antiseizure medications. 2.4.2 Provide guidance regarding pregnancy, including teratogenicity of the various antiseizure medications (e.g., valproate. 2.4.3 Provide guidance regarding post-partum activities e.g., breastfeeding and child care.
3	Emergencies	Demonstrate the ability to implement emergency treatment plans (e.g., for status epilepticus, injuries and intoxication and serious adverse effects due to medications) for children and adults in and outside the hospital setting.	5.1.1 Recognize the conditions or elements that constitute an emergency. 5.1.2 Implement emergency management for prolonged or sequential/clustered seizures. 5.1.3 Recognize that an altered level of consciousness may be related to seizures and take appropriate action. 5.1.4 Appropriately manage or advise regarding risk of or actual injuries. 5.1.5 Appropriately manage or advise regarding drug intoxication or adverse reactions. 5.1.6 Implement initial management for psychiatric emergencies (e.g., psychosis, self-harm, harm to others, agitation, suicidal ideation, etc.). 5.1.7 Demonstrate working knowledge of local guidelines and resources for the management of emergencies.

▼ **Table 2.** ILAE primary health care competencies, which were rated as extremely important by 60% or more of the respondents from among epilepsy specialists and primary health care providers (*continued*).

S. No.	Domain	Competency	Learning objectives
4		Demonstrate the ability to manage focal and generalized convulsive status epilepticus in children and adults.	5.2.1 Implement emergency management (e.g., airway breathing circulation, emergency first-line drugs, laboratory work-up, cardio-respiratory monitoring). 5.2.2 Recognize when to refer to a higher level of care. 5.2.3 Recognize and manage common causes or precipitants of status epilepticus (e.g., non-adherence to medication, intoxication, metabolic and electrolyte disturbances, infection, etc.).

Other resources include the Pediatric Epilepsy Training (PET) courses initiated by the British Pediatric Neurology Association, the Practical Approach to Care Kit (PACK) epilepsy folio, and the Latin American epilepsy e-learning initiative [19-21]. The task force regards the available epilepsy educational models as highly valuable and advantageous and believes that the curriculum would add leverage to their purpose and application. The curriculum is based on current evidence at the time of writing. It is inclusive of all epilepsies, in contrast, for instance, to the mhGAP, which covers convulsive epilepsies alone, and of several special populations, e.g., children, elderly and women with epilepsy. Expectantly, the existing packages could align with the curriculum or serve as portals to roll it out.

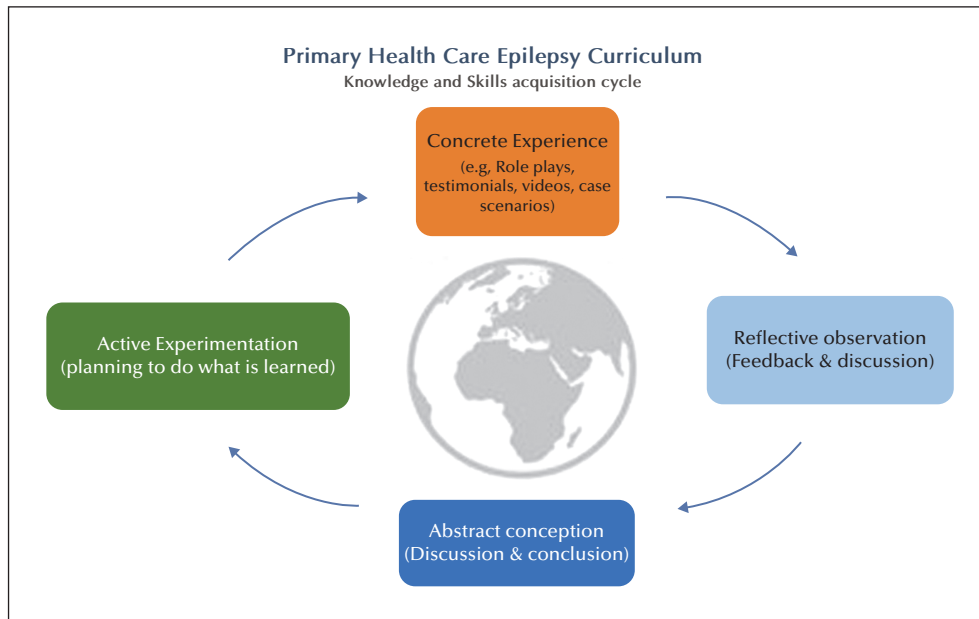
The way forward

Future steps in taking this forward would include: (a) wide dissemination of the educational curriculum to all relevant primary care sectors; (b) adoption of suitable learning platform/s; (c) assessment of learning needs through survey/s of the various stakeholders, involving particularly primary health care providers; (d) content development of educational package/s; (e) scaling-up implementation of educational interventions in member countries of the ILAE; and (f) feedback, accrual as well as content and program evaluation. Suitable platforms should ideally be web-based, easily accessible and inexpensive. These should be endorsed by key stakeholders, inclusive of governments and relevant regional and national professional organizations. Content development and implementation should follow processes relevant to adult learning [13] (*figure 1*). Over three quarters of the world’s population with epilepsy live in L&LMICs and nearly three quarters of

them lack access to treatment [22-24]. Amongst other reasons, a specialist clinician resource gap is a major factor responsible for the wide epilepsy diagnostic and treatment gap [7]. A WHO survey estimated that there are only 0.3 neurologists/100,000 people in the African and Southeast Asian regions in comparison to 9 /100,000 in Europe [9]. Whereas nearly all countries reported availability of neurologists in capital cities, access to neurological care was limited in non-capital cities and even more so in rural areas. With the absence or limited number of specialists, the onus of epilepsy diagnosis and care falls on primary health care providers. Hence, capacity building by appropriately training these practitioners is a crucial step in closing epilepsy diagnostic and treatment gaps [10, 11]. The ILAE task force perceives primary care curriculum development not as one small step in epilepsy education but a giant leap in closing the global epilepsy treatment gap. The present version of the primary care educational curriculum should be re-evaluated and updated in future as experience is gained in its implementation and as needs evolve. This is in keeping with the ILAE’s continuing commitment to reduce epilepsy diagnostic and treatment gaps and consequently the global burden of epilepsy.

Limitations and challenges

Feedback was accrued from relatively fewer primary health care providers in comparison to specialists. This was because the ILAE is a specialty organization making it difficult to approach primary health care providers. Likewise, low-income countries were sparsely represented in the survey. However, feedback was obtained from respondents from all low-income member countries of the ILAE except for Rwanda and Guinea in Africa and Afghanistan, Yemen and Syria from the Eastern Mediterranean region.



■ **Figure 1.** Theoretical basis of the learning cycle for primary health care providers.

The large number of learning objectives might make the curriculum appear daunting to a primary health care clinician who is often burdened with heavy patient loads and has to deal with a range of health conditions. However, the list is complete and entails all that is necessary for optimal care provision. The learning objectives might be construed as reflecting a body of knowledge. It is both inadvisable and unnecessary to assimilate the entire body of knowledge at once. Rather, in keeping with principles of adult learning, care providers may acquire the skills and knowledge piecemeal and on a case-by-case basis.

Another challenge might be the diverse cadres of workforce involved in primary care across socio-demographic settings. These include, for example, physicians, nurses, pharmacists and community health workers, all with different roles and responsibilities. In addition, roles and responsibilities of cadres vary from country to country. For instance, in many African countries such as Sudan, Botswana and Mali, the nearest and first-level health care facility is typically run by a nurse practitioner, midwife or a medical assistant and not a doctor [25]. They are trained to diagnose and provide basic care for several disorders and refer complicated cases to next-level centers. Further, they are often the first contact in the care pathway for someone presenting with seizures. At the other end of the spectrum are primary care providers working in specialized epilepsy centers,

supported by multidisciplinary teams, and requiring a different level of expertise. Covering disparate cadres among the primary care workforce in a unified educational curriculum can be challenging. The task force proposes to work closely with all stakeholders, including those in the primary care workforce to develop necessary educational packages across diverse settings.

To date, the educational curriculum has been translated into six languages to facilitate efforts to disseminate it widely. Eventually, the educational curriculum and content of educational packages will need to be adapted by users in different socioeconomic, cultural and linguistic settings in keeping with their needs. Further, policymakers might well be sensitized to the applicability and integration of the curriculum in future primary health care training programs. ■

Key points

- An enormous specialist resource gap is one of the major reasons for the wide epilepsy diagnostic and treatment gaps.
- Improving epilepsy knowledge and skills among primary health care providers is one practical solution to deal with the specialist resource gap.
- Elucidating a carefully formulated educational curriculum specifically for primary health care

providers is one of the first steps in improving epilepsy knowledge and skills among them.

- The Primary Health Care Providers' Epilepsy Educational Curriculum devised by the Primary Care Task Force of the ILAE Education Council is evidence-based and expert consensus-driven.
- The Curriculum has been endorsed widely by the ILAE leaders and constituency.
- The Curriculum comprises of six domains and 26 competencies.
- The challenge now is to devise and implement educational packages and tools for primary health care providers that draw upon the elements and learning objectives of the curriculum.

Supplementary material.

Supplementary data accompanying the manuscript are available at www.epilepticdisorders.com.

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References

1. Fisher RS, van Emde Boas W, Blume W, Elger C, Genton P, Lee P, et al. Epileptic seizures and epilepsy: definitions proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). *Epilepsia* 2005; 46: 470-2.
2. GBD 2019 Diseases Injuries Collaborators. Global burden of 369 diseases and injuries in 204 countries and territories, 1990-2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet* 2020; 396(10258): 1204-22.
3. GBD 2016 Epilepsy Collaborators. Global, regional, and national burden of epilepsy, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol* 2019; 18: 357-75.
4. Burneo JG, Tellez-Zenteno J, Wiebe S. Understanding the burden of epilepsy in Latin America: a systematic review of its prevalence and incidence. *Epilepsy Res* 2005; 66: 63-74.
5. Ding D, Zhou D, Sander JW, Wang W, Li S, Hong Z. Epilepsy in China: major progress in the past two decades. *Lancet Neurol* 2021; 20: 316-26.
6. Li LM, Fernandes PT, Noronha AL, Marques LH, Borges MA, Borges K, et al. Demonstration project on epilepsy in Brazil: outcome assessment. *Arq Neuropsiquiatr* 2007; 65 (Suppl 1): 58-62.
7. World Health Organization. *Atlas: country resources for neurological disorders*. WHO, 2004. http://www.who.int/mental_health/neurology/neurogy_atlas_lr.pdf?ua=1
8. Lewis AK, Taylor NF, Carney PW, Harding KE. What is the effect of delays in access to specialist epilepsy care on patient outcomes? A systematic review and meta-analysis. *Epilepsy Behav* 2021; 122: 108192.
9. World Health Organization. *Atlas: epilepsy care in the world*. WHO, 2005. http://www.who.int/mental_health/neurology/Epilepsy_atlas_r1.pdf
10. World Health Organisation. *Epilepsy: a public health imperative*. WHO: Geneva, 2019. https://www.who.int/mental_health/neurology/epilepsy/report_2019/en/
11. World Health Organisation. *Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications*, WHA 68.20. WHO: Geneva, 2015. <https://www.ilae.org/files/dmfile/WHO-Epilepsy-2015.pdf>
12. World Health Organisation. *Global actions on epilepsy and other neurological disorders (WHA73.10). Seventy-third World Health Assembly*. WHO: Geneva 2020. https://apps.who.int/gb/ebwha/pdf_files/WHA73/A73_R10-en.pdf
13. Kolb D. *Experimental learning*. New Jersey: Prentice Hall, 1984.
14. Blümcke I, Arzimanoglou A, Beniczky S, Wiebe S. Roadmap for a competency-based educational curriculum in epileptology: report of the Epilepsy Education Task Force of the International League Against Epilepsy. *Epileptic Disord* 2019; 21: 1-12.
15. Hamadeh N, Van Romapaey C, Metreau E. *World Bank country classification by income status 2020-2021*. World Bank Blogs, 2021. <https://blogs.worldbank.org/opendata/new-world-bank-country-classifications-income-level-2021-2022>
16. Kern DE. *Curriculum development for medical education: a six step approach*. Baltimore: Johns Hopkins University Press, 1998.
17. World Health Organization. *Update of the mental health Gap Action Programme (mhGAP) guidelines for mental, neurological and substance use disorders*. Geneva: World Health Organization, 2015. <https://www.ncbi.nlm.nih.gov/books/NBK344372/>
18. Dos Santos PF, Cumbe V, Gouveia ML, de Fouchier C, Teuwen D, Dua T. Implementation of mhGAP in Mozambique: integrating epilepsy care into the primary health care system. *Int J Ment Health Syst* 2019; 13: 36.

19. Knowledge Translation Unit. *Adult Primary Care 2020 full course*. <https://ktuonlineschool.datafree.co/courses/APC-full-course>
20. Patel AA, Wibecan L, Tembo O, Kalyelye P, Mathews M, Ciccone O. Improving paediatric epilepsy management at the first level of care: a pilot education intervention for clinical officers in Zambia. *BMJ Open* 2019; 9: e029322.
21. Carrizosa J, Braga P, Albuquerque M, Bogacz A, Burneo J, Coan AC, et al. Epilepsy for primary health care: a cost-effective Latin American E-learning initiative. *Epileptic Disord* 2018; 20: 386-95.
22. Mbuba CK, Ngugi AK, Fegan G, Ibinda F, Muchohi SN, Nyundo C, et al. Risk factors associated with the epilepsy treatment gap in Kilifi, Kenya: a cross-sectional study. *Lancet Neurol* 2012; 11: 688-96.
23. Meyer AC, Dua T, Ma J, Saxena S, Birbeck G. Global disparities in the epilepsy treatment gap: a systematic review. *Bull World Health Organ* 2010; 88: 260-6.
24. Singh B, Mahajan N, Singh G, Sander JW. Temporal trends in the epilepsy treatment gap in low- and low-middle income countries. *J Neurol Sci* 2022; 434: 120174.
25. Willcox ML, Peersman W, Daou P, Diakité C, Bajunirwe F, Mubangizi V, et al. Human resources for primary health care in sub-Saharan Africa: progress or stagnation? *Hum Resour Health* 2015; 13: 76.

TEST YOURSELF

- (1) Which of the following epilepsy learning objectives is within the competency of primary health care providers?
 - A. Ability to order and interpret total and free serum antiseizure medication levels in routine clinical practice
 - B. Extract information on the semiology of seizures from history provided by patients, their caregivers and people who witness their seizures
 - C. Ability to report electroencephalograms and make management decisions based on their results
 - D. Provide care to patients soon after epilepsy surgery
- (2) Which of the following is a reasonable learning objective for primary health care providers?
 - A. Knowledge about mutations responsible for monogenic epilepsies
 - B. Ability to recognize atonic, astatic and negative myoclonic seizures
 - C. Understand the association between traumatic brain injury and subsequent epilepsy
 - D. Identification of rare and complex epilepsies
- (3) Which of the following is NOT an area that primary health care providers need to be familiar with?
 - A. Psychiatric comorbidities
 - B. Accidents, injuries and SUDEP related to epileptic seizures
 - C. Infectious causes of acute symptomatic seizures
 - D. Types and management of non-convulsive status epilepticus

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