

# Improving quality of life beyond seizure control

Steven C. Schachter

Comprehensive Epilepsy Program, Beth Israel Deaconess Medical Center, Boston, Massachusetts, USA

**ABSTRACT** – More than 50 years ago, Lennox and Markham urged physicians who treated patients with epilepsy to “match modern drug and surgical therapy with practical sociopsychological therapy” and to be “concerned not only with turbulent brain waves but with disturbed emotions”. Indeed, while seizure frequency and severity correlate with quality of life and psychosocial outcomes for patients with drug-resistant epilepsy, numerous other epilepsy-related factors may also be significant determinants. These factors include medical and psychiatric co-morbidities, side effects of therapy, stigma, parental anxiety, employment status, seizure worry, self-esteem and self-mastery. Importantly, these epilepsy-related factors may be amenable to educational or therapeutic interventions, which if successful may benefit patients even without a concomitant reduction in seizure frequency or severity. Therefore, while further research is needed, physicians and other health care providers should comprehensively attend to these factors and refer patients with treatment-resistant seizures, when appropriate, for further evaluation and treatment to improve their quality of life beyond seizure control.

**Key words:** epilepsy, quality of life, stigma, depression, anxiety, self-mastery, employment

Multiple factors determine the quality of life experienced by patients with epilepsy. Two of the most important are the duration of epilepsy and whether seizures are fully controlled (Birbeck 2002, Baker 1998, Baker 1997, Au 2002), especially for patients in developing countries (Nubukpo 2004). Traditionally, physicians have been primarily concerned with eliminating seizures without introducing troubling or disabling therapy-related side effects. However, because many determinants of quality of life in this patient population are independent of or indirectly related to epilepsy-related variables, including seizures (Suurmeijer 2001, Bishop 2003), the quality of life of patients with refractory epilepsy will not be maximized by focusing solely on interventions that reduce seizure fre-

quency and severity. Indeed, this topic has been the subject of many publications as well as a book (Baker 2000). The relative importance of these non-epilepsy factors for any given patient may vary, for example as a function of age (Baker 2001, Devinsky 2005, Martin 2003) or knowledge about epilepsy (Baker 2005).

As pointed out by Lennox and Markham over 50 years ago, physicians who treat patients with epilepsy should «match modern drug and surgical therapy with practical sociopsychological therapy» and be «concerned not only with turbulent brain waves but with disturbed emotions» (Lennox 1953). In this care model, physicians and other health care providers have an important role in improving quality of life for their patients with epilepsy even if their seizures are

---

**Correspondence:**

Steven C. Schachter, MD  
330 Brookline Avenue, K-478  
Boston, MA 02215, United States  
Tel.: 617 667 4460  
Fax: 617 667 7919  
<sschacht@caregroup.harvard.edu>

Presented at the 26<sup>th</sup> International Epilepsy Congress, Paris 2005

refractory to therapy. This goal requires an understanding of the non-epilepsy factors that influence quality of life. Therefore, this paper highlights relevant published findings and suggests the need for additional research of interventions that may positively impact patients' well-being even when complete seizure control is not attainable. The impact of psychiatric co-morbidities on quality of life is discussed elsewhere in this supplement, and the effects of medication side effects and medical co-morbidities, such as sleep disorders (De Weerd 2004, Gupta 2004, Bazil 2003) and infertility (Boro 2003), as well as techniques for assessing quality of life (Privitera 2004, Panayides 2004, Sabaz 2003, Baker 1993, Baker 1994), particularly in patients with refractory epilepsy (Selai 2000), are beyond the scope of this review.

## Social factors

A number of social and interpersonal factors influence quality of life for patients with epilepsy independent of seizure frequency, including social anxiety, stigma, parental anxiety and employment.

### Social anxiety

Baker *et al.* (2005) used the Social Avoidance and Distress Scale (Watson 1969) to measure social anxiety in 70 adolescents with epilepsy and correlated the results with knowledge about epilepsy as measured by the 51-question Adolescents' Knowledge of Epilepsy Questionnaire (Richardson 1974). The investigators found that the level of social anxiety did not correlate with seizure frequency, but was inversely proportional to knowledge about epilepsy, suggesting that increasing knowledge about epilepsy will lower social anxiety in adolescents with medically refractory epilepsy. Consistent with this hypothesis, Snead *et al.* reported the development and initial implementation of a 6-week, structured, psycho-educational group intervention for adolescents with epilepsy and their parents (Snead 2004). Educational topics included medical aspects of epilepsy, healthy lifestyle behaviors, family and peer relationships, understanding self-image and self-esteem, and techniques for stress management. A post-intervention outcome measurement revealed an overall positive trend for improvement in quality of life as measured by the Quality of Life for Adolescents with Epilepsy scale (Cramer 1999) compared with pre-intervention.

### Stigma

As defined by Goffman (1963), stigma is "an attribute that is deeply discrediting". People with epilepsy often encounter stigma, as well as societal restrictions and discrimination, in the course of everyday activities, such as going to school, driving, working, and obtaining insurance

(Jacoby 2004). Jacoby has written extensively on the inter-relationships between stigma and quality of life in patients with epilepsy (Jacoby 2002). The impact of perceived and enacted stigma on quality of life is felt worldwide by people with epilepsy (Baker 1997, Morrell 2002) and may be particularly acute in developing countries (McLin 1995, Khan 2004, Meinardi 2001).

MacLeod and Austin conducted a literature review with a focus on adolescents with epilepsy and concluded that stigma is related to quality of life in this population and may manifest in different ways, including not disclosing the condition (MacLeod 2003). The researchers concluded that interventions should be designed and tested that counter the effects of stigma on individual patients by addressing 1) the lack of knowledge about epilepsy in the general population, 2) self-perceptions of stigma and 3) disclosure management strategies. Baker (2002) found that self-reported level of stigma among adults with epilepsy was predicted by their level of knowledge about epilepsy. Further research should evaluate the role of education in reducing self-reported stigma and the resulting effect on quality of life.

### Parental anxiety

Williams and co-workers assessed the impact of parental anxiety on the quality of life of pediatric patients with epilepsy (Williams 2003). Two hundred parents took the State-Trait Anxiety Scale and completed the 30-item Impact of Childhood Illness Scale, which assesses quality of life in children with a chronic illness from the parents' perspective. Parental anxiety was significantly associated with decreased quality of life, suggesting to the authors that targeted interventions and support such as respite care, parent support groups and increased education about seizure risks and psychosocial development may be helpful. Family-oriented education and counseling was shown in another study to lessen parental anxiety; whether parent- or child-reported quality of life improved was not assessed (Lewis 1991).

### Employment

Employment for adults with epilepsy capable of working is important for self-esteem, self-image and quality of life (De Boer 2005, Schachter 1993). Therefore, physicians should refer unemployed or underemployed patients to employment programs designed for people with epilepsy when possible.

## Psychological factors

In addition to neuropsychological function, several psychological factors influence quality of life, including seizure worry, self esteem and self-mastery.

### Seizure worry

Fisher *et al.* (2000a, 2000b) conducted a community-based survey to assess the concerns of people with epilepsy in the US. Mailings were sent to 2500 people, including 1250 individuals from the Epilepsy Foundation database. Among the 1023 respondents, nearly half reported fear as "the worst thing about having epilepsy". Specific examples included fear of dying, fear that others would witness a seizure, fear of embarrassment in public, fear of losing employment and fear of being involved in an automobile accident.

Loring *et al.* (Loring 2004) administered the 20-item Epilepsy Foundation of America (EFA) Concerns Index (Gilliam 1999) to 115 epilepsy surgery candidates with normal Full Scale IQs, and applied linear regression analyses to identify significant predictors of quality of life as measured by the QOLIE-89 (Devinsky 1995). Seizure worry from the EFA Concerns Index was nearly as predictive of quality-of-life scores as symptoms of depression. Therefore, one might predict that reducing seizure worry would be beneficial to patients. Gunter *et al.* evaluated the impact of a comprehensive, multifaceted disease management program on self-reported quality of life for adult patients with epilepsy (Gunter 2004). Patients randomized to the active intervention showed statistically significant positive changes in Seizure Worry ( $p < 0.001$ ) and Emotional Well-being ( $p < 0.05$ ) compared with the control group.

### Self-esteem

Baker *et al.* (2005) measured self-esteem in adolescents with epilepsy using the Rosenberg Self-Esteem Scale (Rosenberg 1965). Self-esteem scores correlated both with seizure frequency (the higher the seizure frequency the lower the self-esteem score) and with knowledge about epilepsy as measured by the 51-question Adolescents' Knowledge of Epilepsy Questionnaire (Richardson 1974). The medium and high knowledge groups exhibited significantly higher levels of self-esteem than the low knowledge group, suggesting that increasing knowledge about epilepsy in adolescents with epilepsy will improve their self-esteem, including patients who are not seizure-free. Further research is needed to test this prediction.

### Self-mastery

Several studies have evaluated the relationship between quality of life and self-mastery, generally measured by locus of control and self-efficacy. Amir *et al.* studied 88 patients with epilepsy and found that mastery mediated the correlation between disease severity and quality of life, suggesting to the authors that quality of life could be improved by interventions to reinforce self-efficacy and locus of control (Amir 1999). Similarly, Gramstad *et al.* showed that self-efficacy measures were important predictors of perceived emotional adjustment, psychosocial adjustment and quality of life (Gramstad *et al.* 2001). Au *et al.*

evaluated the effect of eight, 2-hour, weekly sessions of cognitive therapy on quality of life (QOLIE-31) (Cramer 1998) in 17 adult patients with at least two seizures per month (Au 2003). Among the 8 patients randomized to active treatment, which emphasized coping skills and stress management, overall quality-of-life scores improved significantly compared to scores of the 9 patients randomized to a wait list control group.

Self-mastery may also improve quality of life by lessening the impact of stigma, and improving adherence to medication regimens, possibly leading to improved seizure control. Dilorio *et al.* tested a psychosocial model of medication self-management among adults with epilepsy based on social cognitive theory that included personal (self-efficacy, outcome expectations, goals, stigma, and depressive symptoms), social (social support), and provider (patient satisfaction and desire for control) variables (Dilorio 2004). Self-efficacy and patient satisfaction explained the most variance in medication management. Social support and stigma were related to self-efficacy.

### Summary

Numerous non-epilepsy factors impact the quality of life in patients with treatment-resistant epilepsy, including medical and psychiatric co-morbidities, side effects of therapy, stigma, parental anxiety, employment status, seizure worry, self-esteem and self-mastery. Physicians may not have sufficient training to provide patients all the assistance they require. For example, nurses may play a critical role in teaching patients self-management skills (Shafer 1999). Resources are available to help ensure that patients receive appropriate education and support (Morrell 2000). Physicians, therefore, should refer patients with treatment-resistant seizures, when appropriate, for further evaluation, treatment, training, or education since successful interventions may benefit patients even without a concomitant reduction in seizure frequency or severity. Indeed, while further research is needed to conclusively demonstrate that quality of life can be improved beyond seizure control, it is, nonetheless, time to practice what we preach (Devinsky 2000). □

### References

- Amir M, Roziner I, Knoll A, *et al.* Self-efficacy and social support as mediators in the relation between disease severity and quality of life in patients with epilepsy. *Epilepsia* 1999 ; 40(2) : 216-24.
- Au A, Chan F, Li K, *et al.* Cognitive-behavioral group treatment program for adults with epilepsy in Hong Kong. *Epilepsy Behav* 2003 ; 4(4) : 441-6.
- Au A, Li P, Chan J, *et al.* Predicting the quality of life in Hong Kong Chinese adults with epilepsy. *Epilepsy Behav* 2002 ; 3(4) : 350-7.

- Baker GA, Gagnon D, McNulty P. The relationship between seizure frequency, seizure type and quality of life : findings from three European countries. *Epilepsy Res* 1998 ; 30(3) : 231-40.
- Baker GA, Jacoby A, Buck D, *et al.* Quality of life of people with epilepsy : a European study. *Epilepsia* 1997 ; 38(3) : 353-62.
- Baker GA, Jacoby A, Buck D, *et al.* The quality of life of older people with epilepsy : findings from a UK community study. *Seizure* 2001 ; 10(2) : 92-9.
- In : Baker GA, Jacoby A, eds. *Quality of life in epilepsy : beyond seizure counts in assessment and treatment*. Reading, U. K : Harwood Academic, 2000.
- Baker GA, Jacoby A, Smith DF, *et al.* Development of a novel scale to assess life fulfillment as part of the further refinement of a quality-of-life model for epilepsy. *Epilepsia* 1994 ; 35(3) : 591-6.
- Baker GA, Smith DF, Dewey M, *et al.* The initial development of a health-related quality of life model as an outcome measure in epilepsy. *Epilepsy Res* 1993 ; 16 : 65-81.
- Baker GA, Spector S, McGrath Y, *et al.* Impact of epilepsy in adolescence : A UK controlled study. *Epilepsy Behav* 2005 ; 6(4) : 556-62.
- Baker GA. People with epilepsy : what do they know and understand, and how does this contribute to their perceived level of stigma? *Epilepsy Behav* 2002 ; 3(6 Supplement 2) : 26-32.
- Bazil CW. Epilepsy and sleep disturbance. *Epilepsy Behav* 2003 ; 4(Supplement 2) : 39-45.
- Birbeck GL, Hays RD, Cui X, *et al.* Seizure reduction and quality of life improvements in people with epilepsy. *Epilepsia* 2002 ; 43(5) : 535-8.
- Bishop M, Allen CA. The impact of epilepsy on quality of life : a qualitative analysis. *Epilepsy Behav* 2003 ; 4(3) : 226-33.
- Boro A, Haut S. Medical comorbidities in the treatment of epilepsy. *Epilepsy Behav* 2003 ; 4(Supplement 2) : 2-12.
- Cramer JA, Perrine K, Devinsky O, *et al.* Development and cross-cultural translations of a 31-item quality of life in epilepsy inventory. *Epilepsia* 1998 ; 39(1) : 81-8.
- Cramer JA, Westbrook L, Devinsky O, *et al.* Development of a quality of life inventory for adolescents : the QOLIE-AD-48. *Epilepsia* 1999 ; 40 : 1114-21.
- De Boer HM. Overview and perspectives of employment in people with epilepsy. *Epilepsia* 2005 ; 46 (Suppl 1) : 52-4.
- de Weerd A, de Haas S, Otte A, *et al.* Subjective sleep disturbance in patients with partial epilepsy : a questionnaire-based study on prevalence and impact on quality of life. *Epilepsia* 2004 ; 45(11) : 1397-404.
- Devinsky O, Vickrey BG, Cramer J, *et al.* Development of the quality of life in epilepsy inventory. *Epilepsia* 1995 ; 36(11) : 1089-104.
- Devinsky O. Quality of life in epilepsy : Time to practice what we preach. *Epilepsy Behav* 2000 ; 1(2) : 89-90.
- Devinsky O. Quality of life in the elderly with epilepsy. *Epilepsy Behav* 2005 ; 6(1) : 1-3.
- Dilorio C, Shafer PO, Letz R, *et al.* Project EASE : a study to test a psychosocial model of epilepsy medication management. *Epilepsy Behav* 2004 ; 5(6) : 926-36.
- Fisher RS, Vickrey BG, Gibson P, *et al.* The impact of epilepsy from the patient's perspective I. Descriptions and subjective perceptions. *Epilepsy Res* 2000 ; 41(1) : 39-51.
- Fisher RS, Vickrey BG, Gibson P, *et al.* The impact of epilepsy from the patient's perspective II : views about therapy and health care. *Epilepsy Res* 2000 ; 41(1) : 53-61.
- Gilliam F, Kuzniecky R, Meador K, *et al.* Patient-oriented outcome assessment after temporal lobectomy for refractory epilepsy. *Neurology* 1999 ; 53(4) : 687-94.
- Goffman E. *Stigma : notes on the management of spoiled identity*. Englewood Cliffs, N. J : Prentice-Hall, 1963.
- Gramstad A, Iversen E, Engelsen BA. The impact of affectivity dispositions, self-efficacy and locus of control on psychosocial adjustment in patients with epilepsy. *Epilepsy Res* 2001 ; 46(1) : 53-61.
- Gunter MJ, Brixner D, von Worley A, *et al.* Impact of a seizure disorder management program on patient-reported quality of life. *Dis Manage* 2004 ; 7(4) : 333-47.
- Gupta M, Aneja S, Kohli K. Add-on melatonin improves quality of life in epileptic children on valproate monotherapy : a randomized, double-blind, placebo-controlled trial. *Epilepsy Behav* 2004 ; 5(3) : 316-21.
- Jacoby A. Stigma, epilepsy, and quality of life. *Epilepsy Behav* 2002 ; 3 (6 Supplement 2) : 10-20.
- Jacoby K, Jacoby A. Epilepsy and insurance in the UK : an exploratory survey of the experiences of people with epilepsy. *Epilepsy Behav* 2004 ; 5(6) : 884-93.
- Khan A, Huerter V, Sheikh SM, *et al.* Treatments and perceptions of epilepsy in Kashmir and the United States : a cross-cultural analysis. *Epilepsy Behav* 2004 ; 5(4) : 580-6.
- Lennox WG, Markham CH. The sociopsychological treatment of epilepsy. *JAMA* 1953 ; 152 : 1690-4.
- Lewis MA, Hatton CL, Salas I, *et al.* Impact of the children's epilepsy program on parents. *Epilepsia* 1991 ; 32 : 365-74.
- Loring DW, Meador KJ, Lee GP. Determinants of quality of life in epilepsy. *Epilepsy Behav* 2004 ; 5(6) : 976-80.
- MacLeod JS, Austin JK. Stigma in the lives of adolescents with epilepsy : a review of the literature. *Epilepsy Behav* 2003 ; 4(2) : 112-7.
- Martin R, Vogtle L, Gilliam F, *et al.* Health-related quality of life in senior adults with epilepsy : what we know from randomized clinical trials and suggestions for future research. *Epilepsy Behav* 2003 ; 4(6) : 626-34.
- McLin WM, de Boer HM. Public perceptions about epilepsy. *Epilepsia* 1995 ; 36(10) : 957-9.
- Meinardi H, Scott RA, Reis R, *et al.* The treatment gap in epilepsy : the current situation and ways forward. *Epilepsia* 2001 ; 42(1) : 136-49.
- Morrell MJ. Caring for people with epilepsy : Resources for the healthcare provider. *Epilepsy Behav* 2000 ; 1(4 part 2) : S21-SS4.
- Morrell MJ. Stigma and epilepsy. *Epilepsy Behav* 2002 ; 3(6 Supplement 2) : 21-5.

- Nubukpo P, Clement JP, Houinato D, *et al.* Psychosocial issues in people with epilepsy in Togo and Benin (West Africa) II: Quality of life measured using the QOLIE-31 scale. *Epilepsy Behav* 2004 ; 5(5) : 728-34.
- Panayides S, Goldstein LH, Mouratoglou V, *et al.* Patient-validated content of a Greek version of the Quality of Life in Epilepsy Inventory (QOLIE-89) combined with individualized measures. *Epilepsy Behav* 2004 ; 5(3) : 367-79.
- Privitera M, Ficker DM. Assessment of adverse events and quality of life in epilepsy : design of a new community-based trial. *Epilepsy Behav* 2004 ; 5(6) : 841-6.
- Richardson DW, Friedman SB. Psychosocial problems of the adolescent patient with epilepsy. *Clin Pediatr* 1974 ; 13 : 121-6.
- Rosenberg M. *Society and the adolescent self-image*. Princeton : Princeton Univ Press, 1965.
- Sabaz M, Lawson JA, Cairns DR, *et al.* Validation of the Quality of Life in Childhood Epilepsy Questionnaire in American epilepsy patients. *Epilepsy Behav* 2003 ; 4(6) : 680-91.
- Schachter SC, Shafer PO, Murphy W. The personal impact of seizures : Correlations with seizure frequency, employment, cost of medical care, and satisfaction with physician care. *J Epilepsy* 1993 ; 6 : 224-7.
- Selai CE, Elstner K, Trimble MR. Quality of life pre and post epilepsy surgery. *Epilepsy Res* 2000 ; 38(1) : 67-74.
- Shafer PO. Epilepsy and seizures : advances in seizure assessment, treatment, and self-management. *Nurs Clin North Am* 1999 ; 34(3) : 743-59.
- Snead K, Ackerson J, Bailey K, *et al.* Taking charge of epilepsy : the development of a structured psychoeducational group intervention for adolescents with epilepsy and their parents. *Epilepsy Behav* 2004 ; 5(4) : 547-56.
- Suurmeijer TP, Reuvekamp MF, Aldenkamp BP. Social functioning, psychological functioning, and quality of life in epilepsy. *Epilepsia* 2001 ; 42(9) : 1160-8.
- Watson D, Friend R. Measurement of social-evaluative anxiety. *J Consult Clin Psychol* 1969 ; 33 : 448-57.
- Williams J, Steel C, Sharp GB, *et al.* Parental anxiety and quality of life in children with epilepsy. *Epilepsy Behav* 2003 ; 4(5) : 483-6.