

Let the best not be the enemy of the good!

To the Editor,

We congratulate the ILAE, the EpiEd task force and authors of the competency-based epileptology curriculum (Blumcke *et al.*, 2019). Seeking to systematically minimize the knowledge gap may prove to be the most incisive step yet for reducing the epilepsy treatment gap (TG). The report is comprehensive, insightful and nuanced and the roadmap may need little to no modification in those countries that are already providing access to basic epilepsy care to most persons with epilepsy (PwE). However, in low/middle-income countries (LMICs) which account for about 80% PwE, and continue to battle high TG amongst millions, some fine-tuning may be considered. Our suggestions stem not from any substantive disagreement with the EpiEd report but more from a perspective of trying to be realistic. The EpiEd report provides hope of reducing the TG, but we would also not want to whittle away this opportunity by preferring idealism to pragmatism. As the ILAE celebrates 110 years of its flagship role, our urgent one-point agenda for LMICs should be *to get every PwE started on an AED*. No patient should remain untreated and this should not have to wait any more. Everything else can and will follow.

What kind of education is needed to get every PwE started on an AED? In addition to what will be taught and how it will be taught, one has to consider *who is available* to be taught and the *resources that are available* to them. The diagnosis of epilepsy is essentially clinical. One needs to be able to distinguish acute symptomatic seizures from epilepsy and also be familiar with non-epileptic seizures including PNES. After that, the choice of a first-line AED based upon whether the epilepsy is focal or generalized is often possible without investigations (Kumar *et al.*, 2017). For longer-term care, monitoring AED side effects, encouraging compliance and ensuring seizure control is needed until the epilepsy remits and AEDs can be tapered and stopped. In fact, we have evidence to show that in desperate situations, patients may continue taking AEDs and benefit even without regular follow-ups (Prajapati *et al.*, 2019). If all goes well, which is likely to be the case in at least 50% PwE, competence in providing such Level 1 care may be enough to significantly reduce numbers of untreated PwE. Only when patients do not achieve seizure control, experience excessive side effects or have complications may referral to higher care for review and investigations be needed.

It is important to be aware of who the Level 1 care providers are likely to be. Most LMICs currently experience an extreme shortage of doctors. In many of these

countries, nurses or health workers may have to be roped in. In better circumstances, internists or medical graduates may be available. Only rarely, will Level 1 providers be more specialized doctors such as psychiatrists, internal medicine specialists or paediatricians. Neurologists are either totally absent or in extremely small numbers. With a well-designed basic training module, it is conceivable that this diverse group of largely non-specialist Level 1 care providers can be made competent and adequately empowered to manage uncomplicated epilepsy safely. However, to expect any more from them may be impractical and even counterproductive.

In addition to the challenge of finding Level 1 care providers, there is also the question of availability of reliably performed and reported investigations. Even tests that may be available are often poorly performed, incorrectly reported and needlessly increase treatment cost (*figure 1*). This is why we propose that



Figure 1. An 'EEG' being performed in Kota, Rajasthan, India. The out-of-pocket cost of EEG in India varies between INR 1500-2000 or USD 20-30. (This should be seen in the context of the annual cost of treatment with one first line AED that also amounts to about USD 20-30).

Level 1 providers remain unencumbered from the responsibility of ordering or deciphering investigation reports. Instead, emphasis should be maintained on enabling them to make a sound clinical diagnosis, start AED treatment, perform patient reviews and educate patients. Familiarity with common drug interactions should also be a part of the required basic knowledge for Level 1 practitioners although other details of pharmacokinetics and pharmacodynamics may not be needed. Recommending second-line AED treatment may also be included in the curriculum especially when more qualified practitioners are not readily available. In another deviation from the EpiEd proposal, Level 1 may include contraception guidance and counselling for pregnant patients. This is an everyday occurrence and relegating it to Level II may translate into unsupervised pregnancies with respect to epilepsy. Educating schoolteachers about epilepsy could also be in the purview of Level 1 care providers. Most epilepsy patients in LMICs will be treated at Level 1 and this is where all possible resources are immediately needed. If a realistic effort has to be made to reduce Treatment Gap, another crucial component of epilepsy education could be the incorporation of technology in providing care. Existing models of care have fallen short and easily available technology has shown definite promise in at least two areas. One is a simple phone App that can be used even by lay, non-medical Level 1 care providers to screen for whether an event is epileptic or not (Patterson *et al.*, 2017). The second is training of care providers to use the ubiquitous mobile phone for long-term follow-up (Bahrani *et al.*, 2017). These and other technology-driven solutions may be valuable additions to the curriculum. □

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Supplementary data.

Summary didactic slides are available on the www.epilepticdisorders.com website.

References

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TEST YOURSELF



(1) Which of the following in your opinion is the most valuable tool for making a diagnosis of epilepsy and determining if it is focal or generalized?

- A. Clinical history and examination
- B. EEG
- C. Cranial MRI
- D. PET scan

(2) In which of the following categories of patients do you think a routine 40-minute interictal EEG may provide the most useful information with a bearing on management?

- A. PNES
- B. Juvenile myoclonic epilepsy
- C. Focal epilepsy due to a frontal calcified lesion in a patient who has become seizure-free on one AED
- D. Focal drug-resistant temporal lobe epilepsy

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