

Platform Presentation 2 (5007-5012)

Impact of Epilepsy on Health-Related Quality of Life. §J. L. Ribeiro, †§D. Mendonça, †J. Gomes, †L. Gonçalves, and *†§A. Martins da Silva (*Serviço de Neurofisiologia, Hospital de Santo António; †Laboratório de Biometria, ‡Unidade de Fisiologia Humana, Instituto de Ciências Biomédicas Abel Salazar; §Unidade Neurofisiologia e Psicofisiologia do IBMC, Universidade do Porto; and †Faculdade de Psicologia, e Ciências da Educação da Universidade do Porto, Porto, Portugal)—5007.

Quality of Life (QOL) is a broad concept that can be defined as individuals' overall satisfaction with life and their sense of personal well-being. Health is the most important domain in QOL, and in clinical settings health related QOL (HRQOL) is a domain studied in itself. HRQOL (a) is based on personal perception of the patient and not on the perception of relatives or peers or on the opinion of medical staff; (b) includes psychological, social, and physical aspects; and (c) involves either objective and subjective aspects. In an exploratory study, we wished to determine HRQOL in epileptic patients, how HRQOL is affected by epilepsy characteristics, and how HRQOL is affected by personal characteristics of epileptic patients. Our research was started in 1993 in patients followed up at the epileptic outpatient clinic of Hospital Santo António (Porto). The analysis is based on data collected from a sample of 90 patients, men and women aged 15-65 years, who had completed basic education level, and had seizures of various severity levels and types (simple partial, complex partial, myoclonic seizures, generalized tonic-clonic, seizure-free). Data were collected by trained psychologists when patients came to the hospital to undergo routine EEG. The questionnaire was an adaptation of the Medical Outcomes Study Short-Form General Health Survey (MOS-20) and the Epilepsy Surgery Inventory (ESI-55). It includes 33 items, Likert-type response distributed across nine subscales (emotional well-being, role limitations due to disease, pain, physical functioning, health perceptions, cognitive functioning, overall QOL, changes in health).

Self-Control in Epilepsy and Quality of Life. Christiane Schmid-Schönbein (Freie Universität Berlin, UKRV, Children's Hospital, Berlin, Germany)—5008.

Matthews et al. (1982) characterized the so-called "epileptic condition" by three aspects: unpredictability of seizures, overt manifestation of the symptom, and seizure-related loss of control. In particular, the feeling of lack of control over seizure activity represents a serious reduction in quality of life (QOL), as loss of control over seizures often is generalized to other aspects of life. Thus, the feeling of awareness of being in control of seizures must be considered a central aspect of QOL for patients with epilepsy. But what applies to patients with refractory epileptic seizures?

A study in which 20 patients with refractory seizures were trained in self-control (behavioral control of seizures) showed that all patients could improve their "sense of control" during training to a considerable degree; three components of the patients' concept of sense of control could be differentiated. The relations between this seizure-related concept of sense of control and the general concept of perceived internal control/mastery and other psychological variables included in the complex model of health-related QOL by Baker et al. (1993) were assessed.

Development of an Instrument to Assess Quality of Life in Children with Epilepsy and Learning Disability. Gus Baker, †Ann Jacoby, §Tom Berney, †Mike Dewey, *Gwilym Hosking, *Elaine Forret, and David W. Chadwick (Walton Hospital, Liverpool; *The Wellcome Foundation, Kent; †University of Newcastle; ‡Uni-

versity of Liverpool; and §Prudhoe Hospital, Northumberland, England)—5009.

Quality of life (QOL) is recognized as an important outcome measure in clinical trials, and its assessment may be particularly relevant for children with severe seizure disorders, in whom, owing to the nature and frequency of seizures, seizure counts are not always helpful. We developed a brief QOL questionnaire intended for completion by the parents of children with severe epilepsy and based on in-depth interviews with parents and discussion with expert clinicians. The questionnaire consists of novel scales to measure parents' perceptions of seizure severity, adverse drug effects, child's mood and behavior, and single items relating to injuries associated with seizures, overall health, and overall QOL.

The psychometric properties of the scales and items were examined in a pilot study of 50 children with a severe seizure disorder, all of whom had accompanying mental handicap. They had good face and construct validity and good reliability, as assessed by their internal consistency (alpha range 0.71-0.84) and test-retest correlation (r 0.67-0.84). The questionnaire is currently being used in a European clinical trial of the efficacy of lamotrigine in treatment of Lennox-Gastaut syndrome and other severe epileptic disorders of childhood.

New Method for Measuring Quality of Life Based on Repertory Grid Technique. C. E. Selai, A. Kendrick, and M. R. Trimble (Institute of Neurology, The National Hospital, Queen Square, London, England)—5010.

We report a novel technique for quality of life (QOL) measurement based on repertory grid technique. The key feature is that individuals can define the areas they consider relevant to their own QOL. Subjects choose two constructs (items) in the five domains commonly accepted as being relevant to a comprehensive assessment of QOL, i.e., Physical, psychological, social, work/economic, and cognitive.

Within this framework, subjects design their own QOL schedule and rate the items on a 5-point rating scale according to how much a problem each item is for them at the moment. In addition, they are asked to rate other situations and persons in their lives. In this way, a picture is constructed (repertory grid) of their view of their current situation in relation to their past, their expectations for the future, and other persons.

The method measures the subjects' view of their current life situation (NOW) in relation to how far they must progress to achieve their desired state (LIKE). It is suggested that the shorter this distance (NOW-LIKE), the greater the QOL of the individual. QOL data can be provided at two levels: global level (composite score) and individual level (profile).

Preliminary data were obtained in a sample of patients with epilepsy who have elected to undergo temporal lobectomy or other surgical procedures to relieve their symptoms. QOL will be appraised preoperatively and at 3-month follow-up.

Psychosocial Situation of Children and Adolescents with Epilepsy in Parent's Estimation. Margarete Pfäfflin, Joachim Sander, Hans-Erich Boenigk, and *Hans-Helmut Richardt (Epilepsie-Zentrum Bethel and *Kinderklinik Königsborn, Bielefeld, Germany)—5011.

In three outpatient epilepsy clinics, a parent questionnaire was distributed to collect data about variables such as illness-induced stress, knowledgeability of education staff, social integration, and treatment status. In a primary survey, parents of 103 children were questioned (children aged 0-19 years). Results show that parents usually overestimate the success of treatment and underestimate illness-related familiar stress. Results were assessed in terms of strategies used by parents to cope with children's illness, and conclusions were drawn for use in information to be disseminated in outpatient clinics.