

Quality of Life in Patients with Epilepsy. Carlos Cardoso, *Inês Cunha, †Margarida Silva Dias, Rui Durval, *Ana Grilo, Maria João Heitor, Alice Nobre, †Vitorina Passão, and †Ana Sacramento (Psiquiatra do H. Miguel Bombarda, *Psiquiatra do H. Júlio de Matos, †Neurologista do Hospital de St. António dos Capuchos, Lisbon, Portugal)—5028.

Epilepsy and its symptoms tend to be chronic and potentially incapacitating and may lead to physical, psychological, and social deficits that determine impairment of the patient's quality of life (QOL). We studied a population of 56 ambulatory patients, 21 males (aged 15–72 years, median 29) and 35 women (ages 16–59 years, median 39), using a semistructured interview, to assess place of residence, financial situation, general health, family, friends, work, self-confidence, what others think of the person, life, medication, seizures, symptoms, sexuality, and social anxiety. We noted good QOL in 34% of patients, medium QOL in 55% and poor QOL in 11%.

We analyzed the relevance of the selected areas, interview results, and their relation to other variables such as age and sex, marital status, profession, duration of illness, type of epilepsy, pharmacologic treatment, and psychopathology. More specific and accurate instruments to evaluate QOL of epileptic patients must be designed, considering implications at different levels of prevention.

Domains of Quality of Life and Epilepsy. §J. L. Ribeiro, †D. Mendonça, †J. Gomes, †L. Gonçalves, and *†A. Martins da Silva (*Serviço de Neurofisiologia, Hospital de Santo António (Porto); Laboratório de Biometria and, †Unidade de Fisiologia Humana, Instituto de Ciências Biomédicas Abel Salazar, †Unidade de Neurofisiologia e Psicofisiologia do IBMC, Universidade do Porto, and †Faculdade de Psicologia e Ciências da Educação da Universidade do Porto, Porto, Portugal)—5029.

Overall satisfaction of healthy individuals expressed as quality of life (QOL) is influenced by several different domains ranging from physical personal well-being to cultural and social interrelations. The domains affecting this "broad concept" were previously identified by other researchers. To study QOL domains in epileptic persons, we constructed a 16-item Likert-type questionnaire. In an exploratory study, we wished to determine (a) the importance of QOL domains in epileptic patients, (b) how domains of QOL are affected by epilepsy characteristics, and (c) how domains of QOL are affected by personal characteristics of epileptic patients. Research began early in 1993, with patients followed up at the epileptic outpatient clinic of Hospital Geral de Santo António at Porto, and was based on analysis of data collected from a sample of 90 men and women, aged 15–65 years, who had completed the basic education level and had seizures of various severity and type (simple partial, complex partial, myoclonic, generalized tonic-clonic, seizure-free). Patients were interviewed by trained psychologists for 20 min. From patients' answers, we defined the domains of QOL affecting epileptic patients' overall satisfaction and well-being.

Development and Validation of a Health-Related Quality of Life Questionnaire for Persons with Epilepsy. Anita K. Wagner, Mark Kosinski, San Keller, *Gus Baker, †Ann Jacoby, †Ming-Ann Hsu, *David Chadwick, and John E. Ware (New England Medical Center, Boston, MA, U.S.A.; *The Walton Hospital, Liverpool; †University of Newcastle upon Tyne, Newcastle upon Tyne, England; and †Schering-Plough Corporation)—5030.

Epilepsy and antiepileptic drug (AED) therapy have impact on patients' quality of life (QOL). To measure this impact in clinical trials of AED, we evaluated a 172-item patient-completed questionnaire containing previously validated and newly developed measures of general and epilepsy-specific health-related QOL (HRQOL), along with a symptom checklist. Included are the

MOS SF-36 Health Survey; additional mental health items, measures of cognition, epilepsy-specific perception of control, behavior problems, distress, worries and experiences, and the Liverpool Epilepsy Impact and Seizure Severity Scales. Reliability, validity, and patient acceptance were evaluated in a cross-sectional, multicenter study of 136 patients treated with AEDs in the United Kingdom. Mean HRQOL scale scores significantly discriminated among groups of patients differing in seizure control, consistent with hypotheses. Regardless of seizure control, mean HRQOL scale scores were also significantly lower for patients reporting systemic and neurologic symptoms. For further study, we developed a shorter 100-item questionnaire to construct 22 scales, and a 16-item symptom checklist. Use of a reliable and "clinically" valid HRQOL questionnaire will make it possible to estimate the burden of epilepsy and the HRQOL benefits of AEDs. (Supported by Schering-Plough International.)

Novel Scale to Measure the Impact of Epilepsy on Quality of Life. Ann Jacoby, *Gus Baker, and *David W. Chadwick (Centre for Health Services Research, University of Newcastle, Newcastle upon Tyne; and *Department of Neurosciences, Walton Hospital, Liverpool, England)—5031.

The impact of chronic illness on an individual's quality of life (QOL) is experienced not only through physical symptoms, but also as a result of its effect on psychosocial functioning. We devised a novel scale to measure patients' perceptions of the impact of their epilepsy and its treatment on various aspects of daily functioning. The scale is brief, comprising 10 items, selected on the basis of interviews with patients and previous research. Patients are asked the extent to which epilepsy affects particular aspects of their daily life; a simple 4-point Likert scoring system is used, with responses ranging from "a lot" to "not at all."

The psychometric properties of the scale have been demonstrated in two recent studies, one a pilot study of 136 epilepsy patients drawn from two epilepsy clinics and a single general practice in the United Kingdom, the other a community study of 700 people with active epilepsy, undertaken in one U.K. health region. In both studies, the scale showed good validity and high reliability ($\alpha = 0.89$). The scale represents a potentially valuable, simple measure for clinical trials of de novo antiepileptic persons and a useful tool for identification of areas of need for counseling among persons with epilepsy.

Quality of Life in Patients with Epilepsy: Psychology, Neuropsychology, and Medical Aspects. *†Nicole von Steinbüchel, *†Stefanie Krauth, *†Inge Kirchberger, *Monika Bullinger, †Beat Hiltbrunner, *†Ernst Pöppel, †Karl Zander, †Stefan Stodieck, †Gerhard Bauer, †Diana Soucek, †Peter Hiedl, and †Ulrich Scheidereiter (*Institut für Medizinische Psychologie; †Sciencia Gesellschaft für Forschung im Gesundheitswesen, München, Germany; †Ciba-Geigy Limited, Basel, Switzerland; †Forschungszentrum Jülich GmbH; †Zentralklinik, Münster, Germany; †Universitätsklinik für Neurologie, Innsbruck, Austria; and †Neurologische Praxis, Freising, Germany)—5032.

Assessment of quality of life (QOL) in patients with epilepsy is a relatively new issue in epileptology. We report results of a study of 202 patients with epilepsy, 102 treated with carbamazepine (CBZ) and 100 treated with phenytoin (PHT). Study aims were (a) translation and psychometric analysis of 10 generic and disease-specific QOL instruments and four predictors; (b) identification of prerequisites for development of a new comprehensive disease-specific German QOL instrument, and (c) comparison of the QOL status of the two patient groups. Elementary and complex neuropsychological functions (NPSY) were also assessed, as were medical data, with focus on comparison of self- and observer-ratings concerning QOL-related medical aspects.