Quality of life in epilepsy

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Abstract
This article will review the various stressors in epilepsy and disease, treatment and psychosocial factors that may contribute to disrupting daily activities and interfering with lifestyles and interests, that impact on overall well-being or quality of life (QOL). We will introduce the concept of illness intrusiveness in epilepsy that reflects disease- and treatment-induced lifestyle disruptions that compromise QOL.

Overview
Chronic and potentially life-threatening conditions, such as epilepsy, introduce significant psychological challenges and adaptive demands. Affected individuals experience the continuing threat of unpredictable and uncontrolled seizures and prolonged periods of confusion that sometimes follow the occurrence of seizures. These stressors collectively may contribute to disrupting daily activities, interfering with lifestyles and interests, and generally compromising quality of life (QOL). As compared to individuals without the condition, people with epilepsy report a significant personal impact of unpredictable seizures and the effects of seizure management in terms of reduced social opportunities and leisure activities, limitations on activities and ambitions, family dysfunction, memory changes, increased anxiety and depression, and reduced personal control and self-esteem (Shidharan, Radhakrishnan, Ashok, & Mousa, 1986; Aziz, Ali, Frances, Khan, & Hassan, 1994). These can significantly compromise educational, employment and vocational opportunities, as well as health-related quality of life (HRQOL).

In spite of pharmacological or surgical treatment, individuals with epilepsy frequently experience various stressors. Common stressors in epilepsy include unpredictable and uncontrolled seizures with or without loss of awareness, medication side effects, cognitive changes, reduced physical strength and memory, vocational problems, economic strains, inability to drive, dependency on medications or caregivers and/or complications of treatment that are generally believed to introduce significant lifestyle disruptions or limitations (Aziz et al., 1994; Engel, 2000).

Understandably, such disruptions are believed to compromise the QOL extending far beyond the influence of the medical situation alone (Dodrill, Batzel, Queisser et al., 1980; Jacoby, Baker, Steen, Potts & Chadwick, 1996). Given both the chronic nature of epilepsy and its common psychosocial consequences, the goal of clinical intervention with pharmacological or surgical treatment has increasingly been extended beyond the control of seizures to improve QOL as much as possible (Jacoby, 1992).

This article will review disease, treatment and psychosocial factors in epilepsy that compromise overall well-being or QOL.

Quality of life and health-related quality of life
Researchers have long been interested in addressing the concept of quality of life (QOL) in chronic diseases. “Quality of life” is a global and multidimensional concept (Mayou & Bryant, 1993), including physical, functional and psychological states, social interaction and somatic sensation (Schipper, Clinch, & Powell, 1990; Wagner, Keller, Kosinski, Baker, Jacoby, Hsu et al., 1995). It has been defined and measured in various ways. Over the last two decades, however, researchers in different fields of human study have identified a consistent set of core domains as important determinants of QOL. Initially among the most frequently and consistently identified domains of QOL were those that focused on “objective” QOL, which referred to the circumstances of life, such as availability of higher education, occupational prestige, financial income, owning one’s home, etc. (WHO, 1980). However, over the years, researchers noted that objective QOL indicators did not correlate significantly with “subjective” QOL indicators, such as happiness or distress (Peters, 1995). This led researchers in the “social indicators” movement to move toward an emphasis on so-called subjective indicators of QOL to the exclusion of “objective” indicators of QOL (O’Donoghue, Duncan, & Sander, 1998). This evidence led many in health research to focus on “subjective” QOL, including psychological or emotional health, such as positive and negative mood, relationships and social support that impact on daily activities and functional capabilities (Baker, Smith, Dewey, Jacoby, & Chadwick, 1993).

Epilepsie et qualité de vie
Mots clés: qualité de vie, qualité de vie reliée à l’état de santé, épilepsie, invasion de la maladie

Résumé
Cet article révisera les facteurs de risque de l’épilepsie, la description de la maladie et le traitement incluant l’aspect psychologique qui pourrait entraver les activités journalières tout en altérant le style de vie et le choix d’occupations qui contribuent au bien-être et à la qualité de vie. Nous allons discuter du concept de l’invansion de la maladie (illness intrusiveness) qui se reflète dans les changements du style de vie par l’entremise de la combinaison maladie-traitement qui, en soi, occasionne une diminution de la qualité de vie.
Health-related quality of life (HRQOL) has been described as those aspects of QOL that relate specifically to a person's health (Patrick & Deyo, 1989). Ware (1987) stated that HRQOL is a general measure from the patient's viewpoint that includes social and psychological functioning as well as physical and physiologic aspects of performance. It includes dimensions of physical functioning, social functioning, role functioning, mental health and general health perceptions (Ware, 1987), as well as the “judgment of one's well-being based on consideration of physical, mental, social, and general health status” (Vickrey, Hays, Graber, et al., 1992).

These definitions of HRQOL seem comprehensive and useful. However, including various indices of physical, psychological and social well-being may present some difficulties for the measurement of QOL. The inclusion of health-related stressors as well as subjective well-being within a single concept of QOL presents concerns for researchers who want to delineate how disease and treatment affect QOL.

**Quality of life in epilepsy**

Although the term “quality of life” has been used only in the last decade to identify an important health outcome in epilepsy, considerable attention has long been devoted to psychological and social issues. The QOL of an individual with epilepsy has been proposed to derive from multiple determinants, such as financial status, relationships, housing, recreation, driving or health that encompass the effects of epilepsy on daily activities or functional capabilities, perception of control and depressive symptoms (Baker et al., 1993).

**Depressive symptoms**

Depression is the most common co-morbid condition associated with epilepsy, based on epidemiological studies. Its prevalence in published studies ranges from 20% to 55% in patients with recurrent seizures and three to nine per cent in patients with controlled epilepsy (Lambert & Robertson, 1999). Clinicians have observed the strong association between depression and epilepsy. Mendez, Cummings, and Benson (1986) assessed 175 consecutive patients in an epilepsy clinic, using the Hamilton Depressive Rating Scale, and found that 55% met criteria for depression. Jacoby et al. (1996) conducted a community-based study that used the Hospital Anxiety and Depression Scale and observed that 21% of 168 patients with recurrent seizures reported high levels of depression. O'Donoghue, Duncan, and Sander (1999) used the same scale and showed that from a group of 155 patients in primary care practice in the United Kingdom, 33% of patients with recurrent seizures and 6% of patients in remission had depression. Although these studies have some limitations in methodology, including self-reported diagnoses and potential selection bias, depression is consistently reported to be at least three to 10 times more prevalent in individuals with uncontrolled seizures than the general population (Lambert & Robertson), with overall implications on psychological well-being and perception of QOL.

A study conducted by Lehrner, Kalchmayr, Seres, Olbrich, Pataria, and Aull (1999) investigated 56 consecutive patients with temporal lobe epilepsy. HRQOL and depression were measured with valid and reliable instruments developed for native German speakers. The significant association of depression with HRQOL persisted after controlling for seizure frequency and seizure severity.

Gielliam and Kanner (2002) found a strong negative correlation between Beck Depression Inventory scores and self-reported health status in a cohort of 195 epilepsy clinic patients. In a separate study, Gilliam, Kuzniecky, Meador et al. (1999) found that mood status was the strongest clinical indicator of patients' assessments of their health status in 125 patients one year after temporal lobe surgery. Although these studies showed a significant association of depression with HRQOL in individuals with epilepsy, different generic tools were used to assess depression and HRQOL, and the diversity in methodologies and sample populations across studies and the under-reporting of symptoms of depression by patients and families have important clinical implications in interpreting results or under-diagnosis by clinicians.

**Personal control**

Epilepsy is a disorder characterized by loss of control (Baker, 1996). The experiences of reduced control and uncertainty are central to the subjective experience of patients with epilepsy. This applies to seizures, the associated lack of bodily control and substantial dependencies on medication and significant others (Gehlert, 1994). For many, seizures can occur at any time with little or no warning. The constant threat of a sudden unpredictable loss of control has been thought to comprise a fundamental facet of the condition responsible for significant impairments in HRQOL (Baker et al., 1998; Collings, 1990a, 1990b; Vickrey et al., 1992, 1993, 1995a, 1995b; Wagner et al., 1995; Devinsky, Vickrey, Cramer, Parrine, Hermann, Meador, et al., 1995). Jacoby (1992), using the term “mastery” in the sense of predicting seizures, found that as the feeling of mastery increased, patients worried less about their disease. Mastery was conceptualized as a patient’s general belief that he/she can control the course of his/her life in spite of the medical condition. Two variables were chosen to represent this dimension: locus of control and self-efficacy (Jacoby, 1992).

Amir, Roziner, Knoll, and Neufeld (1999) investigated the role of social support and mastery (measured by locus of control and self-efficacy) as a major psychological mechanism determining the influence of the medical condition of 89 patients with chronic epilepsy (as measured by perceived seizure severity) on their QOL. Mastery was found to mediate the relationship between disease severity and QOL. Social support acted as a mediator between disease severity and mastery. Thus, social support is influenced by disease severity and, in turn, influences the person's sense of mastery, which then influences QOL. The study findings emphasize the possibility of improving QOL in persons with epilepsy by counselling and treatment aimed at reinforcing their self-efficacy and locus of control.

DeVellis, Wallston-Strudler, and Wallston (1980) noted that patients with epilepsy have to contend with lack of control in their lives caused by the random occurrence of seizures and tested the learned helplessness theory of depression in epilep-
sy patients. The central premise of learned helplessness is that uncontrollability over important outcomes produces depression. A group of 289 people with epilepsy was surveyed via a questionnaire assessing seizure-related variables, locus-of-control beliefs and depression. Depression and external locus-of-control variables were conceptualized as indexes of learned helplessness. Regression analyses indicated that dimensions of seizure disorders (perceived controllability/predictability of seizures, severity of seizures, and extent of exposure to having seizures) accounted for the variance in helplessness, corroborating the hypothesis that events that are as aversive as epileptic seizures contribute to feelings of uncontrollability and/or depression.

Lack of control over the disease process is a significant stressor (Devis & Seland, 1987) that compromises self-efficacy and contributes to learned helplessness. Reduced personal control reduces the ability to get the “good” things in life one desires and the ability to avoid the “bad” things one would prefer not to encounter. However, in at least one condition, end stage renal disease (Devis, Binik, Hutchinson, Holomby, Barre, & Guttmann, 1983), control over the disease itself was not an important influence on subjective well-being or emotional distress.

Measuring quality of life in epilepsy

Traditionally, measurement of treatment outcome in epilepsy has been in the realm of the health care provider who usually assesses benefits of treatment by assessing seizure frequency and severity, adverse effects or antiepileptic drug (AED) blood level parameters. However, patients’ perceptions of outcome usually include additional considerations that involve the effects of epilepsy and/or its treatment on daily life. Some of the issues that are especially relevant to the measurement of QOL in epilepsy are loss of awareness during seizures and co-existent memory problems, both of which may influence the accuracy of the reported data. The length of the assessment tool (questionnaire) might also have an impact on the responses for this patient population because fatigue can interfere with responses. A variety of instruments are available for evaluating QOL in the general population.

In epilepsy, researchers and clinicians have developed and utilized various QOL measurement instruments, including generic (Bergner, Bobbitt, Cater, & Gilson, 1981; Ware & Sherbourne, 1992) and disease-specific instruments (Cella, Sarafian, Snider, Yellen, & Winicour, 1993; Vickrey, Hays, Rausch, Sutherland, Engel, & Brook, 1994). Generic HRQOL instruments include the Sickness Impact Profile (SIP) (Bergner et al., 1981), Nottingham Health Profile (NHP) (Hunt, McKenna, McEwen, Backett, Williams, et al., 1985) and Short-Form-36 (SF-36; Ware & Sherbourne, 1992). The main advantages of generic tools are comprehensiveness, broad applicability (allowing comparisons across patient populations), and the gained knowledge about their measurement properties from extensive use in a variety of populations. However, the major disadvantages are lack of emphasis on specific aspects of patient conditions, and possible inability to detect clinically important changes.

Essential for the formulation of epilepsy-specific HRQOL instruments was the early recognition that epilepsy imposes adaptive challenges and coping demands that, if not dealt with effectively, can produce distress and unhappiness. As early as 1960, Lennox discussed the impact of epilepsy on the patient’s life, family, overall behaviour and vocation. Two decades later, Dodrill et al. (1980) developed the Washington Psychosocial Inventory (WPSI), the first comprehensive 132-item self-administered psychosocial instrument specific for individuals with epilepsy. However, the WPSI is a long instrument, which may lead to fatigue and response burden, failing to detect small, but clinically important changes in response to therapy. However, this instrument paved the way in developing HRQOL instruments in epilepsy.

Over the years, the importance of measuring patient status outcomes and overall well-being in epilepsy resulted in the development of epilepsy-specific HRQOL instruments. A concerted effort by the Quality of Life in Epilepsy (QOLIE) Development Group (Vickrey, Hays, Hermann, Bladin, & Batzel, 1993; Devinsky et al., 1995) led to the introduction of a number of HRQOL instruments for measuring intervention outcomes in epilepsy. A number of QOL measures assess the impact of epilepsy and its treatment, such as the Epilepsy Surgery Inventory (ESI-55) (Vickery et al., 1992), the widely used 89-item Quality of Life in Epilepsy (QOLIE-89) questionnaire (Devinsky & Cramer, 1993) and its abbreviated versions, the 31-item QOLIE-31, and the 10-item QOLIE-10 (Cramer, Perrine, Devinsky, & Meador, 1998).

All of these scales demonstrate good correlations between their items and the source scale in QOLIE-89, which was developed by adding epilepsy-specific items to a widely used generic instrument, the SF-36. Their usefulness in AED trials (Wagner et al., 1995) and epilepsy surgery has been demonstrated (Vickrey et al., 1995a, 1995b; Wiebe, Rose, Derry, et al., 1997).

Impact of epilepsy treatment on health-related quality of life

Research measuring the impact of epilepsy on QOL has traditionally emphasized illness-related factors, such as seizure frequency and severity, or the evaluation of treatment effectiveness, such as pharmacological agents or surgery, adverse effects of AEDs, or complications of surgical treatment for intractable seizures. Despite effective treatment, epilepsy introduces a variety of psychological and social issues that influence HRQOL. Some studies have revealed that epilepsy has a major impact on employment, social life and sense of well-being of people with epilepsy (Dodrill et al., 1980; Jacoby et al., 1996). Others have highlighted the stigmatization, a sense of “loss of control”, fear of seizures, social isolation and emotional difficulties that can be important problems for people with epilepsy (Hermann, Whitman, Wyler, Anton, & Vanderzwaag, 1990; Baker, Jacoby, & Chadwick, 1996). The most important factor determining the self-reported QOL appears to be the degree of seizure control (Vickrey et al., 1995a, 1995b; Jacoby et al., 1996; Wiebe et al., 2001).

Clinicians and researchers have long recognized that seizure frequency influences the well-being of their patients with epilepsy. Those who are seizure-free with pharmacological...
treatment report HRQOL levels similar to that observed in the general (physically healthy) population (Leidy, Elixhauser, Vickrey, Means, & William, 1999). The end-point used to define efficacy in various AED trials is a ≥50% reduction in seizure frequency. However, rather than complete seizure freedom (Ben-Menachem, Henriksen, Dam, Mikkelsen, Schmidt, Reid, et al., 1996; Gabapentin Study, 1993; Beran, Berkovic, Dunagan, Vajda, Danta, Black et al., 1998; Loiseau, Hardenberg, Pestre, Guyot, Schechter, & Tell, 1986).

Recognizing that complete eradication of seizures often cannot be achieved, there has been much discussion about the degree to which partial seizure reduction may improve HRQOL, especially when baseline seizure frequency has been relatively high (Birbeck, Hays, Cui, & Vickrey, 2002). Some have speculated that a 50% reduction in seizure frequency may not reflect a clinically meaningful improvement in certain contexts (e.g., such as inability to drive a motor vehicle (Chadwick, 1997). Individuals achieving partial seizure control continue to experience reduced personal control, inability to drive or participate in the workforce. Although seizure frequency is the primary criterion used to evaluate the efficacy of AEDs, no consensus exists as to the magnitude of seizure reduction that is required to produce a “clinically meaningful change” or to produce an improvement in QOL.

Surgery for epilepsy often provides patients with significant reductions in seizure frequency. For many patients, temporal lobectomy, the most common form of resective surgery (Wiebe, Blume, Grivin, & Eliasziw, 2001), may result in complete seizure freedom, or only rare, isolated seizures (Engel, Van Ness, Rasmussen, & Ojemann, 1993; Spencer & Inserni, 1991).

Studies that have evaluated the effectiveness of temporal lobectomy in patients with medically refractory seizures have, in general, demonstrated improved psychological functioning due to substantially reduced seizure frequencies or complete seizure control (McLachlan, 1998; Dodrill, Batzel, & Fraser, 1991; Guldvog, Loyning, Hauglie-Hassen, Flood, & Bjornaes, 1991; Vickrey et al., 1995a, 1995b; Rose, Derry, & McLachlan, 1997). However, improved seizure control has not always correlated with patients’ overall well-being and improved HRQOL (Vickrey et al., 1993; Jones, Berven, Ramirez, Woodward, et al., 2002). Differences in practice patterns, cultural viewpoints, sample sizes, methodology, measurement instruments, seizure measurement methods, and the various concepts associated with QOL as it relates to epilepsy contribute to inconsistencies in observations and conclusions. This reinforces, therefore, the need for consistent methods and the use of validated measures in order to compare findings and assess impact of interventions with greater confidence.

Future directions

A substantial body of research findings indicates that a chronic physical illness, such as epilepsy, is often associated with a variety of psychological and social issues contributing to individual’s QOL. Measuring the impact on QOL has traditionally been in the realm of illness-related factors, such as seizure frequency and severity, AED and adverse effects, or in attempted evaluation of the effectiveness of treatment fac-

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