

Review

Psychosocial aspects of epilepsy: a wider approach

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Summary

Epilepsy is one of the most serious neurological conditions and has an impact not only on the affected individual but also on the family and, indirectly, on the community. A global approach to the individual must take into account cognitive problems, psychiatric comorbidities and all psychosocial complications that often accompany epilepsy. We discuss psychosocial issues in epilepsy with special focus on the relationship between stigma and psychiatric comorbidities. Social barriers to optimal care and health outcomes for people with epilepsy result in huge disparities, and the public health system needs to invest in awareness programmes to increase public knowledge and reduce stigma in order to minimise such disparities.

Declarations of interest

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Epilepsy is among the most common serious neurological conditions with incidence rates, in high-income countries, ranging between 40 and 70 per 100 000 persons per year and generally higher in young children and in the elderly.^{1–3} In resource-poor countries, the incidence is usually much higher, often above 120/100 000/year, and in high-income countries, poor people also seem to have a higher incidence.^{4,5} Poor sanitation, inadequate health delivery systems and higher risk of brain infections and infestations may contribute to this.^{1,6} Prevalence studies have reported lifetime rates between 4 and 10/1000 in developed countries,^{2,7} but data from resource-poor countries clearly suggest higher lifetime prevalence rates in the region of 23.2–32.1/1000⁸ up to 57/1000 in some selected cases in rural areas.⁹

Many people with epilepsy live a normal life, but there is no doubt that the long-term prognosis of epilepsy is poor in many cases owing to increased morbidity and mortality.¹⁰ This can be because of physical causes (e.g. fractures, scalding, bruising) as well as comorbidity with other systemic diseases¹¹ and increased psychosocial problems.¹² People with epilepsy, particularly if chronic, have an increased risk of premature death.^{6,13,14} Sudden unexpected death, trauma, suicide, pneumonia and status epilepticus have been identified as being more common in people with epilepsy.^{14,15} Symptomatic epilepsy may reduce life expectancy by up to 18 years.¹¹ Little is known about mortality in resource-poor countries as only a few adequate studies have been carried out to address this issue. Circumstantial evidence, however, suggests that the mortality rate is higher, helping to explain the discrepancy between the higher incidence and relatively low prevalence of active epilepsy in these countries.¹

In May 2015, the World Health Assembly approved the WHO Resolution on the Global Burden of Epilepsy which provides a powerful tool to engage national governments into implementing effective actions to improve medical and social services for people with epilepsy, promote public awareness about epilepsy and allocate resources to epilepsy research.¹⁶ The resolution calls on the WHO Secretariat to continue to lead and coordinate support to member states in addressing the global burden of epilepsy so that people with epilepsy can receive timely treatment and can benefit from educational and occupational opportunities, free from stigma and discrimination.

The global perspective

Apart from good seizure control, numerous factors are involved in quality of life (QoL) of people with epilepsy. It is now well recognised that other factors, such as comorbid depression and adverse effects of medications, are far stronger predictors.¹⁷ Even in those in whom remission is achievable, if this is at the expense of unacceptable side-effects, adherence and QoL remain poor.

Successful integration of people with epilepsy into society is another important goal in epilepsy care. Educational level, intellectual ability, psychological stability, family and social support, the ability to overcome stigma, transportation and mobility issues, and employment opportunities are important determinants of successful integration.¹⁸ The combination of these factors influences the life of people with epilepsy and what they consider meaningful.¹⁹ For this reason, sport and leisure is becoming a new topic in epilepsy care and the International League against Epilepsy has a specific task force dedicated to Epilepsy and Sport and a report is now available.²⁰

The QoL of people with epilepsy also appears to be related to the level of social support they receive through the various societal structures, including emotional support, informational support, instrumental support, appraisal, social companionship and affectionate support.²¹ Social support mechanisms help people to overcome many of the difficulties they encounter. Individuals with good social support usually have an increased sense of control over their lives, enabling them to have better coping mechanisms for handling adversities.²¹ It is now clear that people with the highest level of social support have significantly lower reported stigma scores.²²

Epilepsy is a condition still highly stigmatised, and stigma greatly affects the QoL of people with epilepsy, leading to increased anxiety and depression and poor adherence with medication.²³ Unfortunately, even today, stigma is present in both high-income and resource-poor countries.¹ Stigma is not only responsible for poor QoL but also seems to play a role in mood and anxiety problems in both people with epilepsy and their caregivers. Perceived stigma is also responsible for increased rates of aggressive behaviour associated with depression and anxiety.²⁴ In low- and middle-income countries, 20% of mothers of children with epilepsy feel stigmatised because of their child's neurological condition,²⁵ and the caregiver's perception of burden, together with the level

of family function, are indirectly correlated with depressive symptoms in people with epilepsy via the mediating effect of caregiver depression.²⁶ This is also present in high-income countries where social aspects of stigma are an important determinant of anxiety and depression.²⁷

The US Centers for Disease Control and Prevention, Epilepsy Program, pointed out that one in five of those with epilepsy lives alone and less than one in four live in households with two adults and children.²⁸ Adults with epilepsy living alone may be at increased risk of injury associated with uncontrolled seizures, mental distress associated with social isolation, lower QoL and early mortality. Stigma affects attitude towards epilepsy and the more intimate life domains such as cohabitation and marriage. A number of studies have shown that people with epilepsy are less likely to be married and people suffering from the enacted stigma are significantly more likely to get divorced in comparison with others.^{29–31}

In resource-poor countries, stigma directly affects access to healthcare^{32,33} and probably contributes to the discrepancy between the incidence and prevalence of epilepsy in lower-income regions of the world because diagnoses and clinical information are sometimes unreliable.³⁴ As already stated, perceived stigma is a problem even in high-income countries and is probably a major determinant of poor adherence with medications.²³ The information–motivation–behavioural skills model is a useful framework for understanding the pathways linking perceived stigma and adherence in the population with epilepsy.³⁵ Living in a European country with better health system performance and higher health expenditure per capita does not necessarily lead to a reduction in perceived discrimination, unless the public health system invests in awareness programmes to increase public knowledge and reduce stigma.³⁶ Low socio-economic status alone does not account for felt stigma, but depressive symptoms and poor social supports have the greatest impact on reported felt stigma in people with epilepsy.³⁷ Social barriers to optimal care and health outcomes for people with epilepsy result in huge disparities.³⁸ Disparities are a complex phenomenon that requires research and action. A systematic review has identified five domains of potential disparities in epilepsy care: access to medical and surgical treatment, outcomes following medical/surgical treatment, attitudes/knowledge about epilepsy, epidemiology and disability.³⁹ Data on these domains were, however, limited. For example, a US national study has shown that White people and those privately insured were found to be more likely to have surgery compared with their respective minority and publicly insured counterparts.⁴⁰ Furthermore, robust data collection and surveillance to identify points of intervention are urgently needed.

Cognitive problems

About 40% of people with epilepsy aged between 4 and 15 years have one or more additional neurological problems, the most common being intellectual disabilities, speech and language difficulties or other specific cognitive disabilities.¹ In addition, intellectually disabled individuals are at an increased risk of behavioural problems.⁴¹ Those severely affected have higher healthcare needs than others because of the concomitant presence of other neurological disabilities (i.e. feeding and swallowing difficulties, inability to walk).⁴²

Epilepsy can have an impact on cognition in several ways. A degree of impairment in cognitive functions is frequently reported by people with epilepsy, ranging between 44% for difficulties in learning and psychomotor retardation to 59% for sleepiness or tiredness.^{43,44}

In clinical practice, the majority of cognitive problems have multifactorial origins with many different variables often interlinked.⁴⁴ Cognitive dysfunction in epilepsy is generally regarded as either trait dependent or state dependent.⁴⁵ Trait-dependent dysfunction is a stable condition owing to the underlying brain disorder, while state-dependent dysfunction is a potentially reversible condition owing to modifiable factors such as anti-epileptic drugs (AEDs), seizure frequency and pattern, and psychiatric comorbidities.

Whether poorly controlled epilepsy is associated with progressive cognitive deterioration is still controversial, and this has been demonstrated only for some specific syndromes: mesial temporal lobe epilepsy and epileptic encephalopathies.⁴⁶ Different epileptic encephalopathies seem to have specific patterns of cognitive deficits such as short-term visuospatial memory problems, executive dysfunction and frontal lobe dysfunction in Unverricht–Lundborg syndrome,^{47,48} language dysfunction in Landau–Kleffner syndrome⁴⁹ and poor language acquisition and visuospatial defects in Dravet⁵⁰ and Rett syndrome.⁵¹ Finally, epileptic encephalopathies associated with frequent and uncontrolled seizures during sleep are characterised by memory and language problems.⁵²

Cognitive problems are important in the long-term management of people with epilepsy, having an impact on QoL and everyday functioning.^{53,54} A US study showed that a self-management intervention targeting cognitive dysfunction can significantly improve not only cognitive performance but also QoL.⁵⁵ Access to investigations, appropriate testing and review are important parts of the management.

Epilepsy has also a clear impact on relatives and carers of people with epilepsy, especially when seizures start during childhood. A Swedish study showed that mothers and fathers of children with drug-resistant epilepsy have poorer QoL compared with population norms, and symptoms of anxiety seem to be common especially among mothers.⁵⁶

Psychiatric problems

Psychiatric disorders are relatively frequent comorbidities in epilepsy, with a lifetime history identified in one in three people with epilepsy.⁵⁷ Mood and anxiety disorders are the most frequently reported⁵⁸ for both biological and psychosocial reasons. The burden of stigma, social limitations and discrimination in epilepsy lead to demoralisation and poor self-esteem, but the pathophysiology of epilepsy *per se* is interlinked with mood problems as demonstrated by neuroanatomical and neurochemical principles. The involvement of the temporal lobes⁵⁹ and the psychotropic effects of AEDs⁶⁰ seem to be relevant contributors to the increased rates of psychiatric problems in epilepsy but much remains unknown regarding the role of shared versus syndrome-specific variables and the role of cortico-subcortical networks. In addition, a number of epidemiological studies have suggested that the relationship between epilepsy and psychiatric problems is not necessarily unilateral but rather bidirectional and some people may present with a psychiatric disorder before the emergence of seizures.^{61–63}

Depression is an important predictor of poor QoL,⁶⁴ seizure severity,⁶⁵ drug-resistance⁶⁶ and a poor outcome after epilepsy surgery.⁶⁷ Nonetheless, mood disorders are still under-recognised, under-treated and sometimes fully ignored, unless they are severe enough to reach medical attention. A number of reasons can explain the diagnostic delay and inaccuracy, including individuals' reluctance spontaneously to volunteer information about existing psychiatric problems, a paucity (or total lack) of training for the treating neurologist to recognise psychiatric symptoms and a lack of time in very busy clinics to screen for them. The result is

that epilepsy is often complicated and burdened by psychiatric disturbances or behavioural problems that are not adequately addressed or managed.

Suicide is a severe complication of untreated and undiagnosed depression. In the context of epilepsy, suicide is gaining increasing attention, and it has been recently reinvigorated by the Food and Drug Administration alert on a supposedly increased risk of suicidal ideation and behaviour in people taking AEDs.⁶⁸ In the general population, suicide is the 11th cause of death and the second in the age group between 25 and 34 years.⁶⁹ It is now evident that the overall risk of death by suicide is about three times higher in people with epilepsy than in the general population.^{70–72} Several studies have attempted to identify reasons for this increased risk. In the general population, about 90% of people who die by suicide have at least one psychiatric disorder at the time.⁷³ Epilepsy is burdened by psychiatric comorbidities, but it is unlikely that such a problem is the only responsible element. A Danish study reported that the rate ratio of suicide in people with epilepsy is still doubled even after excluding people with psychiatric comorbidity and adjusting for various factors.⁷² Some have suggested a link with temporal lobe epilepsy,⁷⁰ but a recent study, using retrospective and prospective methods, found no epilepsy-related factors.⁷⁴ The issue of epilepsy and suicide is still far from being elucidated, but it is likely to be multifactorial with biological, constitutional and psychosocial variables being implicated. It seems evident that suicide prevention is another relevant issue in epilepsy care deserving further clinical attention.

People with epilepsy historically have been considered to have an increased risk of developing psychotic disorders. Epidemiological evidence suggests that the incidence of non-organic, non-affective psychoses, including schizophrenia and schizophrenia spectrum disorders, is generally over-represented among people with epilepsy compared with the general population or other chronic medical conditions.⁷⁵ A family history of psychoses and a family history of epilepsy were significant risk factors for psychosis suggesting strong neurobiological underpinnings.⁷⁶ In general terms, psychoses represent a rare but serious complication of epilepsy. Close attention to the relationship between psychotic symptoms and seizure pattern is crucial to identify seizure-based phenomena such as postictal psychoses or the forced normalisation phenomenon.⁷⁷ Chronic interictal schizophrenia-like psychoses can be occasionally seen and deserve careful consideration.

The increasing attention to the psychiatric comorbidities of epilepsy brings to light the issue of double stigma. No studies investigated the relative contribution of the two conditions, epilepsy and mental health issues, but the problem of double stigma is well-known in other medical conditions such as obesity and mental health⁷⁸ or the comorbidity between HIV and tuberculosis⁷⁹ in low-income countries. Double stigma means double challenge and for this reason it becomes even more important to invest energies and resources.

Epilepsy is one of the most common neurological conditions, and it has an impact not only on the individual with epilepsy but also on the family and, indirectly, on the community. A global approach to the individual must take into account the cognitive problems and psychiatric comorbidities that often accompany epilepsy. The burden of epilepsy concerns not only the physical hazards of epilepsy but also the psychosocial consequences involved, such as the negative attitudes of people towards the patients, manifested as social stigma, social isolation and lack of support. Social barriers to optimal care and health outcomes for people with epilepsy result in huge disparities, and the public health

system should invest in awareness programmes to increase public knowledge and reduce stigma in order to minimise such disparities.

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