



## Review

# The societal integration of individuals with epilepsy: Perspectives for the 21st century



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## ABSTRACT

Epilepsy is a common neurologic disorder seen throughout the world. Advances in therapy have made it possible for persons with epilepsy (PWEs) to have improved seizure control and a better quality of life. However, it is not entirely clear whether this has resulted in their successful integration into society.

This review examines the societal integration of PWEs, identifying both the progress made and the challenges that continue to hamper further advances. In general, PWEs are more integrated in western-oriented cultures. However, there continue to be ongoing difficulties due to poor education and intellectual functioning, poor social and family support, the undertreatment of coexisting psychiatric conditions, transportation and mobility limitations, and problems obtaining employment.

This review also discusses the effects of low socioeconomic status on integration and the persisting prejudices that affect certain racial groups. Most importantly, this review underscores the fact that societal stigma towards PWEs is still very much alive.

At the beginning of the 21st century, PWEs still encounter difficulties in their quest for full societal integration. Along with medical advances being made to improve seizure control, much still has to be done to bring about the reforms necessary to help PWEs live more meaningful and productive lives.

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## 1. Introduction

Epilepsy affects nearly 1% of the population. It is a worldwide phenomenon that cuts across cultures, geography, and age groups, with somewhat increased prevalence in developing nations [1]. The past century has witnessed significant advances in diagnostic and treatment options for persons with epilepsy (PWEs). These range from advances in antiepileptic drug (AED) regimens, epilepsy surgery, the use of the ketogenic diet in specific populations, and, more recently, the use of neurostimulation. It has been estimated that with current therapies, the vast majority of PWEs should have a significant improvement in seizure control [2]. Good seizure control has been associated with better quality of life and improves the chances for employability [3–7].

One issue that needs to be addressed is how successfully PWEs have integrated into society. To a significant extent, the successful societal integration of PWEs is one of the main aims of treatment, providing PWEs the opportunity to work, raise a family, and lead normal lives [8]. However, as will be discussed, the successful integration of PWEs requires much more than mere seizure control.

The aim of this review is twofold: to examine the integration of PWEs into society, focusing on those factors that continue to hamper

their integration, and to propose solutions that may help them to overcome these hurdles.

## 2. Factors influencing the integration of individuals with epilepsy into society

Aside from good seizure control, numerous factors are involved in the successful integration of a PWE into society. These include educational level and intellectual ability, psychological stability, familial and social support, the ability to overcome societal stigma, transportation and mobility issues, and employment opportunities [9,10]. These issues and others will be addressed throughout the review with the premise that each PWE is a unique individual with his/her own perception of how and in what particular combination these factors influence their lives, what they consider meaningful, and how they should respond.

### 2.1. Locus of control

Locus of control is an important element in how PWEs view their situation and how society affects their functioning. Certain individuals have an external locus of control, meaning that they perceive factors outside of their personal control as influencing the outcome of their lives, often resulting in a more passive personality, while others have a more internal one, believing that they can control their actions and, to an extent, their destiny [9]. Unfortunately, it has been shown that

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an external locus of control is seen more frequently in PWEs even when compared with persons with diabetes and orthopedic issues and control populations [11–13].

## 2.2. Social support

The quality of life reported by PWEs appears directly related to the level of social support that they receive through the various societal structures. Social support encompasses multiple domains that include emotional support, informational support, instrumental support, appraisal, social companionship, and affectionate support [14]. These social support mechanisms help PWEs overcome many of the difficulties they encounter. Persons with epilepsy with strong social support report less debilitation due to their epilepsy compared with those with poor to no social support [15]. This is especially relevant in the context of the external locus of control often expressed by PWEs. Persons with good social support usually have an increased sense of control over their lives, enabling them to have better coping mechanisms for handling adversity [16]. The South Carolina Health Outcome Project on Epilepsy was a prospective cohort study of PWEs wherein 8 stigma questions modified from the Stigma Scale [17] were used to assess internal and external stigma. The study concluded that PWEs with the highest level of social support had significantly lower reported stigma scores [18]. Another population study examined the association between social support and epilepsy utilizing the 2003 California Health Interview Survey and found that PWEs who reported lack of affectionate support were significantly more likely to self-report fair-to-poor health status. This study also found higher levels of social support among persons completing college degrees, with annual incomes greater than \$50,000 per year, and those who were married [14]. Whatley and colleagues studied 147 patients with epilepsy and found a negative correlation between depressive symptoms, stigma, and quality of life and a positive correlation between social support and quality of life [19]. Another study of 89 patients confirmed the strong correlation between existing social support and quality of life of patients with epilepsy [20].

The association between poor social support and not being married is an important finding given that PWEs are more likely to report never being married compared with persons without epilepsy [21]. Marriage can provide financial resources, assistance with medical care, transportation, promotion of a healthy lifestyle, and stability. However, marital stress has been reported among families with a PWE [22].

The importance of good social support has been validated in other cultures. A recent study by Elafros and colleagues examined the effects of a peer support group meeting monthly consisting of men, women, and youth with epilepsy in Zambian clinics over the course of a year. Utilizing peer support groups has been shown to decrease internalized stigma, and youths who attended at least 6 meetings demonstrated significantly less stigma [23].

It is important for health-care professionals to pay attention to a patient's perception of those factors that contribute to their mental and physical wellness. In one such study in which 210 patients were surveyed, in decreasing order of importance, "psychological distress", "loneliness", "adjustment and coping", and "stigma perception" appeared to contribute most significantly to quality of life as judged by the patients themselves. Interestingly, none of the clinical variables listed (seizure onset, seizure frequency, AED side effects) seemed to significantly influence these patients' assessments of their quality of life [24].

## 2.3. Education and intellectual functioning

While intellectual disability occurs in approximately 0.9% of the general population, it has been estimated that 16 to 50% of PWEs have some degree of cognitive dysfunction [25,26], the degree of which is often proportional to the severity of epilepsy as well as decreased social integration and higher rates of institutionalization [27–29]. Cognitive

impairment has been ranked as one of the most significant problems associated with having epilepsy [30]. Memory deficits are the most common problem, which range from mere forgetfulness to obvious psychomotor retardation [31]. Approximately 25% of PWEs have learning disabilities [32]. The causes of these disabilities are multifactorial, but underlying brain pathology in the setting of epilepsy is a major cause. Persons with temporal lobe epilepsy have decreased gray matter thickness, which is associated with memory difficulties and cognitive impairment [20,33]. Cognitive impairment has been seen in children prior to the onset of developing seizures [34]. In addition to anatomic brain abnormalities contributing to cognitive dysfunction, the effect of AEDs on cognitive function must also be addressed [35], especially because persons with existing cognitive impairments are frequently found to be taking AEDs [36]. Cognitive impairments such as reduced attentiveness, memory difficulties, and slowed mentation have been associated with a variety of AEDs [37]. This is compounded when PWEs are taking multiple AEDs to control their epilepsy. These elements are important when one considers that approximately 25–50% of children with epilepsy have educational difficulties [38] resulting in lower graduation rates from United States (U.S.) high schools compared with the national average (63% versus 81.7%) [39].

## 2.4. Psychological comorbidity

In recent years, it has become apparent that depression and mood disorders, as well as anxiety disorders, are significant comorbidities encountered in patients with epilepsy that significantly impair quality of life. Depression is much more prevalent among patients with epilepsy compared with the general population. Data from the Canadian Community Health Survey estimated that the lifetime prevalence of major depression in the population with epilepsy was 17.4% compared with 10.7% in individuals without epilepsy [40]. In a review article, Kanner and Palac indicated that up to 80% of individuals with epilepsy report having feelings of depression and that endogenous depression has been diagnosed in up to 40% of patients seen in epilepsy centers [41].

Anxiety disorder is also frequently encountered among PWEs. Tellez-Zenteno and colleagues [40] estimate a lifetime prevalence of anxiety disorder in 22.8% of PWEs compared with 11.2% among individuals without epilepsy. Likewise, adults with epilepsy are twice as likely to report anxiety in the previous year compared with those without epilepsy [42].

Several demographic and clinical variables appear to be associated with the occurrence of mood disorders in the population with epilepsy. Kimiskidis and colleagues studied the association between scores on the Beck Depression Inventory on 201 individuals with epilepsy and various clinical and demographic data. The authors showed that the presence of symptomatic focal epilepsy and high seizure frequency was associated with depression [43]. When using the Center for Epidemiologic Studies Depression Scale, Ettinger and colleagues showed that being depressed was associated with a younger age, female gender, and having a lower income [44].

Many reasons have been postulated as to why epilepsy and depression are closely associated conditions. These range from neurobiological causes such as the site of seizure origin and the presence of various neurotransmitter abnormalities such as biogenic amine depletion to psychosocial reasons such as feelings of learned helplessness, sexual dysfunction, and the frustrations encountered by individuals with epilepsy in education, employment, and family life [45].

Studies have shown that adequately treating depression in the population with epilepsy is vital in helping patients optimize their quality of life. When asked to list their main concerns related to living with seizures, 33% of patients with epilepsy indicate the occurrence of depression and other mood problems [46]. Aside from its effects on worsening quality of life, depression among patients with epilepsy has been associated with poor seizure control and a heightened perception of seizure severity [47]. Depressed patients with epilepsy also have

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