

Epilepsy: Looking Beyond Seizures

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World Epilepsy Day falls on 26 March 2013. As we observe this important date in Singapore, it is perhaps instructive to take a step back to review epilepsy as a disease, to reflect on progress made, and as yet unresolved challenges.

Epilepsy is a fairly common disease affecting 5 to 10 out of every 1000 persons worldwide; the prevalence in Singapore is much the same.¹ It contributes significantly to the global burden of disease.² Despite many new antiepileptic drugs (AEDs), about 25% to 30% of people with epilepsy (PWE) continue to have seizures;^{2,3} such refractory epilepsy continues to have significant impact on quality of life.

AED costs contribute significantly to the economic burden of PWEs and society. In a recent study in Singapore,⁴ newer AEDs (NAEDs) such as levetiracetam, lamotrigine and topiramate were found to be substantially more costly than conventional AEDs such as carbamazepine, phenytoin, valproate, phenobarbitone and benzodiazepines. Inclusion of NAEDs in combination therapies further increases the economic burden of epilepsy care. These might lead to unsustainable long-term NAED usage; PWEs may self-reduce dosages due to cost concerns, resulting in suboptimal seizure control.

In Singapore, many misperceptions about epilepsy remain. There are medical misperceptions about antiepileptic drugs—that the drugs need to be lifelong, and that the drugs are toxic with unpleasant side effects. There are mistaken beliefs about epilepsy surgery as well. Despite compelling evidence demonstrating the long-term efficacy and safety of epilepsy surgery for refractory epilepsy,^{5,6} many PWEs who would benefit from surgery instead decline such surgery, due to the mistaken belief that surgery is dangerous or ineffective.

Besides medical misperceptions, there are also social and cultural misperceptions. Many Asian cultures ascribe seizures to spiritual or otherworldly reasons, and thus PWEs (or their family members) who subscribe to such belief systems may decline appropriate treatment. One study⁷ found that 32% of Singaporeans still believe that an object should be placed in the mouth during a seizure to

avoid biting of the tongue, despite the risks of such objects. Employers shun PWEs due to misguided concerns about suitability to work. Parents object to their children marrying a PWE,⁷ due to the mistaken belief that the children from such a union will have epilepsy. Such fallacious beliefs only serve to decrease employability, increase stigma and reduce quality of life.^{8,9}

So what influences quality of life (QOL) in epilepsy?⁹ One would be forgiven for saying seizures are the only determinant—after all in medical school we focus on the seizures, and learn about the antiepileptic drugs used to control these seizures. The stated goal of epilepsy treatment is to render the patient seizure-free.

While seizure freedom does improve QOL, we need to look beyond seizures.⁹ There are several other factors that negatively impact QOL—psychiatric comorbidities such as depression or anxiety,⁸ drug side effects, cognitive or memory dysfunction, stigma of epilepsy, or social limitations relating to interpersonal relationships or employability.⁹ These important issues should be detected and explored during consultations, with a view towards actively resolving such issues to improve QOL.

Faced however with increasing patient loads and ministry-tracked waiting times, the neurologist or primary care physician faced with a PWE in the outpatient clinic might be tempted to ask only about seizures, prescribe the antiepileptic drugs, and send the patient off, hoping to minimise waiting time. We feel however that it is eminently possible to optimise epilepsy care. The key is to function within an epilepsy care team.

At the National Neuroscience Institute, we are fortunate to have epilepsy advanced practice nurses (APN) who provide an additional layer of care for our patients. We partner our APNs in the wards and epilepsy clinics. Our APNs actively ask about and discuss psychosocial issues, screen for depression if indicated, and counsel patients not just about epilepsy but also about psychosocial issues. If needed, a referral to the next member of the team, the medical social worker, is initiated, often by the APN. There is encouraging data about the effectiveness of specialised epilepsy nurses,¹⁰⁻¹² and our experience with our APN

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colleagues has been extremely positive.

Besides APNs and social workers, other valuable members of the care team include psychiatrists who have an interest in epilepsy and its psychiatric comorbidities. Finally, lay support groups such as the Singapore Epilepsy Society and the Epilepsy Care Group can also provide community-based psychosocial support.

In order to measure the quality of epilepsy care, we are putting into place quality indicators¹³ at our institution that track not just processes aimed at optimising seizure control, but also processes aimed at detecting and treating drug side effects, psychiatric comorbidity and psychosocial issues. This way, we hope to shape behaviour and encourage our fellow neurologists to consider issues besides seizures in the treatment of epilepsy. Seizures are undoubtedly important, but on World Epilepsy Day, we hope all of us can look beyond seizures, and instead see the person with epilepsy.

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