

## The quality of life of epileptic patients

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### ABSTRACT

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*Univ Med 2008; 27: 194-203*

Epilepsy has historically been surrounded by prejudice and myth, and associated with many misconceptions. Even today, people with epilepsy experience psychosocial problems, especially in their relationships and employment. Age, seizure severity and frequency, stigma of epilepsy, social deprivation, fear and anxiety, factors responsible for inadequate treatment, treatment gap, and healthcare needs may affect the quality of life of epileptic patients. Improving the diagnosis, treatment, prevention, and social acceptability are important factors in achieving the objective of the management of epilepsy. Treatment of epilepsy refers to any intervention that is intended to restore health status including quality of life. Quality of life is recognized as an important outcome in epilepsy treatment. Quality of life has been reported to vary across epileptic patients with different clinical, demographic, and socio-economic variables. Seizure type and frequency have been found to be significant predictors of quality of life scores. For measuring quality of life in clinical practice, such as in epileptic patients, a wider range of properties is required to ensure that a measure can be used routinely. These include validity, appropriateness and acceptability, reliability, responsiveness to change, and interpretability.

**Keywords:** Quality of life, epilepsy, stigma, anxiety, treatment gap

### INTRODUCTION

Epilepsy is the most common serious neurological disorder affecting people with intellectual disabilities (mental retardation), with prevalence ranging from 20-40%, 30 times higher than the general population rate. Three-quarters of affected individuals in the general population become seizure free on anti-epileptic drug (AED) therapy. On the other hand, epilepsy

in people with intellectual disabilities is more difficult to manage, although clinical guidelines have recently been developed by a working group of the International Association for the Scientific Study of Intellectual Disability. Chronic epilepsy may also be associated with psychiatric, behavioral and socioeconomic sequelae, and with increased risk of hospitalization and failures of community care. It is particularly important, therefore, to

understand the functional and behavioral consequences of epilepsy in this population.<sup>(1,2)</sup>

Quality of life (QOL) is recognized as an important outcome in epilepsy treatment, and various instruments have been developed to assess QOL in epilepsy. The last 20 years has seen an increased interest in identifying the factors that affect QOL for individuals with epilepsy. The great majority of this research has focused on the impact of medical interventions on QOL. At the same time, increased understanding has developed regarding the significant impact that physical, social, and psychological factors make on the QOL and life satisfaction of people with epilepsy. In an effort to better understand the relationships of the physical and psychosocial factors to each other and to QOL among people with epilepsy, the authors developed and evaluated an exploratory model. The results have implications for rehabilitation professionals who work with people with epilepsy.<sup>(3)</sup>

Typically, studies exploring the impact of epilepsy treatments on QOL compare the mean score of instruments among various treatment groups and assess whether the differences are statistically significant. However, it is difficult to interpret the importance of mean changes in QOL, regardless of their statistical significance. This is because aggregate data group convey no information about the number of individuals in a group who experience clinically important change. For example, when the mean change for the group is not statistically significant or when it is lower than a prespecified minimum threshold, clinicians may erroneously conclude that the treatment has no important effects.<sup>(4,5)</sup>

QOL has been reported to vary across epileptic patients with different clinical, demographic, and socioeconomic variables. With regard to clinical variables, seizure type and frequency have been found to be significant predictors of QOL scores. The role of

demographic variables such as age, sex, and education, as well as socioeconomic status in determining QOL is less clear. In some studies age, sex, and education did not correlate significantly with the QOL. Several studies have highlighted that patients with epilepsy are more likely to be underemployed or unemployed, and have lower rates of marriage.<sup>(5,6)</sup> Many factors influence the QOL of people with epilepsy, including impact of age and seizures, stigma, social deprivation, fear and anxiety, the presence of cognitive or psychiatric problems, and others.<sup>(7)</sup> Bishop and his colleagues also concluded from their study that epilepsy has a broad impact on a patient's life, cutting across interpersonal, intrapersonal, and extrapersonal domains.<sup>(8)</sup>

Referring to the above description, the following discussion will focus on the tendencies of decreased QOL of epileptic patients. Understanding such phenomena will help physicians to do appropriate and comprehensive management of epileptic patients. The purpose of epilepsy management is not merely to maintain the patient free of seizures but also to keep the QOL of the epileptic patients as defined by the World Health Organization (WHO).

### **General considerations**

According to the definition of the WHO, "Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity." A disturbance of health can affect all or some aspects or subsets covered by this definition. Treatment refers to any intervention that is intended to restore health.<sup>(9)</sup>

The International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE), and the WHO in June 1997 launched the global campaign against epilepsy. The major objective of this campaign is to bring epilepsy

“out of the shadows” by improving the diagnosis, treatment, prevention, and social acceptability of this worldwide disorder, especially in developing countries. It also looks for “a removal of barriers to a better QOL for those with the disease”.<sup>(9,10)</sup>

People with epilepsy living in Europe or in North America have significant impairment in their QOL. Seizure severity and frequency and AEDs appear to be particularly problematic.<sup>(10,11)</sup> QOL is impaired in Tunisian people with epilepsy. A prospective study was conducted of patients with refractory epilepsy being admitted to an inpatient video-EEG monitoring unit. The impact of clinical variables (age, sex, marital status, seizure frequency, duration and type of seizure disorder, seizure localization, number of AEDs, depression) on QOL was analyzed. This study showed that depression was a powerful predictor of QOL.<sup>(12)</sup> The influencing factors differ from the previously published data. Several possible reasons such as family support and cultural and religious beliefs are proposed to explain the cross-cultural differences.<sup>(13)</sup> Meanwhile, epidemiologic data on QOL of epileptic patients in Indonesia are not yet available.

### Measurement of QOL

The underlying reason for using QOL measures in clinical practice is to ensure that treatment plans and evaluations focus on the patient rather than the disease. QOL is not the only way to measure patient-centered outcome; measures of disability, social interaction and support, and psychological wellbeing may be also appropriate. QOL measures are no substitute for measuring outcomes associated with disease but are an adjunct to them.<sup>(14)</sup>

QOL measures have eight potential uses in aiding routine clinical practice. They can be used to prioritize problems, facilitate

communication, screen for potential problems, identify preferences, monitor changes or response to treatment, and train new staff. They can also be used in clinical audit and in clinical governance. The first five of these items are of immediate value in clinical encounter, while the last three contribute to training, reviewing care, and improving care in the future.<sup>(14)</sup>

The Danish QOL Survey is based on the philosophy of life known as the integrative quality-of-life (IQOL) theory. It comprises eight different quality-of-life concepts, ranging from the superficially subjective via the deeply existential to the superficially objective. Definitions of what makes up a good life are bound to be subject to numerous and diverging interpretations. The IQOL theory states that the QOL emanates from (1) well-being “*how are you feeling now?*”, (2) satisfaction with life “*how satisfied are you with life now?*”, (3) happiness “*how happy are you now?*”, (4) meaning in life “*how meaningful is your life now?*”, (5) inner balance and biological order “*how balanced (your inner equilibrium and state of health) are you now?*”, (6) realizing life potential “*how well are you realizing your deepest dreams and desires now?*”, (7) fulfillment of needs “*how well are your needs being fulfilled now?*”, and (8) objective factors (ability, societal norms) “*how many of the following societal norms do you fulfill now?*”.<sup>(15)</sup>

The objective QOL comprises all nonsubjective aspects of life related to external status and achievement, measured in terms of the norms that are dominant in the culture of the respondent. As theories of objective QOL typically tend to be theories of lists, in which many things and qualities a person ought to possess are enumerated, such a list was also constructed. It is possible to make many other lists. However, as stated in the methodological criteria, these lists must be based on the theory or overall philosophy of life.<sup>(15)</sup>

In line with the measurement of QOL, epilepsy-related quality of life (ERQOL) is assessed with administration of the Quality of life in epilepsy (QOLIE)-31. This instrument was developed by Cramer et al, derived from the longer QOLIE-89 developed by Devinsky et al. The QOLIE-31 is a self-administered questionnaire designed for completion by the patients themselves. This instrument includes 7 of the 17 QOLIE-89 subscales, i.e. seizure worry, overall QOL, emotional well-being, energy-fatigue, cognitive functioning, medication effects, social function, and health status. Responses can be scored to provide subscale scores and a total score. Higher scores represent better function.<sup>(4,16)</sup>

For measuring QOL in clinical practice, such as in epileptic patients, a wider range of properties is required to ensure that a measure can be used routinely. These include validity (does the instrument measure what it is intended to measure, such as QOL?), appropriateness and acceptability (is the measure suitable for its intended use?; this is crucial in clinical practice), reliability (does the measure produce the same results when repeated in the same population?) responsiveness to change (does the measure detect clinically meaningful changes?; this is sometimes called sensitivity) and interpretability (can results from the measurement be interpreted clinically and are they relevant?).<sup>(14)</sup>

### **Impact of age, seizure severity and frequency**

Patient age was inversely related to QOL in the areas of physical functioning and physical role limitation.<sup>(17)</sup> The location, type, and frequency of seizures may contribute to psychosocial problems. Seizures may affect the temporal lobes or limbic structures, which are crucial areas for emotions and coping, as well as cortical areas, which are necessary for cognitive and physical functioning. Studies

have demonstrated that frequency and type of seizure injuries correlate with seizure severity and frequency. Patients often report that complex partial seizures in which the patient is partially aware of altered emotions, hallucinations, experiential phenomena, or behavior are especially frightening. Patients with more frequent seizures experience the greatest burdens; their healthcare costs are five times greater than those of patients with well-controlled seizures. Greater seizure severity was also correlated with poorer QOL in many studies of adolescents and adults. However, even patients with well-controlled seizures report that their condition affects their life in many ways.<sup>(16)</sup> As seizure frequency increases, patients showed more impaired QOL in the areas of physical functioning, vitality, general health, mental health, and social functioning.<sup>(17,18)</sup>

The above description indicates that older age and frequency as well as severity of seizures have a significant impact on QOL and healthcare costs of the epileptic patients. Those variables should be considered properly in the management of epileptic patient.

### **Stigma of epilepsy**

Epilepsy has historically been surrounded by prejudice and myth, and associated with many misconceptions. Even today, people with epilepsy experience psychosocial problems, especially in their relationships and employment. These problems are usually not directly related to the severity of the seizures, but are based on misconceptions about the condition. There is a vicious circle concerning attitudes towards people with epilepsy. The negative attitudes and fear displayed by the public and employers towards people with epilepsy lead them to continue to conceal their diagnosis. This in turn makes changes to the social attitudes and increased acceptance of people with epilepsy a slow process. These

problems are universal but are greatest in the developing world where a majority of the patients with epilepsy receive no diagnosis or treatment. Education plays a key role in increasing professional knowledge about epilepsy as a treatable brain disorder and in reducing, and ultimately preventing, social exclusion of patients with epilepsy.<sup>(19)</sup>

Stigma and factors that contribute to it should be addressed as the top priority in epilepsy self-management and advocacy. These factors include (a) lack of awareness, (b) lack of timely, complete, and accurate information, (c) misperceptions, (d) the broad, varied spectrum of disability among people with epilepsy, (e) over-concern about safety and over-protection limiting choices and options, (f) social tolerance for stigma and discrimination, (g) insufficient research on stigma and psychosocial aspects of epilepsy, (h) liability concerns, and (i) fear.<sup>(19)</sup> Mielke et al. in their study showed that people with epilepsy face various psychosocial challenges, including such simple functions as getting from one location to another and maintaining employment even when seizures are well controlled.<sup>(20)</sup>

Stigma of epilepsy is constructed by misconception about the condition amongst the community, not limited to lay people, but also in the well-educated groups. This misconception can be waived by continuous counseling either by direct activities or dialogue, such as seminars, symposia, and small-group discussions, or by indirect action, i.e. leaflets, flyers, daily new papers.

The effect of stigma, which is somewhat cross-cultural, has also been reported in studies among epileptics in Nigeria.<sup>(21)</sup> In Nigeria, epilepsy is associated with shame and social isolation, and patients often present late for hospital care. Most patients would have visited traditional and religious healers before finally presenting for orthodox medical care, and

indeed, many combine the various treatment modalities. This practice often affects patients psychosocial functioning, resulting in low QOL.<sup>(22)</sup>

### **Social deprivation**

The relation between illness, health and social deprivation has been well documented. Previous studies dating from nearly 60 years ago have shown that this finding remains valid for psychiatric illness, although there is debate as to the direction of causality and whether the relation is specific to diagnosis.<sup>(23)</sup> Patients with epilepsy tolerate higher levels of unemployment than the general population and it would be expected that this will impact on deprivation. Unemployment is regarded as a key variable in all deprivation indices and has been identified independently as a strong indicator of health need. Patients with epilepsy are also more likely to have unskilled jobs and consequently to be of lower social class. It is likely therefore that a positive association between epilepsy and social deprivation will exist, which may be increased by the confounding effect of psychiatric illness and learning disability. Epilepsy is well documented as a comorbidity of both these conditions.

### **Social relationship and community living**

Epilepsy is associated with a wide range of markers of social and economic disadvantage, including poor academic achievement and low income. Because of this association, it is often assumed that people who are socially and economically deprived are more likely to develop epilepsy. This hypothesis is supported to some extent by the observation that the incidence of epilepsy is higher in developing countries than in developed countries.<sup>(24)</sup>

Epilepsy can affect the way a person develops healthy relationships and independent living skills (Box 1).



**Box 1. Issues in social relationships and community living for patients with epilepsy<sup>(7)</sup>**

1. Personal adjustment to epilepsy
2. Sexual issues
3. Education and employment
4. Recreational opportunities
5. Disclosure of epilepsy to employers
6. Stigma and discrimination
7. Independent living
8. Transportation
9. Respite care

These social issues, or indirect costs, can have greater impact than the direct costs of medical care. Many patients and family members say “It is more than just the seizures” when explaining the challenges of living with epilepsy. Community resources can address the burden of living with epilepsy from broader perspectives, helping people identify their strengths and available sources of support. State vocational rehabilitation departments, local epilepsy centers, and Epilepsy Foundation affiliates can provide a range of employment assistance, support services, information, case management, and educational programs.<sup>(7)</sup>

The background of social deprivation related to epilepsy comprises misconception about the condition as well as the consequences of the illness. Social deprivation can be minimized by proper management of the patients and providing sheltered workshops or vocational rehabilitation for the patients according to their capacities and disabilities. Local epilepsy centers, organizations for epileptic patients, and epilepsy foundations will be useful to assist the patients in closing their gaps in social relationships and community living.

### **Fear and anxiety**

For people with epilepsy, fear can be enormous and often is overlooked. In the survey of Fisher and associates, 45% of respondents listed fear as the worst thing about living with epilepsy.<sup>(25)</sup> In addition, Austin identified fear and anxiety as common in children with new-onset seizures. Patients may fear dying during a seizure, suffering brain damage, having a seizure in public, losing control, or losing their friends, their driver’s license, or their job. Women with epilepsy may fear for their safety during or after a seizure. In addition, they may wonder about their ability to successfully bear or rear children; unfortunately, many women with epilepsy are still erroneously advised not to have children.<sup>(26)</sup>

The psychological impacts of seizures are fear and anxiety which disturb the patients’ activities of daily living. In the long run, fear and anxiety may worsen the QOL of epileptic patients.

### **Factors responsible for inadequate treatment**

Various studies in developing countries have shown that many constraints and difficulties hinder the adequate treatment of epilepsy. These factors are not restricted to one particular social sector but exist in the economic, political, and cultural frameworks of societies. Different perceptions and understanding, lack of prioritization, lack of infrastructure and structural adjustment programs, supply of anti-epileptic drugs, and choice of drug are the prominent factors responsible for inadequate treatment in developing countries.<sup>(27)</sup>

Cultural beliefs vary from country to country and may influence individuals’ health-seeking strategies. For example, people may not seek treatment with AED if epilepsy is not seen as a condition that can be treated by western medicine. This is equally true of people in both

industrialized and developing countries. Despite its importance and the existence of an often-effective remedy, epilepsy is not generally recognized as a public health priority. Where there are low budgets for health, resources are inevitably prioritized for conditions perceived to be more important than epilepsy, such as infectious diseases. Lack of infrastructure and structural adjustment programs are linked to and may further accentuate the lack of priority. Supply of AED is an important factor. Ideally, the choice of AED for each patient should be based on seizure type and/or syndrome as well as the individual person's needs. Unfortunately, in most developing countries both the choice and supply of drugs are limited. Phenobarbitone has become WHO's front-line AED in developing countries, where it is the most commonly prescribed AED. Phenytoin, carbamazepine, and valproate are up to 5, 15, and 20 times as expensive, respectively. Questions have, however, been raised about its suitability with respect to its efficacy and the profile of adverse effects. Indeed, ILAE commissions have argued that the WHO list of essential drugs needs to be discussed further, as the status of phenobarbitone seems to be based on economic factors rather than on efficacy and suitability.<sup>(27)</sup>

There are various factors responsible for inadequate treatment, ranging from a simple reason such as individual noncompliance in taking AED to a complicated situation involving socio-cultural, political and economical aspects. These factors should be considered in the management of epileptic patients.

## **POTENTIAL REASONS FOR THE TREATMENT GAP**

### **Level of health care development**

The level of health care development is important because it influences knowledge

about the true nature of the problem and its potential solutions. It also influences the means to reduce the treatment gap. Whether the means available will be sufficient depends on the demand. Thus it might be argued that health care should be primarily directed toward prevention. However, in the first place, the prevalence of symptomatic epilepsies is less than one third of all cases. Not all symptomatic cases are attributable to preventable causes, such as deficient perinatal care or cysticercosis. It should also be stated that before the effects of prevention are felt, incidence cases, which occurred before prevention became effective, will have on average a duration of 13 years (the ratio of prevalence over incidence data). Therefore closure of the seizure treatment gap remains a high priority.<sup>(9)</sup>

### **Culture beliefs**

Cultural values affect people's health-seeking strategies. If people see epilepsy as caused by something that is not natural or biomedical, then treatment through western medicine may not be sought.<sup>(28)</sup> Such beliefs may mean that people with epilepsy seek treatment by traditional or faith healers or that continued compliance with AEDs is difficult to obtain. These decisions may be rational within these people's cultures, but they may also lead to epilepsy being untreated or not treated successfully. It should also be mentioned that levels of literacy and knowledge will impinge on cultural beliefs insofar as choices arising from alternative beliefs, or evidence to back up choices, are limited if the means of communication and acquiring background knowledge are restricted.<sup>(29)</sup>

### **Economy**

As some of the sections concerning health care and financial coverage for each region indicate, the provision of AEDs through

government-funded schemes may in some cases be impossible. It should also be stated that many developing countries' health sectors are hindered by World Bank structural adjustment programs, so that what little income they have is spent on debt repayment rather than on health expenditure. Although this is not the only sector to be adversely affected.<sup>(9)</sup>

### **Distance from health facilities**

The problem of distance from health care facilities is in fact a problem of the know-how available at the community health care level. It has been shown that a reasonable level of seizure treatment can be achieved by primary health care workers. However, notwithstanding the objections to vertical programs, sufficient back-up for the primary health care workers should be available to give epilepsy care its proper place among their many other duties. Some participants argued that epilepsy care would be better off, if undertaken by community-based rehabilitation programs.<sup>(2)</sup>

### **Supply of AEDs**

Distance may also play a role in the lack of a sustained supply of prescribed AEDs. AEDs are used to prevent or interrupt seizures.<sup>(30)</sup> The majority of developing countries also have an extremely limited choice of drugs, with newer AEDs being mostly unavailable. However, the reasons for this are more based on income (both personal and government) and inequalities than on geography and distance. The problem is compounded by the evil of counterfeit drugs.<sup>(9)</sup>

### **Lack of prioritization**

Although epilepsy is an important factor in the burden of neurologic and noncommunicable disease and effective treatment often exists, it is not generally recognized as a public health priority. Epilepsy has to compete with many

other conditions and illnesses. Such competition is even harsher where there are low health budgets, so that resources are prioritized for conditions perceived to be more important, such as malaria, HIV/AIDS, tuberculosis etc. Although not wanting to detract from the scale of such communicable diseases, it may be more cost-effective to treat epilepsy than to treat these other conditions.<sup>(9)</sup>

Political will of the national as well as local government is needed to solve this problem. Such political will can be initiated by the Ministry of Health (as a national policy) and then implemented by the primary, secondary and tertiary health care. The political will should have comprehensive matters such as diagnostic, therapeutic and restorative services.

### **Identification of healthcare needs**

Successful management of epilepsy involves many factors (Box 2). Patients and families should be taught basic skills, such as observing and recording seizures, managing adverse drug effects, identifying and managing stress and other triggers, and maintaining personal safety. The ability to record seizures and identify triggers may lead to behavioral or lifestyle changes that improve seizure control. It is vital that both physician and patient understand medication management issues, such as identifying optimal times to make medication or dosage changes and knowing how to respond to adverse effects and how to enhance compliance. Physicians handling epileptic patients with uncontrolled seizures may have to consider many factors when choosing or changing treatment. Women have unique issues because their epilepsy and general health needs vary across their life span; they depend on primary care physicians to assist in coordinating care across many specialties.<sup>(7)</sup>



**Box-2. Healthcare issues for patients with epilepsy <sup>(7)</sup>**

1. Coping with the diagnosis
2. Observing and recording seizures
3. Identifying potential triggers and high-risk times
4. Maintaining personal safety
5. Handling seizures emergencies
6. Managing adverse drug effects
7. Understanding the nonmedical options for seizure management
8. Managing concomitant illness
9. Understanding the relationship between seizures and hormonal states
10. Practicing family planning
11. Managing pregnancy and menopause
12. Maintaining bone health

## CONCLUSIONS

The QOL of epileptic patients tend to be poorer compared with healthy people. The background of such tendencies consists of age, medical, socio-cultural, economical, psychological, political and geographical aspects. Hence, management of epileptic patients should be based on a comprehensive and integrated intervention in line with the achievement of health status as defined by the WHO. Successful management of epilepsy involves many important factors such as early diagnosis, choosing the appropriate AED, compliance in taking AED, and social acceptability. However, QOL is a highly individual concept rather than that of a group or community.

In addition to the successful management of epileptic patients, the following issues are important and should be kept in mind: age, sex, stigma of epilepsy, frequency and severity of seizures, fear and anxiety, social deprivation, factors responsible for inadequate treatment,

potential reasons for the treatment gap, and healthcare needs.

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