QUALITY OF LIFE OF PEOPLE WITH EPILEPSY IN ESTONIA

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VI **M. Herodes**, A. Õun, S. Haldre, A.-E. Kaasik. The Estonian version of the Quality-of-Life in Epilepsy Inventory (QOLIE-31): a psychometric assessment and quality-of-life measurement. Medical Care (submitted).

ABBREVIATIONS

AED	antiepileptic drug
ANOVA	analysis of variance
CI	confidence interval
EEG	electro-encephalographic
ESI-55	Epilepsy Surgery Inventory
HAD	Hospital Anxiety and Depression Scale
HRQOL	health-related quality of life
ILAE	International League against Epilepsy
MOS	Medical Outcomes Study
QOL	quality of life
QOLIE	Quality of Life Inventory in Epilepsy
RAND	a contraction of the term research and development
RAND-36	RAND 36-Item Health Survey 1.0
SD	standard deviation
SF	short form
VA	Veterans Affairs
WHO	World Health Organization
WPSI	Washington Psychosocial Seizure Inventory

INTRODUCTION

People with epilepsy usually appear to be physically well but they often suffer social and psychological handicaps impairing their quality of life (QOL). Living with epilepsy necessitates paying attention to more than seizures and the antiepileptic drug (AED) treatment. It is now widely acknowledged that people with epilepsy are as likely to be distressed by social and cultural problems as they are by continuing seizures and also that epilepsy has profound physical, psychological, and social consequences (Scambler and Hopkins, 1980). Although current seizure frequency is one of the most important predictors showing the efficacy of treatment, it is not the only measure, especially from the patient's viewpoint, commonly used in clinical studies of new AEDs (Smith *et al.*, 1993). The effect of any disease is determined by several factors, including underlying biology, as well as host factors and available medical interventions, but also the attitudes and reactions of the surrounding society (Eisenberg, 1997). Assessment of health-related quality of life (HRQOL) is a relatively new concept within the epilepsy area that meshes traditional medical care with psychosocial concerns. Several studies have used HRQOL in epilepsy as an outcome measure and have also used it to give a broader measure of the burden of the disease (Nortvedt *et al.*, 2000). The purposes of addressing the QOL include the improvement of the quality of patient care, differentiating among treatment options, and evaluating the allocation of health care resources. Because of the emphasis on the phenomenological experience of the individual, it is necessary that QOL be determined from the patients' subjective viewpoint, the physicians' viewpoint being deliberately excluded, as the individual patient's perspective has become an integral aspect of health care assessment (Cramer, 1994).

In recent years there have been a number of initiatives to develop QOL outcome measures for epilepsy. Although proven useful in their country of origin, standard scales are not directly applicable across nations due to cultural diversity. In order to use such instruments in a new national context, a thorough translation and testing phase, preceding the inclusion of an instrument in a study, is necessary. Measures also need to be psychometrically tested in a specific cultural context to assure their psychometric soundness (Bullinger, 1995; Mathias *et al.*, 1994; Hunt, 1993). It is generally agreed from the work on QOL to date that the best approach is to use a standard generic instrument with disease-specific additions and much of the work in QOL of adults having epilepsy has followed this approach (Baker, 2001; Chadwick, 1996).

There is a growing awareness of the psychosocial implication of epilepsy. People with epilepsy face social disadvantages not shared by those suffering from other chronic diseases. Psychiatric problems, particularly anxiety, depression, and loss of self-esteem are common among people with epilepsy (Col-

lings, 1994; Baker *et al.*, 1996; Collings, 1990b; Trostle *et al.*, 1989; Dodrill *et al.*, 1984a; Britten *et al.*, 1986). Most patients feel that a prospective employer's knowledge of a diagnosis of epilepsy will make it more difficult for them to get a job (Chaplin *et al.*, 1992). A number of studies have addressed the stigmatising nature of epilepsy and its associated psychological distress (Baker *et al.*, 1997a; Baker *et al.*, 1996; Jacoby, 1994; Baker *et al.*, 1997b; Austin, 1996; Levin *et al.*, 1988). Information on these issues has come mainly from developed countries (Baker *et al.*, 1997a; Jacoby *et al.*, 1996; Levin *et al.*, 1988; Boshes and Kienast, 1970; Bagley, 1972; Rodin, 1972; Zielinski, 1972; Ryan *et al.*, 1980b). Very few studies originate from developing countries (Placencia *et al.*, 1995; Danesi, 1984; Virmani *et al.*, 1977; Aziz *et al.*, 1997) and there is clearly a lack of documented evidence regarding the impact of epilepsy in Eastern Europe (Mirnics *et al.*, 1998; Bielen *et al.*, 2000; Lam *et al.*, 2001).

REVIEW OF THE LITERATURE

1. The problem of epilepsy

Epilepsy is an example of a medical diagnosis that is retained even when signs and symptoms (i.e., seizures) are well controlled and all laboratory tests are normal (Cramer *et al.*, 1996). Jacoby (1992) has described epilepsy as both a medical diagnosis and a social label, which means that there are several psycho-social problems accompanying the disease, therefore, its impact on a person's everyday-life can be significant.

Throughout history, myths and mystery have surrounded epilepsy and people suffering from this disease have been seen as possessing "an undesired differentness" (Goffman, 1963). Though known as "the sacred disease" to the ancient Greeks (Temkin, 1971), epilepsy has more often been associated with negative and pejorative imagery. Across time and different cultures, it has been variously viewed as the outcome of sin, as the product of demonic possession or a form of madness and consequently, as a condition to be feared and rejected (Jacoby and Baker, 2000). When in some societies the seizures are still viewed as contagious or demonic (Rwiza *et al.*, 1993) in western culture the traces of such beliefs are mirrored in reactions of fear toward persons with epilepsy, as well as in discrimination by employers (Krauss *et al.*, 2000). Scambler (1988) hypothesises three dimensions regarding this ambiguity relating to the unpredictability of epilepsy, the dramatic nature of the attacks, and the fear on the part of others of having to cope with a person's seizures.

The possibility of recurrent seizures is a silent but ever-present component of daily life for most patients who carry the diagnosis of epilepsy, creating uncertainty regarding diagnosis, occurrence of seizures, nature of seizures and effectiveness of medication and over the remittance of seizures another defining quality of the disease (Jacoby and Baker, 2000). Thus, epilepsy has sometimes been termed a "silent disability" because for many individuals the QOL limitations, caused by the unpredictable occurrence of seizures with altered awareness or altered sensation and by the side-effects of antiepileptic medications, are underestimated by society (Vickrey, 1995).

At the same time, epilepsy is one of the most common neurological conditions, with an age-adjusted incidence of between 20 and 70 per 100,000 and an estimated prevalence of 0.4 to 1% (Jacoby and Baker, 2000; Bharucha and Shorvon, 1997; Forsgren, 1992; Joensen, 1986; Keränen *et al.*, 1989). World wide, there are around 50 million people with epilepsy (Bharucha and Shorvon, 1997). According to the present available data, originating from Tartu, the estimated prevalence ratio of active epilepsy is 5.3 per 1,000. This means, in Estonia, with a population of approximately 1.4 million people, epilepsy

roughly affects 7950 adults with approximately 530 new cases yearly (Õun *et al.*, accepted for publication-a; Õun *et al.*, accepted for publication-b).

Epidemiological studies have shown that seizures in 70-80% of people developing epilepsy will be well controlled by AED treatment (Sander, 1993) and the disease should not profoundly diminish the quality of everyday life in this group (Jacoby, 1992; Baker *et al.*, 1997a).

Epilepsy is not a single disorder, but a group of disorders in which seizures recur. According to the classification of epileptic syndromes by the Commission of the International League against Epilepsy (ILAE) (1989), there must be taken into account a range of factors including seizure type, neurological history, family history, age of seizure onset and aetiology. The most important subdivision of the epileptic syndromes is between those with a recognisable cause, the "symptomatic" epilepsies and those without, the so-called cryptogenic and idiopathic epilepsies. Also, there are many different types of epileptic seizure. In everyday use, however, clinicians still use one of the simplest solutions. This is the classification by the ILAE Commission (1981) (ILAE, 1981), which divides seizures into those originating from a localised abnormality in the cortex (partial or localisation-related seizures), and those arising from some innate abnormality in the neuronal function (primary or idiopathic generalised seizures) (Leach *et al.*, 2000). Seizures can also be differentiated according to whether or not they involve any alteration or impairment of consciousness. Because different seizures manifest themselves differently, they also vary in the degree to which they present a risk to physical safety, their predictability, response to treatment and the potential to interfere in the everyday-life of the individual (Jacoby and Baker, 2000).

Epilepsy remains a "stigmatising disease". The social stigma is apparent when people speak openly about having cancer, but do not about having epilepsy, even when the seizures are well-controlled (Cramer, 1993). At the same time, an epileptic seizure, unlike hypertension, diabetes, and most forms of heart disease, usually cannot be hidden (Morrell and Pedley, 2000).

Epilepsy is an episodic disorder rather than a condition. The disabling effects of seizures are short-lived, and for much of the time a person's ability to function physically is unimpaired. Regardless of that, it has been found that people with epilepsy are more dysfunctional compared to those in the general population and also even to ones who suffer from some other long-standing illness (Baker *et al.*, 1997a). Adolescents with epilepsy have a higher frequency of behavioural problems than do healthy or chronically ill control groups (Austin *et al.*, 1996; Wirrell *et al.*, 1997; Clement and Wallace, 1990). They also express more worries: adolescents with epilepsy are less interested in competitive sports; others are concerned that epilepsy will prevent them from becoming parents or successfully employed (Rossi *et al.*, 1997). Epilepsy appears to globally affect emotional status (Collings, 1990c; Collings, 1994; Baker *et al.*, 1996). When a group of people with epilepsy was compared to a group of people with diabetes, a chronic but non-neurological disease, and a

group of people with multiple sclerosis that may have an early impact on mobility with some patients becoming wheel chair bound as the disease progresses, the epilepsy and multiple sclerosis groups scored significantly worse than the diabetes group on the criteria describing well-being and emotional status. Despite this the epilepsy group reported better health perceptions compared to the other two groupings (Hermann *et al.*, 1996). When comparing QOL among young people, with inactive or active epilepsy, with that of a similar sample of youths with asthma, which is also an episodic condition that requires daily medication during active treatment, the evaluation showed that the epilepsy group had more problems in the psychological and social domain and, in addition, the youths with epilepsy had more problems at school (Austin *et al.*, 1996).

In addition to the physical impact of seizures and their medication, people have to cope with the limitations imposed by statute, which embrace implications for social functioning, the prejudice, fear and lack of understanding by other people and with impact on the psyche due to these factors. People with epilepsy find themselves in a condition to which they must somehow adapt and adjust (Jacoby and Baker, 2000).

2. The concept and purposes for research into health-related quality of life

Assessment of HRQOL is a relatively new concept within the epilepsy area that meshes traditional medical care with psychosocial concerns. The modern concept of QOL arose in England during the Industrial Revolution in the 19th century. This sociologic concept has been applied to the medical field and called HRQOL, which reflects the degree of satisfaction of patients as the end users of medicine. The therapeutic outcome needs to be judged from two aspects (i.e., QOL and quantity of life). QOL must be determined from the patients' subjective viewpoint with the physicians' objective viewpoint being deliberately excluded (Kugoh, 1996).

The concept of QOL has not yet been defined in a uniform way. It is a multi-dimensional term describing a field of interest rather than a single variable (Hunt, 1997). The concept of QOL may be defined as "a complex amalgam of satisfactory functioning in terms of physical, social, psychological and vocational well-being" (Scambler, 1993). Devinsky and Cramer (1993) stated that the essence of QOL is the balance between patients' perceived and desired status. It is also defined by how well one is able to function and how he/she feels about daily life (Cramer, 1994), on the assumption that aspects of functional health status have an impact on QOL. It is a uniquely personal perception comprising health status and/or non-medical aspects of life that can be

measured by determining opinions of subjects (patients) and by using an "expert" instrument (Gill and Feinstein, 1994). Calman (1984) discussed the concept of QOL as the difference between a person's expectations and actual experience. The definition is known as Calman's Gap. When the gap between actual achievements and desired status is wide, the dissonance can lead to a conceived low QOL. When the gap is small, QOL often is perceived as high. Schipper *et al.* (1990) have described it as the functional effect of an illness and consequent therapy on a patient as perceived by the patient. The concept is broader than the sum of individual components because it represents a synergy among multiple domains and differs from status or the patient's outcome (Spilker, 1990). Another definition of HRQOL is the degree of subjective well-being, attributable to or associated with lack of symptoms, psychological state and activities pursued (Bulpitt, 1997). Compared to the World Health Organization's definition of 1948 (WHO, 1948), which stated that "Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity", the concept of QOL covers a much larger field of human necessities, although a clear definition is still missing (Zeitlhofer *et al.*, 2000).

The main components that determine QOL are subjective well-being and satisfaction with different aspects of life, objective functioning in social roles and environmental living conditions. With the increase of wealth, indicators of QOL have expanded from the material terms of income or possessions to include also more spiritual rewards such as satisfaction, personal development, and participation within the community (McDowell and Newell, 1996). Although there are certain basic facts, which obviously influence life quality such as age, health, social status, etc., the final assessment of QOL has to be made by the individual through his own estimation. Notwithstanding the risk of arbitrary self-misinterpretation, the QOL concept emphasises the value of self-determination, placing the personal dimension of man in the foreground (Zeitlhofer *et al.*, 2000).

QOL issues are most relevant to disorders that are chronic and associated with problems beyond the experience of the obvious disease symptoms. Epilepsy is the paradigm of such a disorder. Seizures are usually infrequent, and AED therapy, side effects, and attendant psychosocial problems are usually chronic (Devinsky, 1993). In the field of epilepsy, the formal assessment of QOL is a relatively recent science. The QOL studies in epilepsy focus on dimensions that are specific or very closely connected to health and medical care, for which reason we should talk about HRQOL (Patrick and Erickson, 1993), the reason being that it is often impossible to separate out health-related and non-health-related aspects of QOL (Hunt, 1997).

Use of the term "quality of life in epilepsy" was first documented in the title of the proceedings of a UK Royal Society of Medicine Round Table in 1990 (Chadwick, 1990). QOL became a main conference topic for the first time in 1991 and results of the first randomised trial of epilepsy treatment to incorpo-

rate a comprehensive and systematic QOL assessment were published in 1992 (Jacoby, 2000). Several studies have used HRQOL in epilepsy as an outcome measure and these give a broader measure of the burden of the disease (Nortvedt et al., 2000). In the 1990's, there has been a significant number of publications of QOL assessment tools for epilepsy, including the Epilepsy Surgery Inventory (ESI-55) (Vickrey et al., 1992), the Liverpool QOL Battery (Baker et al., 1993; Baker et al., 1994a), and the QOLIE scales (Devinsky et al., 1995) and their application in a range of descriptive studies and clinical trials of treatment for epilepsy.

Advances in the assessment of HRQOL in epilepsy are needed for clinical effectiveness research and for quality of care research in epilepsy. Monitoring HRQOL in epilepsy enables patients to express their concerns about a variety of issues affected by the diagnosis that often are not brought to the attention of the physician. There are growing numbers of pharmacological treatment options for epilepsy, with new antiepileptic medications recently released in the USA and Europe, and more under evaluation (Wieser, 1994). Comparison of the effects of different antiepileptic medications on HRQOL is desirable to enable informed clinical decision-making about the optimal medical management in epilepsy (Testa and Nackley, 1994). There is also a need to include assessment of HRQOL outcomes in studies of treatment discontinuation for epilepsy (Jacoby et al., 1992).

In addition to medical management, the impact of surgical treatment of epilepsy on HRQOL is not well established (Vickrey, 1995). It has been suggested that the HRQOL may actually decrease over time among epilepsy surgery patients who have less than a 90% reduction in seizure frequency post-operatively (McLachlan et al., 1997), although a 50% reduction in seizures has become a traditional endpoint for add-on AED therapy (Perucca, 1997). The National Institute of Health (NIH) consensus conference on surgery for epilepsy has called for the incorporation of HRQOL measures into future studies of surgery (NIH, 1990). There is also a nascent recognition of the need to investigate HRQOL outcomes of rehabilitative therapies (Vickrey, 1995).

Universally, there are increasing efforts to control health care costs. In this setting, there are many unanswered questions about the optimal mechanisms for management of epilepsy (Begley et al., 2000). Thus, there is a great need for research in quality of care assessment for epilepsy. Because HRQOL is a central outcome for these kinds of studies, advances in measurement of HRQOL in epilepsy are also needed for quality of care research (Greenfield et al., 1992; Kravitz et al., 1992).

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3. The stigma of epilepsy

Much of the literature on the social consequences of epilepsy assumes that the disorder bears a universal and devastating stigma (Baker *et al.*, 1996; Placencia *et al.*, 1995; Baker *et al.*, 1999; Jacoby, 1994; Baker *et al.*, 1997b). Used in the past to indicate a mark or brand to identify slaves and criminals, the word stigma in modern times has come to refer to what Goffman (1963) has described as "any attribute that is deeply discrediting". The stigma of epilepsy consists of deeply discrediting attributes such as propensity to crime and violence, sexual deviance, heritability and mental illness, restrictions or denials of common benefits (such as a drivers' license or life insurance) and limitations on opportunities that lead to independence (such as housing or employment discrimination) (Livneh and Antonak, 1997).

Several authors have argued (Schneider and Conrad, 1981; Dell, 1986) that stigma is not solely the outcome of societal devaluation of differentness, but in order for stigma to exist, individuals possessing such differentness must also accept this devaluation. Given that its physical manifestations are transient, individuals with epilepsy may be seen as possessing a characteristic, which is, in Goffman's (1963) terminology, potentially discreditable. Those people must continually decide what, when and to whom to disclose. For some people with epilepsy, managing information about their condition can be a potent source of stress and anxiety (Jacoby, 1994).

The aetiology of stigma is complex, with multiple origins. A number of authors cited the importance of parental reaction to the diagnosis (e.g., shame and concealment (Austin, 1996), or alternatively, over protection of the child (Scambler and Hopkins, 1986)). Feelings of stigma may arise as a direct consequence of experiencing the fear of others or the worry about having to communicate with someone having a seizure, also the problem may be exacerbated by lack of accurate information about epilepsy (Baker *et al.*, 1999; Hills and Baker, 1992).

The severity of the condition, as defined by seizure type and frequency and the personality of the individual (Ryan *et al.*, 1980a) may affect the responses to any direct or indirect experiences of discrimination (Schneider and Conrad, 1981). Scambler (1988) hypothesises that epilepsy is a stigmatising illness because people with epilepsy threaten the social order by failing to conform to cultural norms and by causing ambiguity in social interactions. Dell (1986) argues that stigma is serious and real, limiting the QOL of people with epilepsy. Social function is often impaired because of the stigma associated with a diagnosis of epilepsy. Perception of stigma can reduce motivation for work and social activity, relationships of the patient with family, friends and co-workers may change.

Danesi (1984), in a study evaluating how people with epilepsy perceive their condition, found some evidence of non-acceptance. Persons with epilepsy rated

themselves lower than people without epilepsy with respect to employability and higher with respect to emotional problems and tendencies toward violence.

Studies in the area of adjustment to seizures concern evaluation of the acceptance of the seizure disorder and feelings of not being accepted because of the disorder. Masland (1985) believes that the person's own reaction to having the seizure disorder is the most significant factor in adjustment. Schneider and Conrad (1980) reported that perception of stigma was related to direct exposure to rejection and disapproval from others. Persons with epilepsy maintained selective coping mechanisms to manage their reactions to stigma.

Arnston et al. (1986) have reported significant relationships between patients' feelings of stigma and a number of measures of psychopathology. The stigma of epilepsy and its psychosocial repercussions can best be understood by drawing a distinction between "felt" and "enacted" stigma. In this dichotomy, enacted stigma refers to episodes of discrimination against people with epilepsy, solely on the grounds of their social unacceptability. Whereas felt stigma refers to the feeling of shame associated with being epileptic or what might be called an "ontological deficit", a sense of "being imperfect" and the fear of enacted stigma or, in other words, a fear of meeting with discrimination consequent upon an epileptic identity (Scambler, 1993).

In their article, Ryan et al. (1980a) provided evidence that felt stigma may not be as all-embracing as suggested and that persons with epilepsy do not universally feel stigmatised by the disorder. Among the subjects they studied, the majority felt neither unreasonably limited nor treated differently because of their epilepsy.

The relationship between the severity of seizures and the perception of stigma due to the disorder is found to be highly dependent on other characteristics, such as the perception of employment discrimination, the perception of limitations imposed by the disorder and the years of school education attained by the individual.

Also, Jacoby in her study (1992), reported that for people whose epilepsy was well controlled (who had been seizure-free for at least two years) the psychosocial functioning and adjustment appeared high, with low levels of distress.

Felt stigma can be assessed by using a scale developed originally to measure patient perceptions of the stigma of another neurological condition — stroke (Hyman, 1971) and this is reworded for epilepsy. The scale consists of three questions each of them requiring a yes/no response. Respondents with epilepsy have to state whether they have felt that other people (a) are uncomfortable with them, (b) treat them as inferior, or (c) prefer to avoid them. An individual's score is the sum of the "yes" responses, and the higher the score the greater is the perception of stigma (Jacoby, 1994).

Stigmatisation seems to vary from region to region, and it tends to be more severe outside the developed world (Theodore, 2000; Jallon, 1997; Shorvon and Farmer, 1988; Van Ree, 1972; Walker, 1972; Senanayake and Abeykoon,

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1984). However, despite its changed manner, it is still a difficult problem in Western countries. According to the results from the European quality of life study that included patients from 15 countries, the highest proportions of stig-matised persons were found among the respondents from France and Germany. Respondents were more likely to feel stigmatised if they had a combination of seizure types or if they had frequent seizures (Baker *et al.*, 1997a).

4. Epilepsy and employment

Employment is a crucial topic for people with epilepsy because working, being an employee and earning a living are outward signs of the psychosocial integration and of acceptability by others (Chaplin, 2000; Dodrill, 1983).

There are a number of ways in which epilepsy appears to have an impact on employment. Firstly, the person with epilepsy is barred by law from certain occupations because of the potential hazards to him and others if a seizure occurs in the workplace. Secondly, the stigma attached to epilepsy and the resulting prejudice on the part of employers and co-workers limits employment opportunities for individuals with epilepsy. The employment problems of people with epilepsy may be further compounded by the effects of AEDs on cognitive functions, which can reduce educational and work performance and by poor self image, which may limit attempts to seek employment and affect interpersonal relationships at work (Fraser *et al.*, 1983; Rodin *et al.*, 1972).

Because people with epilepsy have high rates of under- and unemployment they are often dependent on others for financial security (Dodrill *et al.*, 1984b). Clemmons (1983) reported that 50% of a sample of persons with epilepsy were dependent on family or federal subsidy. Although several reports in the relevant literature have maintained that people with epilepsy generally have lower than average income (Fraser *et al.*, 1983; Dodrill *et al.*, 1984b; Batzel *et al.*, 1980; Fraser and Clemmons, 1983; Laaksonen, 1983), few statistical studies have investigated the relationship between epilepsy and lower socio-economic status.

Persons with epilepsy frequently experience psychosocial difficulties especially in terms of employment (Baker *et al.*, 1997a). Difficulties are experienced in all aspects of employment such as job application, promotion and dismissal (Cooper, 1995), and also in interpersonal relationships (Baker *et al.*, 1997a). A number of studies have highlighted the employment difficulties encountered by individuals with epilepsy (Fraser *et al.*, 1983; Rodin *et al.*, 1972), and under- and unemployment have been identified as two of the most serious problems they face (Collings, 1990c; Masland, 1983; Elwes *et al.*, 1991). Among people with epilepsy, it has been reported that unemployment is a major source of stress and that having full-time employment is a major factor in the prediction of overall well-being (Collings, 1990c).

There is general agreement about the fact that the unemployment rate of people with epilepsy is higher than in the general population (Fraser *et al.*, 1989; Chaplin *et al.*, 1998; Elwes *et al.*, 1991). Studies in the UK (Collings, 1990c; Scambler and Hopkins, 1980) have reported that employment rates among people with epilepsy are lower than in the general UK population. In the US labour market, the unemployment rate among people with epilepsy, who are maintaining an active job search is reported to be 13–25% (Thorbecke and Fraser, 1997). The generally accepted rate of unemployment in people with epilepsy has been calculated to even be between 15–50%, although this is a high figure it is lower than is found in other disability groups (Fraser *et al.*, 1989). But, in some studies (Chaplin *et al.*, 1998; Collings and Chappell, 1994), this rate has been questioned and lower rates ranging between 9–11% have been suggested.

In studies by Elwes *et al.* (1991) and Jacoby (1995), higher rates of unemployment were found among persons with active epilepsy compared to people whose epilepsy was in remission or well-controlled. Scambler and Hopkins (1980), in their study of a community sample of adults with epilepsy, found that less than half of those who had worked full-time after the onset of their seizures could recall that their careers had been inhibited by their epilepsy. Yet most felt "at risk" and chose to conceal their condition from their employers or potential employers. Employment disadvantage was found to be related both to a working class status and to a high rate of epileptic activity. The conductors of the study suggested that epileptics were prone to deny themselves career opportunities.

Collings (1990c) found full-time employment to be a predictor of psychological well-being, and less adequate financial status has also been found to be a predictor of depression (Hermann *et al.*, 1992). Hermann *et al.* (1990) have reported that vocational difficulties were among the factors contributing to increased psychopathology in people with epilepsy.

Epilepsy has a negative impact in several aspects of employment. Scambler and Hopkins (1980) stated that among the respondents in their survey, almost all of those with full-time employment experience, after the onset of seizures, believed epilepsy to be stigmatising despite the fact that less than a quarter could recall instances of discrimination. In the Jacoby (1995) study, only 2% of those asked recalled an occasion over the preceding two years when they had been treated unfairly at work because of their epilepsy and only 3%, of those asked, said that during the same time they had failed to get a job they applied for because of the condition. But, nearly a third of the patients (32%) felt that their epilepsy made it more difficult for them than for others to get a job. Among those who felt that having epilepsy made getting a job more difficult, 39% felt this was because employers preferred not to employ people with disabilities of any kind. A third felt it was because of fear and lack of understanding about epilepsy on the part of employers; and a fifth attributed these difficulties to the potential dangers of seizures in the workplace. Although no

specific question about disclosure was asked, a number of respondents commented that they had not disclosed their epilepsy out of fear of discrimination.

In a study from Tunis, Gouider *et al.* (2000) found that 19.2% of people with epilepsy from the group had changed jobs because of epilepsy. Kokkonen *et al.* (1997) found that the epileptic patients even with the same condition of employment had more frequently a less secure job.

A number of authors have emphasised the importance of good seizure control. Seizure frequency has shown to be related to the likelihood of being in employment (Rodin *et al.*, 1972; Scambler and Hopkins, 1980; Jones, 1965), which is to be expected. Collings (1990c), Elwes *et al.* (1991), and Jacoby (1995) all have reported lower rates of employment among people with active epilepsy than among those who were seizure-free. But, Jacoby (1995) specifies that where seizures are well controlled and uncomplicated by other handicaps, people with epilepsy do not generally experience problems with employment.

Chaplin (2000) stated that many people with epilepsy were unnecessarily restricted in their choice of employment due to, ignorance about epilepsy, the stigma associated with epilepsy or the expectations of stigma. Because employment is a major factor in the calculation of QOL, any anticipated QOL improvements from; for example, new medical treatments are reduced or invisible if the individual is still not able to work.

Although a higher rate than among the general population might be expected due to the nature of the condition, it has been found that the frequency of seizures is not the most important factor influencing the employment of people with epilepsy. In areas with high general employment figures, a comparison between a group of people with epilepsy in remission and a group with uncontrolled seizures shows only a slight increase in employment problems in the second group (8% to 10%) (Chaplin *et al.*, 1998).

In Western countries, the main problem for working-people with epilepsy is not unemployment, but integration in the workplace. Many problems are reported by people with epilepsy at work: stigma as already mentioned, limitations for career prospects, a lower salary, an unpleasant atmosphere and loss of job due to the discovery of epilepsy at work (Chaplin *et al.*, 1998; Lassouw *et al.*, 1997). The type of jobs open to people with epilepsy may reflect differences in their medical condition. In a study conducted in the Netherlands (Lassouw *et al.*, 1997), it was found that none, of the group of working-people with epilepsy, were self-employed.

Gouider *et al.* (2000) stated that one third of the patients considered that epilepsy reduced their productivity or awareness. However, Gloag (1985) revealed that the quality of work of epileptic persons was equal to that of the general population.

The lack of declaration of the disease in the workplace was found to be 19.5% by Gouider *et al.* (2000). It was outlined with higher frequency (37%) in a study by McIntyre (1979). Scambler and Hopkins (1980) reported that 80% of patients did not voluntarily declare their disease. Worsening of relationships in

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the workplace, especially with employers, was outlined by Jacoby (1995) in 34% of patients. 27% considered that epilepsy was a cause of discrimination at work (Scambler and Hopkins, 1980).

Gouider *et al.* (2000) reported that in the sample of predominantly manual workers (90%) with disrupted or primary education, epilepsy induced frequent changes of job and deterioration of relationships with employers in the sample where persons had mostly generalised epilepsy and 18% of the patients were having more than one seizure per month. The study investigators concluded that manual workers with epilepsy, especially workers over 40 years, constituted a vulnerable group in terms of employment problems.

5. Impact of epilepsy and its therapy with regard to social adjustment

Limited independence

Epilepsy often begins in childhood. Coping with seizures precludes many normal activities (e.g., work and sport). Parents may become overly protective because of the possibility that a seizure might result in an accident or cause self-harm and limit the child's, and often the young adult's, self-esteem and independence. Most epilepsy patients must take antiepileptic medications daily, often for the duration of their lives. The sense of dependence on medication is fostered by physicians and reinforced when seizures occur after missed doses. A sense of independence can be limited further by the need to report the diagnosis of epilepsy on applications for work and insurance. Restrictions are imposed either by law (e.g., the patient is prevented from driving) or by self-imposed concerns (e.g., social embarrassment). Similar restrictions also affect patients who have infrequent seizures (Cramer, 1993; Cramer, 1994).

Limitations on driving

Driving is often restricted for people with seizure disorders, particularly among those individuals with inadequately controlled epilepsy. Both licensing laws and insurance accessibility (and cost) delay resumption of normal activity after the diagnosis of epilepsy. If the patient does not have alternative modes of transportation (i.e. public transport, assistance from friends or relatives), limitations on driving can further restrict independence and ability to work and he/she can be quite socially isolated (Schwartz *et al.*, 1995). Inability to drive to work or to drive as a job requirement could, in addition, result in demotion to a position with less responsibility or to dismissal (Cramer, 1994). The health risk associa-

ted with social isolation is considerable, so preventing one of the reasons for this isolation would be salutogenic (Berkman and Syme, 1979).

Sexual behaviour and marriage

A large number of indirect relationships exist between epilepsy and problems of sexual behaviour. The existing data suggest that people with epilepsy appear to have lower rates of sexual activity and more sexual disturbance than those not having epilepsy (Max, 1980; Fenwick *et al.*, 1985). Hyposexuality is the most prominent problem. Although it has been specifically associated with temporal lobe epilepsy, this is presumably only one of several factors that may contribute. The individual's overall mental health is an important consideration; depressed or anxious people often have little interest in sex. The chronic use of AEDs may also produce alterations in sex hormone levels and thus affect sexual functioning and fertility (Hermann and Whitman, 1984; Strauss, 1989; Cramer and Jones, 1991). Data from the VA (Veterans Affairs) Co-operative Studies (Mattson *et al.*, 1985; Mattson *et al.*, 1992) clarified the differential effects of AED on sexual function in men. Primidone was associated with decreased libido or impotence significantly more often (22%) than carbamazepine (13%), phenobarbital (16%), or phenytoin (11%).

Adolescents with epilepsy may have limited opportunities for social activities and thus sexual contact because of their isolated position in peer groups (Hermann and Whitman, 1984).

There is evidence that people with epilepsy are less likely to marry and have children (Jacoby, 1992; Collings, 1990b; Dansky *et al.*, 1980; Batzel and Dodrill, 1984; Jacoby *et al.*, 1996). This is an important social issue that has many possible reasons. These include low levels of confidence and self-esteem and over-protection on the part of their family may render people with epilepsy socially more inept. The social isolation because of fear of seizures or restrictions on activities may limit their chances of meeting a prospective partner (Jacoby, 1992).

Dansky *et al.* (1980) reported that the marriage rate for both men and women was significantly reduced when seizures had begun in the first decade of life. Also Jacoby *et al.* (1996) showed that the earlier age at onset was associated with reduced likelihood of being married.

AED therapy and compliance

Evaluations conducted by physicians have mostly concentrated on seizure management, assessing strategies for AED prescribing and for surgery. It is as if seizure control is primary and everything else secondary. It seems that seizure control is equated with "normality" (often restoration of the *status quo ante*) and therefore a person's well-being. Allowing for the undoubted importance of seizure control, research has accumulated to show that epilepsy often does have

a marked, deleterious effect on QOL quite independently of seizure frequency (Scambler, 1993).

Seizures and AED therapy have a major impact on patients' lives that often linger after long-term remission is achieved. AED therapy, by decreasing seizure frequency and possible severity, has the potential to ameliorate the psychosocial consequences of the disease. However, therapy may itself cause new problems in daily living because of adverse effects, interactions with other drugs, frequent blood sampling, feelings of dependency on a potential life-long medication regimen, and financial cost associated with long-term therapy (Wagner *et al.*, 1995).

Low self-esteem, lack of independence, need for AEDs, restrictions on alcohol use and driving, reporting of epilepsy on job and insurance applications, and presence of AEDs in urine tests are chronic problems frequently faced by patients with epilepsy (Ryan *et al.*, 1980a; Hermann, 1991; Hayden *et al.*, 1992).

It has been suggested that patients who successfully discontinue from AEDs are able to think that they not only are free from recurrent seizures, but also from a diagnostic label that many believe to be stigmatising and may derive considerable psychosocial benefits (Jacoby *et al.*, 1992).

For any epilepsy patient, the ideal outcome would be seizure freedom while on no drug therapy. For some patients this may be a realistic goal, others should be controlled on the lowest possible number of drugs at the lowest possible dosage (Reynolds and Shorvon, 1981; Brodie, 1992).

Most patients, with epilepsy of recent onset, will achieve a long-lasting remission soon after the start of therapy, with minimal side effects. Annegers *et al.* (1979) showed that 61% of patients were in 5-year remission ten years after presentation, rising to 70% after 20 years and these rates have remained essentially unchanged until now, despite the introduction of modern AEDs. The patients with an idiopathic generalised seizure disorder usually respond very well to treatment. It would appear that over 80% of those with a clinical and electro-encephalographic (EEG) picture of an idiopathic generalised seizure disorder will be rendered seizure-free on treatment with sodium valproate. In those patients with symptomatic or cryptogenic epilepsy, the response rates are lower. Patients experiencing partial seizures are less likely to get remission than those with only tonic-clonic seizures. The worst prognosis would appear to be in those who have both partial and secondary generalised seizures (Chadwick, 1992).

When an AED, "correct" for the specific syndrome, has been used unsuccessfully, it is reasonable to turn to a second drug, most usually as monotherapy. In some instances a trial of a two-drug combination may be considered. The second drug will be withdrawn in the absence of a satisfactory sustained response. Realistically once patients are demonstrably refactory to two different monotherapies, it is unlikely that they will fully respond to a third or even fourth monotherapy (Leach *et al.*, 2000). The careful use of combination

treatment may be the only option for patients refactory to monotherapy. It has been estimated that some 20% of patients developing epilepsy have a chronic disorder that cannot be controlled by drugs (Jacoby, 1992; Baker *et al.*, 1993; Chadwick, 1998).

In recent years, considerable emphasis has been placed on the desirability of monotherapy (Reynolds and Shorvon, 1981; Brodie, 1992). In general, therapy should be initiated with monotherapy, using an AED that is specific for the epilepsy syndrome being treated and that has the most favourable side effect profile. However, if monotherapy is not effective in controlling seizures without side effects, a rational approach, using more than one AED, or combined AEDs with multiple mechanisms of action, should be used (Leppik, 2000). Combining older AEDs has traditionally been seen as helping few patients while hindering many by causing a multitude of side effects. The truth is probably less dramatic, especially with the newer AEDs (Leach and Brodie, 1995).

When the likelihood of seizure freedom is low, it may be more prudent not to pursue freedom from seizures, but instead to achieve a balance between reducing seizures and inducing side effects, with the minimum number of AEDs. This acknowledges the fact that drug-related adverse effects, especially with AED polypharmacy, can themselves be disabling and worrying (Leach *et al.*, 2000).

AEDs have been shown to have a number of undesirable side effects, both physical and cognitive. The negative effects of AED treatment consist of side effects from the drugs and the intrusion of regular pill taking into daily life. Most patients with epilepsy will have seizures much less often than the times they need to take their medication and the latter serves as a frequent reminder to the patient that not all is well with them. This, in addition, may give rise to embarrassment and stigmatisation at work or school, if dosing is more frequent than once or twice a day. A more common negative effect of AEDs is the side effects. Acute dose-related side effects are generally predictable, such as sedation, dizziness, nausea and impairment of concentration and cognition. Some side effects are more drug specific, such as blurring of vision and diplopia from carbamazepine, hair loss and weight gain from valproate, and oscillopsia and ataxia from phenytoin. Acute dose-related side effects may not result in a patient complaining vociferously and so they should be specifically enquired about, as their occurrence will undoubtedly have a deleterious effect on QOL and on compliance, with subsequent difficulties in making rational drug changes. Chronic cognitive side effects may develop insidiously and not be perceived unless they are looked for, or recognised until a drug is withdrawn, but may have a profound effect on QOL. Most of the AEDs have the potential to cause slowing down, and more widespread cognitive side effects have been associated with barbiturates and phenytoin, and with the use of polytherapy (Thompson and Trimble, 1982; Duncan *et al.*, 1990; Duncan, 1990).

A function of the patient-physician relationship is compliance or non-compliance with treatment regimens (Stanaway *et al.*, 1985; Sadler, 1986). For

patients with epilepsy who become seizure-free after starting AED treatment, the question arises of whether they could then discontinue AEDs.

Lack of control of one's health and resentment of the need to take medication may be major factors leading to non-compliance with a medication regimen. The arguments in favour of discontinuation of AEDs include concerns about side effects or possible long-term effects, sense of disillusionment because therapy can only control, not cure, epilepsy and to some people continuing therapy implies continuing epilepsy, even though they are seizure-free (Jacoby *et al.*, 1992). Compliance with AED therapy is known to be poor (Gibberd *et al.*, 1970; Dawson and Jamieson, 1971). In a study of adults with epilepsy by Scambler (1989), 25% admitted that they had, at some stage, deliberately experimented with or stopped medication without consulting a physician. Stanaway *et al.* (1985) reported that 37% of people with epilepsy, from within their study, were not taking medication as prescribed and that 31% of seizures were estimated to occur as a result of failure to comply. The positive feedback gained by the patient who discontinues or reduces medication intake without immediate reoccurrence of seizures may have an important negative influence on later ability to readjust to a medication schedule if seizures recur (Meador *et al.*, 1990).

Persons who relapse after discontinuation may risk the loss of employment. Their driving-license may be forfeited. And all this may have a considerable impact on the quality of daily life. The uncertainty associated with a possible relapse may affect confidence, self-esteem, and sense of control and, as a result, relationships with others (Jacoby *et al.*, 1992). Although clinical consensus now is that patients should be considered for discontinuation of AEDs after being seizure-free for two years, many continue therapy for prolonged periods because of uncertainty about the outcome of discontinuation (Guberman and Bruni, 1999).

The social and psychological effects

It has been suggested that the psychosocial problems, observed among patients with epilepsy, are more handicapping than the seizures themselves (Livingston, 1981). Baker *et al.* (1996) consider the burden of epilepsy to be so variable that merely the fact of having epilepsy can result in psychosocial problems, independent of the frequency or severity of seizures.

Earlier studies in this field have highlighted several areas of particular concern for people with epilepsy (Collings, 1990c; Cramer, 1994; Chaplin *et al.*, 1992; Hermann, 1992). Fear of physical injuries or social embarrassment, cognitive impairment (due to underlying brain dysfunction and/or anticonvulsant medication) and the stigma historically attached to being "epileptic" are potent factors which lead to self-imposed and societally imposed restrictions on many pleasurable and productive activities (Hermann and Whitman, 1991).

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Anxiety, depression, anger, low self-esteem, social isolation and withdrawal, familial maladjustment and low marriage rates are common (Collings, 1990b; Hermann, 1992; Thompson and Oxley, 1988).

Patients commonly experience anxiety and depression when epilepsy is diagnosed. Fear of seizure disorder exposure can become overwhelming when coupled with a sense of loss of control over their body (Cramer, 1994). The effects of medication and seizures also impinge on the psychological condition, particularly if cognition is impaired or memory loss becomes apparent to the patient (Meador *et al.*, 1990). Standage and Fenton (1975) compared the mental status of patients with epilepsy and patients with musculoskeletal disorders, finding similar symptom profiles. Anxiety and depression were twice as high in the epilepsy group.

People with epilepsy are generally considered to be at greater risk of psychopathology and more likely to be socially dysfunctional than people without epilepsy, but the reasons for this continue to be a focus for debate (Jacoby *et al.*, 1996). Hermann and Whitman (1991) argue that there are three main groups of variables that may contribute to the development of psychopathology in epilepsy: clinical factors related to the natural history of epilepsy, including age at onset, duration of epilepsy, seizure type, aetiology and seizure control; medication factors, including type of AED, number of AEDs, and serum levels; and psychosocial factors, including perceived stigma and discrimination, locus of control, adjustment to epilepsy, social support, and socio-economic status. Previous research into modelling the psychopathology of epilepsy in a hospital-based population highlighted that the number of stressful life events in the past year, poor adjustment to epilepsy and financial stress were the most significant independent predictors of psychopathology (Hermann *et al.*, 1990). The only clinical factor that correlated significantly with psychiatric status was earlier age of onset, although this proved not to be predictive of psychopathology in the population of people with epilepsy studied by Baker *et al.* (1996). A study of people with resistant epilepsy found that perception of seizure severity was a significant predictor of anxiety, self-esteem and locus of control, with seizure frequency only making a negligible contribution (Smith *et al.*, 1991).

Epilepsy has shown to be associated with higher than average rates of psychiatric morbidity (Kogeorgos *et al.*, 1982; Trimble, 1985). Anxiety and depression are the commonest forms of psychiatric morbidity in people with epilepsy and often coexist (Jacoby *et al.*, 1996; Robertson *et al.*, 1987). Arntson *et al.* (1986) and Collings (1990c) too, cite anxiety as the problem most commonly elicited from patients themselves. Smith *et al.* (1991) reported that in a group of patients with intractable epilepsy, 33% were classified as clinically anxious and 15% as clinically depressed by the Hospital Anxiety and Depression (HAD) Scale (Zigmond and Snaith, 1983). At the same time, some authors think that the findings showing that anxiety and depression are the commonest forms of psychiatric morbidity among people with epilepsy, reflect the view that

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anxiety and depression are also the commonest forms of psychiatric morbidity in the general population (Goldberg and Blackwell, 1970; Regier, 1988).

In epilepsy, medical outcomes are usually defined by seizure severity (e.g., frequency, type, intensity, postictal symptoms, etc.) and medication side effects. Devinsky (1993) argues that in all this, we are missing the patient's perspective. Although one might believe in the physician's ability to assess the patient's QOL accurately, there is often a poor correlation between the patient's and the physician's assessments (Slevin *et al.*, 1988).

The individual patient's perspective has become an integral aspect of health care assessment (Cramer, 1994). Several authors have drawn attention to the importance of considering the social aspects of epilepsy (Burden, 1981; Scambler, 1987), which have been recognised as crucial to a comprehensive understanding of the condition (Chaplin *et al.*, 1990).

Severe social problems are most frequently found in those patients having poor seizure control and multiple seizure types or with associated handicaps (Thompson and Oxley, 1988; Dodrill, 1986; Beran and Flanagan, 1987). Collings (1990a) found that the most significant discriminator of well-being was the correspondence between current self-perceptions and the anticipated self without epilepsy, with other predictors consisting of employment status, seizure control, certainty of diagnosis and age. Rodin *et al.* (1977) discovered that more than half the persons with epilepsy, which they sampled, had some sort of psychological or social problem with behavioural manifestations. Interpersonal adjustment refers to a person's ability to relate to other people; i.e., having close personal friends, being able to deal appropriately with the opposite sex, etc. Relationships with other people are viewed as being among the most important variables in psychosocial adjustment (Dodrill *et.al.*, 1980).

Social isolation and withdrawal are also commonly reported in the psychosocial adjustment of the people with epilepsy (Max, 1980; Heisler and Friedman, 1981; Fraser and Smith, 1982; Ziegler, 1982) and are related to marriage and sexual behaviour. Fear, anxiety, and the attitudes of others toward the person with epilepsy contribute to withdrawal (Laaksonen, 1983). Lack of self-esteem reinforces this pattern, reducing the person's opportunity to learn appropriate social interaction skills (Woodward, 1982). Withdrawal and social isolation may also occur within families, increasing the tensions between persons with epilepsy and their families and contributing to the overall pattern of social isolation (Ritchie, 1981).

The person's view of treatment received or medical management significantly affects psychosocial adjustment (Dodrill *et al.*, 1980). Reactions to the physician involved and to having medications administered, as well as the degree of treatment compliance, are considered significant factors.

Psychosocially oriented explanations have emphasised the various psychological and social stress factors associated with having seizures. Seizures are essentially unpredictable traumatic events over which the individual has little or no control. The nature of epilepsy may thus be conducive to "learned helpless-

ness"; and it has been suggested that this may be one way of understanding some of the inter-ictal behavioural concomitants of epilepsy, particularly the apparent high rates of depression and anxiety (Hermann, 1979). Medical misinformation, fear of seizures and fear of death from seizures is widespread among patients and this may affect behaviour in adverse ways. Patients may have concerns about what they think are the potentially destructive effects of epilepsy, such as progressive brain damage, mental deterioration, mental illness and loss of intelligence. A common approach to dealing with such fears and concerns is social and emotional withdrawal. Depression and anxiety in epilepsy may in part be due to such mechanisms (Aldenkamp and Hendriks, 2000).

Baker *et al.* (1997a), in their European study of people with epilepsy, found that when asked to what extent they felt epilepsy and its treatment affected several aspects of daily living, high percentages of respondents reported that it substantially affected their plans and ambitions for the future (47% reported "a lot/some"), feelings about themselves (40% reported "a lot/some"), and their social life (41% reported "a lot/some"). Conversely, there were high percentages who felt that relationships with significant others were unaffected (48% describing relationships with close family members as not affected). More than one third (38%) of respondents believed that epilepsy affected their ability to work and their standard of living (36%) "a lot/some", but there were also substantial proportions who believed that employment (47%) and standard of living (43%) were not affected by epilepsy. Respondents with frequent seizures were more likely than the rest to believe that epilepsy affected the various aspects of their daily lives a lot or some. Similarly, respondents with mixed seizure types were more likely to believe this than those who had only tonic-clonic seizures or only some other types of seizure.

Jacoby *et al.* (1996), in their findings from a U.K. community study, reported that there was a clear relationship between current level of seizure activity and subjects' psychological well-being, as measured by their scores on the HAD Scale. Overall, 25% of subjects were classified as anxious and 9% as depressed, but the percentages increased, from 13 and 4%, respectively, among individuals who were seizure-free to 44 and 21%, respectively, among those reporting frequent seizures, defined as one or more seizures a month. Subjects currently experiencing frequent seizures were two to three times as likely as those currently seizure-free to believe that epilepsy affected the various aspects of their daily lives "a lot" or "some". Current seizure activity thus appeared to be important factor in determining the psychosocial status of this population.

But the investigations, which are based on community populations, suggest that although significant social difficulties may be experienced, many people with epilepsy cope well in society (Zielinski, 1986).

6. Quality of life measures in epilepsy

Review

There is no consensus on which instruments are most suitable for measuring QOL. Commonly, HRQOL instruments are questionnaires made up of a number of items or questions. These items are added up in a number of domains (also sometimes called dimensions). A domain or dimension refers to the area of behaviour or experience that we are trying to measure. Domains might include mobility and self-care (which could be further aggregated into physical function), or depression, anxiety, and well-being (which could be aggregated to form an emotional function domain). For some instruments, investigators do rigorous valuation exercises in which the importance of each item is rated in relation to the others. More often, items are equally weighted, which assumes that their value is equal (Guyatt *et al.*, 1993).

There are two principal types of QOL instruments: generic and specific. The generic instruments assess a variety of general functions (e.g., ability to perform activities of daily life, overall feelings of well-being, limitations of the medical disorder on social functions, etc.) and have the advantage of being useful for a large number of disorders as well as in general population. Most of the instruments are well validated and the result of extensive development. They are relatively brief and efficient and facilitate comparisons between different groups. However, generic instruments are limited because many of the general questions they include (such as how many city blocks can you walk or the severity of pain) may be useful for cardiac and oncological disorders but may not be relevant for less physically disabling disorders such as epilepsy. Further, generic instruments may be insensitive to the most important aspects of specific disorders. Indeed, generic instruments are not sensitive to many of the important medical, medication, cognitive, social, and psychological disorders associated with epilepsy. Disease-targeted instruments concentrate on issues of particular relevance to a specific disease or disorder and therefore may be more sensitive than generic measures to differences within the targeted condition but do not permit comparison of results between disorders or populations (Devinsky, 1993).

In recent years there have been a number of initiatives to develop QOL outcome measures for epilepsy (**Table 1**): those which have concentrated on the development of a novel measure (e.g., Washington Psychosocial Seizure Inventory (WPSI) (Dodrill *et al.*, 1980) and the Social Effects Scale (Chaplin *et al.*, 1990)); those that involve a single previously developed generic measure with epilepsy-specific additions (e.g., Epilepsy Surgery Inventory (ESI-55) (Vickrey *et al.*, 1992) and the Quality of Life in Epilepsy Inventory (QOLIE) (Devinsky *et al.*, 1995)); those that make use of previously validated scales addressing specific QOL domains together with additional disease-specific

questions (e.g., Liverpool QOL Battery (Baker *et al.*, 1993; Jacoby *et al.*, 1992)); and finally the patient-generated approach adopted by Kendrick and Trimble (1994). It is generally agreed from the work on QOL to date that the best approach is to use a standard generic instrument with disease-specific additions, and much of the work in QOL of adults with epilepsy has followed this approach (Baker, 2001; Chadwick, 1996).

Table 1. QOL measures used in the studies of epilepsy or AEDs.

Physical measures
Liverpool Seizure Severity Scale (Baker *et al.*, 1991)
Chalfont Seizure Severity Scale (Duncan and Sander, 1990)
Veterans Seizure Severity Scale (Cramer *et al.*, 1983)
Social functioning
Social Effects Scale (Chaplin *et al.*, 1990)
Impact of Epilepsy Scale (Jacoby *et al.*, 1993)
Life Fulfilment Scale (Baker *et al.*, 1994b)
Seals Inventor (Brown and Thomlinson, 1984)
Stigma Scale (Jacoby, 1994)
Psychological well-being
Hospital Anxiety and Depression Scale (HAD) (Zigmond and Snaith, 1983)
Profile of Mood Scale (McNair *et al.*, 1981)
Affect Balance Scale (Bradburn, 1969)
Mastery Scale (Pearlin and Schooler, 1978)
Self-Esteem Scale (Demo, 1985)
Disease-specific measures
Washington Psychosocial Seizure Inventory (WPSI) (Dodrill *et al.*, 1980)
Quality of Life Inventories for Epilepsy (QOLIE-89, QOLIE-31, QOLIE-10) (Cramer, 1994; Devinsky *et al.*, 1995)
The Liverpool Initiative (Baker *et al.*, 1993)
The Queens Square Initiative (Kendrick and Trimble, 1994)
The Epilepsy Surgery Inventory (ESI-55) (Vickrey *et al.*, 1992)
General health status measures
Nottingham Health Profile (Hunt *et al.*, 1985)
The Medical Outcomes Study 36-Item Short Form Health Survey (MOS SF-36) (Ware and Sherbourne, 1992)
The RAND 36-Item Health Survey (RAND-36) (Hays *et al.*, 1993)

Although proven useful in their country of origin, standard scales are not directly applicable across nations due to cultural diversity. In order to use such instruments in a new national context, a thorough translation and testing phase preceding the inclusion of an instrument in a study is necessary. Measures also need to be psychometrically tested in a specific cultural context to assure their psychometric soundness (Bullinger, 1995; Mathias *et al.*, 1994; Hunt, 1993). A minimal requirement for inferring correct translation and international validity of an instrument is the forward-backward-translation in the language under study, a test of psychometric criteria for healthy (if applicable) and ill persons based on a moderate sample size (e.g., at least 100 patients per study), and a clear-cut description of that translation and evaluation process (Bullinger *et al.*, 1993).

Usually, a simple translation is unlikely to be adequate. It should be recognised, that without rigorous back-translation and pre-testing, the instrument may be interpreted differently in the new language (Berkanovic, 1980). Even if the translation is adequate, cultural differences can adversely effect an instrument's measurement properties (Deyo, 1984). To be fully confident of an instrument's validity in a new language or culture, a complete repetition of the validation process is required (Nord, 1991). The adequate language conversion involves the forward and backward translation of the measure and a quality control of the translations. The consequent piloting involves discussion of the translated version with a health expert group and a small sample test of the questionnaire in a convenience sample of persons of different age, sex, health state and education, as well as a test of the ordinality and equidistance of response choices. Psychometric testing includes examination of classical test theoretical criteria in populations differing in health state in terms of reliability (Cronbach's alpha (α)), the validity (convergent, discriminant) and the responsiveness as well as the discriminant power in distinguishing populations differing in their medical condition (Bullinger, 1995).

The methods of the measurement of QOL must be valid (measure what they are supposed to measure), repeatable, sensitive to change (over time or as a result of treatment), and acceptable to the subjects (Bulpitt, 1997).

Because there is no QOL instrument that can serve as a gold standard by which to judge new QOL instruments, validity must be established in other ways. One way is to make logical predictions about relationships between QOL and other variables and to see whether these predictions are borne out when the instrument is used; this is known as construct validity (MacKeigan and Pathak, 1992).

One possibility for international examination of psychometric performance to infer the international validity and reliability of an instrument is to use the classical cut-off points for instrument performance obtained from each nation. Criteria include discriminant item validity in terms of optimal scale fit, item to scale correlation above 0.40, internal consistency coefficients over 0.70 and correlation coefficients for validity testing of above 0.50. The discriminant vali-

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dity of the measure, or known-groups validity (based on several patient groups known to differ in terms of severity of HRQOL impact), should be established. Thus, this approach simply involves generating or collating the key information on reliability, validity and sensitivity of an instrument. If, in a given country and under diverse conditions, an instrument continues to show excellent psychometric properties, or has been demonstrated to perform similarly to the original instrument, then it can be assumed to be culturally acceptable (Bullinger *et al.*, 1993).

Validity examines whether the instrument is measuring what it is intended to measure. When no gold, or criterion, standard exists, HRQOL investigators have borrowed validation strategies from clinical and experimental psychologists. The most rigorous approach for establishing validity is called construct validity. A construct is a theoretically derived notion of the domain(s) we want to measure. An understanding of the construct will lead to expectations about how an instrument should behave if it is valid, namely, the extent to which the questionnaire supports predefined hypotheses (Jenkinson *et al.*, 1993). It involves comparisons between measures and examines the logical relations that should exist between a measure and characteristics of patients and patients' groupings (Guyatt *et al.*, 1993). Construct validity is considered to be the main requirement of any measuring tool (Baker *et al.*, 1993).

Item-discriminant validity is used to examine the extent to which items correlate more closely with the domain to which they belong than with the other domains; overall scaling success rate summarises the frequency with which they do so, as a percentage of the total number of correlations examined (Jacoby *et al.*, 1999).

Internal consistency reliability, using Cronbach's α coefficients (for group comparisons, a minimum value of 0.70 is recommended; for individual patient comparisons, a minimum of 0.90) should be sought (Cronbach, 1951). Reliability refers to the reproducibility of a measure. In other words, if the instrument were administered again, under similar test conditions, to an individual whose health status had not changed, would the same score be obtained? If the scores obtain contain little random error, they are highly reproducible. There are many ways to compute a reliability coefficient, including Cronbach's α coefficient of internal consistency and Pearson's r or intraclass correlation coefficient for test-retest and interrater reliability (Baker, 2001; MacKeigan and Pathak, 1992).

Ideally an instrument should not often produce a zero result (a floor effect) or a result of 100% (a ceiling effect) as this will limit the sensitivity of the measure to change. A zero (as a good) result cannot improve and a 100% result cannot get worse. Skewness measures the asymmetry of response distributions. The weighting of the instrument should be acceptable. Ideally, the instrument should have been employed previously so that the problems have been identified, assessed and dealt with (Bulpitt, 1997).

The RAND 36-Item Health Survey 1.0 (RAND-36)

A variety of instruments are available for evaluating health-related quality of life in general population. One from among the most widely used questionnaires is the RAND 36-Item Health Survey 1.0. It is a brief and intensively tested instrument that was derived from longer instruments developed by RAND (a contraction of the term research and development) researchers (Santa Monica, California) for the Medical Outcome Study (MOS) and the Health Insurance Experiment (Cramer, 1994).

The purposes and methods of the RAND study have been fully summarised (Hays *et al.*, 1993). The RAND 36-Item Health Survey 1.0 items are identical to the MOS 36-item short-form health survey (MOS SF-36) described by Ware and Sherbourne (1992). These were adapted from longer instruments completed by patients participating in the Medical Outcomes Study (Hays and Shapiro, 1992). The conceptual framework is based on the multidimensional World Health Organisation definition of health (WHO, 1948). Although the RAND version has a slightly different scoring method, it allows users of the MOS SF-36 and RAND-36 to relate their findings (Hays *et al.*, 1993). The RAND 36-Item Health Survey also forms the core component of two quality of life measures in epilepsy, ESI-55 (Vickrey *et al.*, 1992) and the QOLIE-89 (Devinsky *et al.*, 1995). The RAND-36 has a high validity and reliability rate compared with the Nottingham Health Profile and can discriminate between healthy controls and subjects who have mild health problems (Van der Zee *et al.*, 1996; Garratt *et al.*, 1993). It has been carefully tested, validated, and extensively used for patients with chronic disease (Stewart *et al.*, 1989). Due to its long developmental history and use in research as well as in clinical practice, it provides a rich database enabling researchers to compare their results. Thus in the international context it is possible to carry out research on the cultural universality vs. differences in quality-of assessment (Bullinger, 1995).

The Quality of Life Inventory in Epilepsy (QOLIE-31)

A diverse consortium of epilepsy and health services researchers (The QOLIE Development Group) initiated development of a broader, but epilepsy-specific instrument by expanding on the RAND 36-Item Health Survey and ESI-55 concept of a self-report measure of HRQOL (Vickrey *et al.*, 1992). The following three instruments were derived as a result of field testing: QOLIE-89 (17 scales, 89 items), QOLIE-31 (7 scales, 31 items), and QOLIE-10 (10 items selected from the 7 scales in QOLIE-31). The first two instruments have been validated extensively to assure that the identified domains relate to different issues.

The QOLIE-31 is a 31-item questionnaire that addresses seven domains of HRQOL in sub-scales that can be compiled in a summary score reflecting experiences in the previous month. The QOLIE-31 was designed to serve as a

brief assessment of epilepsy-specific and some overall QOL issues. QOLIE-31 is a more detailed instrument than the QOLIE-10 (Cramer *et al.*, 1996). The sub-scales of the QOLIE-31 include seizure worry, overall quality of life, emotional well-being, energy/fatigue, cognitive effects, medication effects, social function, and overall health. Each domain is addressed by asking several questions (ranging from one to six) so that an average of the responses represents the score for that sub-scale. The total score is a weighted sum of the sub-scale scores. An adult, whose reading comprehension is at fifth grade level, can complete the 31 items in approximately 10 minutes (Cramer, 1999).

Sixteen of the QOLIE-31 items were drawn from existing sources and 15 items were developed *de novo* by the QOLIE Development Group. The five-item emotional well-being and four-item energy/fatigue scales of the QOLIE-31 are identical to these scales in the RAND 36-Item Health Survey 1.0 (Hays *et al.*, 1993). Items in this 36-item measure were adapted from longer instruments completed by patients participating in the Medical Outcomes Study (MOS), an observational study of variations in physician practice styles and patient outcomes in different systems of health care delivery (Stewart *et al.*, 1992). The QOLIE-31 cognitive function and social function scales each contain one item incorporated from MOS instruments. The QOLIE-31 also contains an overall quality of life scale that is comprised of one item from a study on patient preferences (Hadorn and Hays, 1991) and one Dartmouth COOP Chart (Nelson *et al.*, 1990). One seizure worry item and one cognitive function item were originally developed for the ESI-55 (Devinsky, 1993). The single item on overall health was adapted from an existing visual analogue scale (Brazier *et al.*, 1993) and added to the QOLIE-31 subsequent to field testing of the other 30 items (Cramer *et al.*, 1998).

AIMS OF THE STUDY

Although epilepsy is one of the oldest known and the most common of the chronic neurological disorders the accompanying substantial psychosocial problems and limitations on peoples' everyday-life are still underestimated in modern society. Stigmatisation in epilepsy, employment of the people with the disease, impact of epilepsy and its therapy on social adjustment as well as the QOL measures used in the studies conducted in recent years vary in different countries and depend on the society's background and arrangement in healthcare system. The QOL information of the people with epilepsy living in the Eastern European countries has been insufficiently investigated.

Therefore, the study was conducted to pursue the following objectives:
- to test the acceptability, reliability and validity of the RAND 36-Item Health Survey 1.0 and the QOLIE–31 questionnaires in the groups of Estonian people;
- to examine the impact of epilepsy and its treatment on employment status and the extent of stigma among individuals with epilepsy;
- to describe the general health status and QOL for patients with epilepsy from two different towns of Estonia on the basis of the above-mentioned scales;
- to analyse how it is affected by the characteristics of epilepsy;
- to analyse how it is affected by the socio-demographic characteristics of the patients.

PATIENTS AND METHODS

1. Study design and population

The research took place in 1997–98. The QOL data was collected from respondents with epilepsy living in two towns of Estonia — Tartu and Viljandi. Tartu, with a population of 100 977 is the country's second largest city. Southern Estonia revolves around Tartu, which is the intellectual and educational centre of Estonia. Viljandi County, with a population of 62 782, is located in south-central Estonia (Statistical Office of Estonia, 1998). The administrative centre of the county is the town of Viljandi, the country's sixth largest town by its population and is situated 81 kilometres from Tartu. In Tartu, the study followed an epidemiological survey of epilepsy (Õun *et al.*, accepted for publication-a; Õun *et al.*, accepted for publication-b). The epidemiological survey included persons who were residents of Tartu, were aged 20 and over and had, before or during the period 01.01.1991–01.01.1996, suffered at least two unprovoked epileptic seizures, at least one of them within the previous five years. Data collection for the epidemiological study consisted of two parts: data registration from a multi-source medical register review and data registration from a personal case re-examination. Case records of patients treated at the University Hospital, Outpatients' Clinics, physicians' offices, emergency rooms or the EEG laboratory with a diagnosis of epilepsy, convulsions, syncope, amnestic attacks or abnormal involuntary movements were reviewed and invitations for re-examination were sent to the relevant persons. During the last two years, all the patients were re-examined at least once by a neurologist in order to specify the type of their seizures.

2. Diagnostic criteria

The study included persons with epilepsy who were aged 20 and older and had had at least two unprovoked epileptic seizures, at least one of them within the previous five years. Persons with provoked and acute symptomatic seizures were excluded.

3. Clinical data

Our study focused on the analysis of data collected from a sample of 203 patients in the 20–72 age group. The patients were selected at random from the

preliminary lists of the epidemiological study conducted in Tartu, excluding people who were not capable of understanding Estonian (mostly Russian-speakers) because no sufficiently well translated and validated questionnaire was available. In Viljandi, primary information about people with epilepsy was gathered through the local epilepsy support group, and clinical information was abstracted from medical notes held in the County Hospital and Outpatients' Clinic Register. To evaluate the accuracy of diagnoses, the problematic cases were investigated and re-examined if necessary. All patients gave their consent for participation in the research and the project was approved by the Ethics Committee of the University of Tartu. In addition, a control group of 200 healthy subjects corresponding in age, sex, and educational level was randomly selected from among the patients receiving treatment from dentists at the University's Dental Clinic. All of the respondents possessed at least a basic education with sufficient ability to read and write, and were capable of understanding and completing the questionnaires.

4. Measures

Clinical information, if needed, was, once again abstracted from medical notes and also during the personal re-examination of subjects. Abstracted information used in the study related to the aetiology of epilepsy, classification of seizure type and current AED therapy. To evaluate the impact of epilepsy on employment status and perceived stigma, the patients were sent a questionnaire by mail. The questionnaire employed a combination of open questions (**Appendix 1**) together with previously translated and validated scales (The Stigma of Epilepsy Scale, the RAND 36-Item Health Survey 1.0 (**Appendix 2**) and the QOLIE-31 (**Appendix 3**)). In addition, single items were included which referred specifically to feelings of stigmatisation in the area of employment. The questionnaire contained a number of scales and questions covering the following issues: (1) Demographic characteristics — information was obtained about subjects' sex, age, marital and employment status, and educational level. (2) Economic and financial status — patients were asked to state whether they considered it to be "very good", "good", "satisfactory", "moderately bad", or "very bad". (3) Seizure frequency — patients were asked whether they had had seizures once or more in a month, less often than once a month, or not at all in the past year. (4) Injuries associated with seizures — subjects, who had had at least one seizure in the past year, were asked whether they had had a burn or scald, a head injury, milder injuries (including dental injuries), any other injuries (unspecified) or no injuries. (5) History of the epilepsy — patients were asked about age at first attack. (6) Previous research has shown that patients' perception of the severity of their seizure disorder may be more important than

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seizure frequency in determining their psychological and social well-being (Baker *et al.*, 1991). Therefore subjects were asked to assess their seizures as "very severe", "severe", "medium", or "light". (7) AED treatment and side effects — patients were asked about the AED they were taking and about the experienced side effects during the past month, as well about satisfaction with the current treatment and about changes in AED medication in the past year. (8) Compliance with medication — patients were asked to state whether they never missed taking their AEDs, missed less often than once a month, missed less often than once a week, or missed more often than once a week. According to other studies, correlation between patient report and objective method have been shown to be high (Patrick and Erickson, 1993). (9) Perceived stigma was measured with a three-item scale, developed originally for stroke (Hyman, 1971), adapted for epilepsy and already used in other QOL studies (Baker *et al.*, 1997a; Jacoby *et al.*, 1996). Respondents with epilepsy had to state whether they (a) felt that other people were uncomfortable with them, (b) treated them as inferior, or (c) preferred to avoid them. Each of the three items required a yes/no response. An individual's score was the sum of the "yes" responses and the higher the score; the greater was the perception of stigma. The internal consistency of the scale was examined using Cronbach's α and found to be acceptable (α=0.71) (Cronbach, 1951). The evidence for the construct validity of the scale was supported by the data received following the hypotheses that patients with frequent seizures and mixed seizure types would score positively on the scale. (10) The impact of epilepsy on employment history — those currently un- or underemployed were asked whether this was caused by their epilepsy, whether they had changed jobs in the preceding two years because of epilepsy, and whether they had been treated unfairly at work because of epilepsy. Each of the items required a yes/no response.

Patients were divided into three groups by seizure type (as having only tonic-clonic, only other types, or both tonic-clonic and other types) and frequency (based on seizure occurrence once or more a month, less often than once a month, or not at all in the past year).

(11) Driving license — patients were asked to state whether they had never had a driving license, whether they had it, or whether its validity was suspended because of their epilepsy. (12) Health status — respondents were asked to complete a comprehensive generic health status measure, the RAND 36-Item Health Survey 1.0 (RAND-36), which consisted of eight multi-item variables: Physical functioning (PF) — ten items, Social functioning (SF) — two items, Role limitations due to physical problems (RP) — four items, Role limitations due to emotional problems (RE) — three items, Emotional well-being (EW) — five items, Energy and vitality (VT) — four items, Bodily pain (BP) — two items, and General perception of health (GH) — five items. There was a further unscaled single item on changes in respondents' health over the past year (CHG). As indicated in standard RAND-36 scoring algorithms, for each variable item scores were coded, summed, and transformed onto a scale from 0 (worst

possible health state measured by the questionnaire) to 100 (best possible health state) (Rand Health Sciences Program, 1992). (13) Epilepsy-specific data about QOL that was collected using the QOLIE-31 questionnaire — respondents were asked to complete an epilepsy-specific measure, the Quality of Life in Epilepsy Inventory-31 (QOLIE-31) (QOLIE Development Group, 1993), which contained seven multi-item scales: Seizure worry (SW) — five items, Overall quality of life (OQL) — two items, Emotional well-being (EWB) — five items, Energy/fatigue (E/F) — four items, Cognitive functioning (COG) — six items, Medication effects (ME) — three items, Social functioning (SF) — five items. A QOLIE-31 overall score was obtained using a weighted average of the multi-item scale scores. The QOLIE-31 also included a single item that assessed overall health. During the scoring procedure, first, the raw precoded numeric values of items were converted to 0–100 point scores, with higher converted scores always reflecting better QOL. Next, the subtotal scores for each scale were summed and divided by the number of items that the respondent answered within each scale. The QOLIE-31 overall score was calculated by summing the product of each scale score times its weight and summing over all scales.

For the use of both questionnaires, written permission was asked and received from the RAND Office of Contract and Grant Services in Santa Monica, California, USA, in October 1997.

5. Translation procedure of the questionnaires

The scales were translated into Estonian independently by two native Estonian speakers who had an excellent knowledge of English. The translators then met to discuss and agree upon common versions of the questionnaires. Subsequently, the common versions were evaluated by another native Estonian speaker in terms of conceptual equivalence, linguistic performance and clarity. The agreed Estonian forms were then translated back into English and rated. If modifications were necessary, reformulation was performed in the Estonian versions.

6. Piloting

The translated Estonian versions of the RAND-36 and the QOLIE-31 questionnaires were given for self-assessment to 15 epilepsy patients who visited their neurologist at the University's Outpatients' Clinic. During individual interviews, each item and response choice was carefully discussed as to its meaning and connotation with the responders. As a result the wording of five questions

of the RAND-36 and four questions of the QOLIE-31 was altered slightly. Then the questionnaires were mailed by post to 15 epilepsy patients. The goal of this administration was to detect problems with the forms in terms of missing data, inconsistent answers and ease of administration. No respondent found the questionnaires either difficult or too personal.

A question, concerning problems with driving for patients on AED treatment, was excluded during the scoring procedure from the QOLIE-31 questionnaire for those who did not have a driving-license because it did not directly assess the Social function domain in these people. The reason was, as in our society, it is quite common for older people, especially for women, not to have a driving licence or use a car. From 30 patients in the pilot-study, 22 had never had a driving licence. From 15 questionnaires mailed to patients, nine of those who had reported not having a driving-license had left the question unfilled, four reported having had no trouble with it and two marked they had had some trouble. Instead, single open questions concerning driving were added to the measure.

7. Response to the study and data completeness

Questionnaires were sent to identified individuals by post, with a covering letter from the study conducters, explaining the purposes of the study. To those who did not respond to the initial questionnaire a reminder was sent about three to six weeks later. Questionnaires to be completed individually were mailed to 290 patients, of whom 225 replied — a response rate of 78%. From all the questionnaires returned, 22 appeared to be unusable; the remaining 203 questionnaires were included in the study.

The distribution of responses, by the respondents from the epilepsy group to the 36 items of the RAND-36, as well as the number and percentage of patients missing each of the 36 items, is given in **Table 2**. Missing value rates for the items were low and did not exceed 1.5% for any item. The total number of omitted items per questionnaire was 8.3%. 92% completed all 36 items.

Missing value rates for the items of the QOLIE-31 did not exceed 2% for any item. The total number of omitted items per questionnaire was 6.5%. 94% completed all 31 items.

Table 2. RAND-36 item frequency distributions — the epilepsy sample.

Item	Nr	Item						Missing nr	%
		1	2	3	4	5	6		
PF1	202	40.1% (81)	33.7% (68)	26.2% (53)				1	0.5
PF2	202	6.9% (14)	26.7% (54)	66.3% (134)				1	0.5
PF3	202	10.9% (22)	24.3% (49)	64.9% (131)				1	0.5
PF4	202	16.3% (33)	34.7% (70)	49.0% (99)				1	0.5
PF5	202	2.5% (5)	18.8% (38)	78.7% (159)				1	0.5
PF6	202	17.3% (35)	31.2% (63)	51.5% (104)				1	0.5
PF7	202	16.3% (33)	20.3% (41)	63.4% (128)				1	0.5
PF8	202	5.9% (12)	15.4% (31)	78.7% (159)				1	0.5
PF9	202	3.5% (7)	9.0% (18)	87.5% (176)				2	1.0
PF10	202	2.5% (5)	9.4% (19)	88.1% (178)				1	0.5
RP1	202	43.1% (87)	56.9% (115)					1	0.5
RP2	202	54.5% (110)	45.5% (92)					1	0.5
RP3	202	49.5% (100)	50.5% (102)					1	0.5
RP4	202	50.0% (101)	50.0% (101)					1	0.5
RE1	202	45.1% (91)	55.0% (111)					1	0.5
RE2	202	61.4% (124)	38.6% (78)					1	0.5
RE3	202	47.0% (95)	53.0% (107)					1	0.5
EF1	201	16.9% (34)	29.9% (60)	22.4% (45)	18.9% (38)	10.5% (21)	1.5% (3)	2	1.0
EF2	202	21.8% (44)	20.3% (41)	27.2% (55)	19.3% (39)	7.9% (16)	3.5% (7)	1	0.5
EF3	202	2.5% (5)	9.4% (19)	15.8% (32)	20.8% (42)	25.3% (51)	26.2% (53)	1	0.5
EF4	202	9.9% (20)	10.9% (22)	24.8% (50)	28.7% (58)	21.3% (43)	4.5% (9)	1	0.5

Item	Nr	Item						Missing nr	%
		1	2	3	4	5	6		
EW1	201	0.5% (1)	9.0% (18)	16.9% (34)	25.9% (52)	31.8% (64)	15.9% (32)	2	1.0
EW2	202	2.0% (4)	5.0% (10)	12.9% (26)	17.8% (36)	20.8% (42)	41.6% (84)	1	0.5
EW3	202	4.5% (9)	19.3% (39)	35.2% (71)	15.4% (31)	20.3% (41)	5.5% (11)	1	0.5
EW4	202	1.5% (3)	10.9% (22)	14.9% (30)	21.8% (44)	31.7% (64)	19.3% (39)	1	0.5
EW5	202	7.4% (15)	26.7% (54)	25.7% (52)	21.8% (44)	15.8% (32)	2.5% (5)	1	0.5
SF1	202	3.5% (7)	16.5% (33)	15.5% (31)	28.5% (57)	36% (72)		3	1.5
SF2	202	5.0% (10)	12.9% (26)	22.8% (46)	17.8% (36)	41.6% (84)		1	0.5
BP1	202	2.5% (5)	11.4% (23)	19.8% (40)	17.3% (35)	20.8% (42)	28.2% (57)	1	0.5
BP2	202	5.5% (11)	10.9% (22)	21.3% (43)	23.3% (47)	39.1% (79)		1	0.5
GH1	202	16.8% (34)	55.9% (113)	22.8% (46)	3.5% (75)	1.0% (2)		1	0.5
GH2	202	11.9% (24)	15.4% (31)	32.2% (65)	24.3% (49)	16.3% (33)		1	0.5
GH3	202	23.8% (48)	22.3% (45)	22.3% (45)	24.8% (50)	6.9% (14)		1	0.5
GH4	202	6.4% (13)	13.9% (28)	44.1% (89)	15.8% (32)	19.8% (40)		1	0.5
GH5	202	31.7% (64)	20.3% (41)	20.3% (41)	23.8% (48)	4.0% (8)		1	0.5
CHG	202	4.5% (9)	22.3% (45)	51.5% (104)	16.8% (34)	5.0% (10)		1	0.5

8. Psychometric analyses

RAND-36

As **Table 3** shows, means and standard deviations (SD) of the scales were in the range of 44-77 (SD 21-42) for the epilepsy group and in the range of 66-88 (SD 9-33) in the control group. In the epilepsy group, mean and median scores were higher for Physical function and lower for General health. Skewness, measuring

the asymmetry of response distributions, was most marked for Physical function in the epilepsy group and for Role – physical in the control group. But most of the scales were negatively skewed, meaning that subjects more often gave responses representing positive health states. There were substantial ceiling effects for four domains — Physical functioning, Role — physical, Role — emotional, Social functioning in both groups, in the epilepsy group in addition to these — for Bodily pain. Floor effects were significant in two domains in the epilepsy group: 31% and 32.5% of subjects had the minimum possible score in the Role — physical and Role — emotional domains, respectively. The internal consistency coefficients, being above 0.70 for all dimensions, met the level acceptable for group comparisons. The internal consistency coefficients ranged from 0.75 to 0.92. Scaling assumptions were tested in two ways. Correlations between items and hypothesised scales were substantial within each scale and reached the level of >0.40 in all instances, supporting the reliability of the RAND-36 scales in both groups. In the epilepsy group the lowest median item-total correlation was 0.53 for general health, the highest 0.84 for bodily pain. Discriminant validity was considered acceptable when the correlation exceeded all correlation between items and other scales. All the eight scales in both groups passed this level.

The descriptive statistics and reliability data is given in **Tables 3 and 4.**

Table 3. RAND-36 sub-scale descriptive statistics.

RAND-36 sub-scales	Mean (0–100)	Median	SD	Range	Skew-ness	Kurto-sis	Floor (%)	Ceiling (%)
The epilepsy group								
Physical functioning	76.56	85.00	24.26	100.00	−1.14	0.55	1.0	18.2
Role-physical	50.62	50.00	42.10	100.00	−0.01	−1.69	31.0	33.5
Role-emotional	48.60	33.33	41.59	100.00	0.10	−1.62	32.5	32.5
Energy/ fatigue	47.64	50.00	22.14	100.00	0.01	−0.73	1.0	0.5
Emotional well-being	59.80	60.00	20.49	96.00	−0.27	−0.73	0	0.5
Social functioning	69.40	75.00	27.68	100.00	−0.54	−0.78	1.5	28.1
Pain	67.69	70.00	28.67	100.00	−0.55	−0.73	2.5	26.1
General health	43.89	45.00	22.46	95.00	0.12	−0.92	2.0	0
The control group								
Physical functioning	87.20	87.00	9.42	30.00	−0.15	−0.83	0	25.0
Role-physical	86.71	100.00	20.76	100.00	−2.36	6.70	3.0	59.0
Role-emotional	69.13	66.00	33.11	100.00	−0.66	−0.75	8.5	45.0

RAND-36 sub-scales	Mean (0–100)	Median	SD	Range	Skew-ness	Kur-tosis	Floor (%)	Ceiling (%)
Energy/fatigue	65.54	64.00	12.36	76.00	–0.19	0.90	0	0.5
Emotional well-being	67.12	64.00	16.92	72.00	–0.05	–0.27	0	3.0
Socialfunctioning	87.82	88.00	11.50	62.00	–1.11	1.83	0	32.5
Pain	78.97	80.00	12.44	78.00	–1.94	5.72	0	3.5
General health	66.85	64.00	14.09	60.00	0.54	0.25	0	3.0

Table 4. Results of scaling success tests and reliability estimates.

Dimension	Internal consis-tency[a]	Homo-genity[b]	Item discriminant validity[c]	Cron-bach's α	Reliability coefficients
The epilepsy group					
Physical functioning	0.55–0.80	0.55	0.21–0.70	0.92	0.91
Role limitations (physical problems)	0.67–0.76	0.61	0.34–0.63	0.86	0.86
Role limitations (emotional problems)	0.58–0.67	0.56	0.31–0.60	0.79	0.78
Energy/fatigue	0.59–0.73	0.57	0.35–0.69	0.84	0.83
Emotional well-being	0.52–0.75	0.55	0.22–0.74	0.86	0.85
Social functioning	0.62	0.63	0.49–0.61	0.77	0.77
Pain	0.84	0.84	0.52–0.67	0.91	0.90
General health	0.54–0.79	0.53	0.31–0.64	0.85	0.83
The control group					
Physical functioning	0.57–0.72	0.55	0.44–0.70	0.77	0.75
Role limitations (physical problems)	0.42–0.69	0.41	0.35–0.61	0.76	0.78
Role limitations (emotional problems)	0.58–0.76	0.52	0.55–0.72	0.80	0.80
Energy/fatigue	0.56–0.68	0.55	0.40–0.65	0.76	0.75
Emotional well-being	0.68–0.73	0.60	0.57–0.70	0.88	0.88
Social functioning	0.61	0.59	0.42–0.60	0.79	0.78
Pain	0.53–0.76	0.48	0.48–0.69	0.82	0.81
General health	0.47–0.69	0.50	0.43–0.63	0.74	0.75

[a]Correlations, corrected for overlap, between items and hypothesised scales.
[b]Average inter-item correlation
[c]Correlations between items and other scales

QOLIE-31

As **Table 5** shows, means and standard deviations of the scales were in the range of 48-64 (SD 18-26). The mean and median scores were higher for medication effects and lower for Energy/fatigue. Skewness was most marked for Seizure worry. But also most of the scales were negatively skewed, meaning that subjects more often gave responses representing positive health states. There were substantial ceiling effects for two domains — Energy/fatigue and Social functioning. Floor effects were significant in two domains: 3.45% and 1.97% of subjects had the minimum possible score in the Seizure worry and Medication effects domains, respectively. The internal consistency coefficients, being above 0.70 for all dimensions, met the level acceptable for group comparisons. The internal consistency coefficients ranged from 0.71 to 0.88. Scaling assumptions were tested in two ways. Correlations between items and hypothesised scales were substantial within each scale and reached the level of >0.40 in all instances, supporting the reliability of the QOLIE-31 scales. The lowest median item-total correlation was 0.43 for Medication effects, the highest 0.62 for Overall quality of life. Discriminant validity was considered acceptable when correlation exceeded all correlation between items and other scales. All the seven scales passed this level.

The data about the descriptive statistics and reliability is given in **Tables 5 and 6**.

Table 5. QOLIE-31 sub-scale descriptive statistics.

QOLIE-31 sub-scales	Mean (0–100)	Median	SD	Range	Skew-ness	Kurto-sis	Floor (%)	Ceiling (%)
Seizure worry	54.67	60	26.26	95	−0.43	−0.97	3.45	0.49
Overall quality of life	49.18	50	17.59	95	0.31	0.12	0.49	0.49
Emotional well-being	60.14	60	19.95	100	−0.30	−0.75	0.49	0.49
Energy/ fatigue	48.40	50	20.17	85	−0.11	−0.70	0.49	4.43
Cognitive functioning	59.41	61.95	23.75	92.50	−0.32	−0.85	0.49	0.99
Medication effects	63.64	63.90	27.70	88.90	0.11	1.05	1.97	0.49
Social functioning	63.54	65	25.08	95	−0.29	−0.83	0.49	11.33
Overall	57.38	50	18.50	100	0.01	0.2	0	0

Table 6. Results of scaling success tests and reliability estimates.

Dimension	Internal consistency[a]	Homogenity[b]	Item discriminant validity[c]	Cronbach's α	Reliability coefficients
Seizure worry	0.59–0.81	0.56	0.21–0.57	0.86	0.86
Overall quality of life	0.62	0.62	0.28–0.67	0.77	0.77
Emotional well-being	0.59–0.75	0.55	0.23–0.73	0.85	0.86
Energy/fatigue	0.53–0.67	0.50	0.19–0.69	0.79	0.80
Cognitive functioning	0.62–0.75	0.55	0.28–0.59	0.88	0.88
Medication effects	0.38–0.50	0.43	0.20–0.48	0.72	0.71
Social functioning	0.51–0.65	0.47	0.30–0.64	0.77	0.78
Overall	0.74	–	–	0.89	0.90

[a]Correlations, corrected for overlap, between items and hypothesised scales.
[b]Average inter-item correlation
[c]Correlations between items and other scales

9. Validity

Validity of both scales was assessed using discriminant techniques. The RAND-36`s and QOLIE-31's ability to distinguish between high and a low symptom load was determined assessing by seizure type and frequency.

RAND-36
The descriptive statistics and features of score distribution for the RAND-36 scales are detailed in **Tables 7 and 8**. Variance between seizure types was statistically significant in five RAND-36 domains. The comparisons between groups were investigated for each domain using Tukey's studentized range test at the 0.05 level. Patients who did not have generalised tonic-clonic seizures or multiple seizure types had significantly higher scores in the Role — physical and Social functioning. Those who had multiple seizure types had lower scores than those with only tonic-clonic seizure types or those with other types of seizures only in the Role — emotional. Those who experienced multiple seizure types scored significantly lower in the Emotional well-being and Bodily pain domains compared to those who did not have generalised tonic-clonic seizures. (Fig. 1)

Variance between seizure frequency statuses was statistically significant in seven domains. The differences were significant between all the three groups in the Role — emotional domain. Between those who had not had seizures in the past year and those who had had seizures at least once a month or less often than once a month the differences were significant in the Role limitations – physical, Energy/fatigue, and General health domains. Those experiencing

seizures once or more in a month scored significantly worse in the Role limitations — emotional, Emotional well-being and Social functioning compared to those who had been seizure-free in the last year. In the Bodily pain domain, the differences were significant between those having seizures once or more in a month compared to those who had had seizures less often than once a month or had not had them in the last year. (**Fig. 2**)

Discriminative power was examined by comparing RAND-36 score profiles of the healthy respondents and respondents with epilepsy. As shown in **Fig. 3**, the respondents with epilepsy scored significantly lower in all RAND-36 domains than the controls ($p \leq 0.001$), indicating that their perceived health status was poorer. The differences were most remarkable in Role — physical, Role — emotional, Social functioning and General health domains. (**Table 9**)

Fig. 1. Comparison of mean scores for the RAND-36 health status measure by seizure type.
* Test of significance was Kruskal-Wallis one-way analysis of variance.

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Table 7. Descriptive statistics and features of score distributions for the RAND-36 Health Survey by seizure type.

Domain	Tonic-clonic only (n=84)				Tonic-clonic and others (n=61)				Others only (n=58)				p-value*
	Mean	Median	CI	SEM	Mean	Median	CI	SEM	Mean	Median	CI	SEM	
Physical functioning	74.5	87.5	68.7–80.4	2.9	74.2	75	67.4–79.0	2.9	83.0	90	77.7–88.4	2.7	0.06
Role-physical	48.5	25	39.1–57.9	4.7	43.9	25	32.5–55.2	5.7	60.8	62.5	51.2–70.3	4.8	0.05
Role-emotional	51.6	33.3	42.5–60.7	4.6	39.9	33.33	29.5–50.3	5.2	53.5	66.66	42.6–64.3	5.4	0.03
Energy/fatigue	46.0	45	40.9–51.2	2.6	45.2	50	39.7–50.6	2.7	52.6	55	47.2–57.9	2.7	0.1
Emotional well-being	60.8	64	56.4–65.1	2.2	55.2	56	49.5–60.9	2.8	63.2	64	58.3–68.2	2.5	0.02
Social functioning	67.7	75	61.6–73.9	3.1	62.5	62.5	55.4–69.6	3.6	79.1	87.5	72.8–85.4	3.1	0.006
Bodily pain	68.4	68.75	62.2–74.6	3.1	60.1	67.5	52.2–67.9	3.9	74.6	77.5	68.1–81.1	3.3	0.04
General health	42.1	40	37.4–46.9	2.4	43.9	40	37.6–50.1	3.1	46.5	45	40.9–52.0	2.8	0.4

CI, 95% confidence interval; SEM, standard error of the mean.
* Variance between seizure types. Test of significance was Kruskal-Wallis one-way analysis of variance.

Table 8. Descriptive statistics and features of score distributions for the RAND-36 Health Survey by seizure frequency status in the last year.

Domain	≥1 seizure a month (n=53)				<1 seizure a month (n=81)				seizure free (n=69)				p-value*
	Mean	Median	CI	SEM	Mean	Median	CI	SEM	Mean	Median	CI	SEM	
Physical functioning	73.0	75	67.3–78.7	2.8	74.3	85	68.5–80.2	2.9	81.9	90	76.3–87.5	2.8	0.07
Role-physical	33.5	25	23.4–43.6	5.0	49.4	50	40.3–58.5	4.6	65.2	100	55.1–75.4	5.1	0.0001
Role-emotional	27.0	30	17.7–36.4	4.7	49.0	33.33	39.9–58.1	4.6	64.7	100	55.0–74.4	4.9	0.0001
Energy/fatigue	45.1	50	39.7–50.5	2.7	43.2	40	38.2–48.2	2.5	54.8	60	49.5–60.1	2.6	0.004
Emotional well-being	55.1	56	49.6–60.6	2.7	58.4	60	53.8–63.0	2.3	65.0	72	60.3–69.8	2.4	0.02
Social functioning	59.2	62.5	51.6–66.8	3.8	69.1	75	63.0–75.3	3.1	77.5	87.5	71.5–83.5	3.0	0.001
Bodily pain	56.2	57.5	48.1–64.3	4.0	68.1	77.5	61.8–74.4	3.1	76.1	80	69.9–82.2	3.1	0.0006
General health	39.3	40	33.6–44.9	2.8	41.0	40	36.0–45.9	2.5	50.9	50	45.4–56.3	2.7	0.005

CI, 95% confidence interval; SEM, standard error of the mean.
* Variance between seizure frequencies. Test of significance was Kruskal-Wallis one-way analysis of variance.
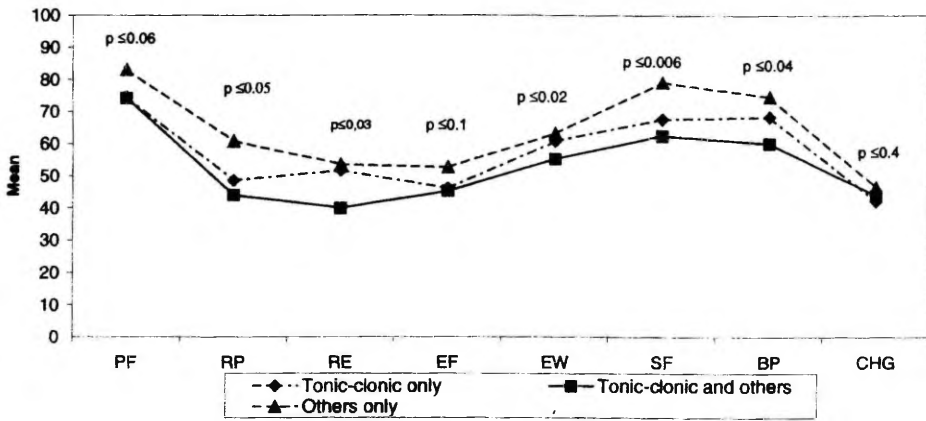
Fig. 2. Comparison of mean scores for the RAND-36 health status measure by seizure frequency status.
* Test of significance was Kruskal-Wallis one-way analysis of variance.

Table 9. Mean scores of dimensions of RAND-36 questionnaire

Dimension	Epilepsy group	Control group	p-value*
Physical functioning	76.56	87.20	0.0001
Role limitations (physical problems)	50.62	86.71	0.0001
Role limitations (emotional problems)	48.60	69.13	0.0001
Energy/fatigue	47.64	65.54	0.0001
Emotional well-being	59.80	67.12	0.001
Social functioning	69.40	87.82	0.0001
Bodily pain	67.69	78.97	0.0001
General health	43.89	66.85	0.0001

* Variance between groups. Test of significance was Kruskal-Wallis one-way analysis of variance.

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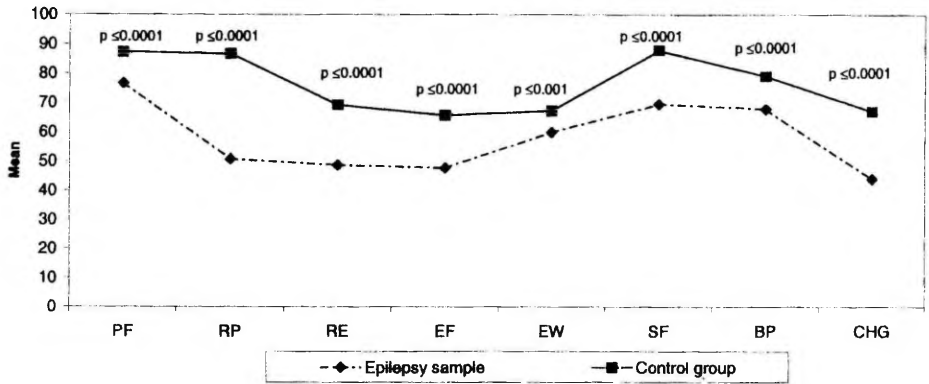
Fig. 3. Discriminative power of RAND-36.
Comparison of mean scores for the RAND-36 health status measure: people with epilepsy and the control group.
* Test of significance was Kruskal-Wallis one-way analysis of variance

QOLIE-31

The descriptive statistics and features of score distribution for the QOLIE-31 scales are detailed in **Tables 10 and 11.** Variance between seizure types was statistically significant in four QOLIE-31 domains. The comparisons between groups were investigated for each domain using Tukey's studentized range test at the 0.05 level.

Patients who did not have generalised tonic-clonic seizures or multiple seizure types had significantly higher scores in the Overall quality of life and Social functioning domains. Those who had multiple seizure types had lower scores than those with only tonic-clonic seizure types or those with other types of seizures only in the Seizure worry and Medication effects. Those who experienced multiple seizure types scored significantly lower in the Seizure worry, Medication effects and Social functioning domains compared to those who did not have generalised tonic-clonic seizures. **(Fig. 4)** The overall score of the QOLIE-31 was significantly different between all the three groups of seizure types.

Variance between seizure frequency statuses was statistically significant in all seven domains. The differences were significant between all the three groups in the Seizure worry, Medication effects and Social functioning domain. Between those who had not had seizures in the past year and those who had had seizures at least once a month or less often than once a month, there were significant differences in the Overall quality of life, Emotional well-being, Energy/fatigue, Cognitive function domains and between the values of the overall score of the questionnaire. **(Fig. 5)**

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Table 10. Descriptive statistics and features of score distributions for the QOLIE-31 by seizure type.

Domain	Tonic-clonic only (n=84)				Tonic-clonic and others (n=61)				Others only (n=58)				p-value*
	Mean	Median	CI	SEM	Mean	Median	CI	SEM	Mean	Median	CI	SEM	
Seizure worry	56.27	60.8	50.8–61.7	2.8	47.83	48.3	40.9–54.8	3.5	59.52	65.7	52.8–66.3	3.4	0.04
Overall quality of life	47.89	50.0	44.2–51.6	1.8	46.27	45.0	41.4–51.2	2.5	54.09	50.0	49.9–58.3	2.1	0.03
Emotional well-being	60.91	62.0	56.7–65.1	2.1	56.85	52.0	51.2–62.5	2.8	62.48	68.0	57.6–67.3	2.4	0.27
Energy/fatigue	46.19	45.0	41.5–50.8	2.3	47.54	45.0	42.4–52.7	2.6	52.50	55.0	47.7–57.3	2.4	0.17
Cognitive functions	60.54	66.1	54.9–66.1	2.8	55.43	56.1	49.5–61.3	2.9	61.96	62.6	56.4–67.5	2.8	0.28
Medication effects	65.04	66.7	59.3–70.8	2.9	58.43	61.1	52.8–66.2	3.4	67.10	62.5	57.6–71.4	3.5	0.05
Social functioning	63.51	65.6	57.9–69.1	2.8	57.68	57.5	51.0–64.4	3.4	69.75	68.8	64.2–75.3	2.8	0.03
Overall	57.50	58.0	53.4–61.6	2.1	53.40	51.3	48.4–58.4	2.5	61.40	59.6	57.1–65.7	2.1	0.05

CI, 95% confidence interval; SEM, standard error of the mean.
* Variance between seizure types. Test of significance was Kruskal-Wallis one-way analysis of variance.

Table 11. Descriptive statistics and features of score distributions for the QOLIE-31 by seizure frequency status in the last year.

Domain	≥1 seizure a month (n=53)				<1 seizure a month (n=81)				seizure free (n=69)				p-value*
	Mean	Median	CI	SEM	Mean	Median	CI	SEM	Mean	Median	CI	SEM	
Seizure worry	44.76	48.0	37.2–52.3	3.7	53.95	62.7	48.5–59.4	2.8	63.12	70.0	57.2–69.0	3.0	0.0005
Overall quality of life	46.79	50.0	43.4–50.1	1.7	45.15	45.0	41.2–49.1	2.0	55.73	55.0	51.2–60.3	2.3	0.0005
Emotional well-being	57.28	56.0	51.9–62.7	2.7	57.09	60.0	52.6–61.6	2.3	65.91	72.0	61.4–70.4	2.3	0.01
Energy/fatigue	46.51	45.0	41.2–51.8	2.7	44.51	45.0	40.1–48.9	2.2	54.42	55.0	49.6–59.3	2.4	0.008
Cognitive functions	53.10	57.0	47.5–58.7	2.8	56.85	61.1	51.7–62.0	2.6	67.27	73.6	61.3–73.3	3.0	0.002
Medication effects	54.98	55.6	47.4–62.5	3.8	59.57	58.3	54.0–65.2	2.8	75.08	77.8	69.6–82.5	3.2	0.0001
Social functioning	53.36	56.3	47.1–59.6	3.1	61.24	62.5	56.1–66.4	2.6	74.07	82.5	68.1–80.1	3.0	0.0001
Overall	51.50	50.9	47.0–56.0	2.3	54.50	54.4	50.7–58.4	1.9	65.20	69.3	60.7–69.8	2.3	0.0001

CI, 95% confidence interval; SEM, standard error of the mean.
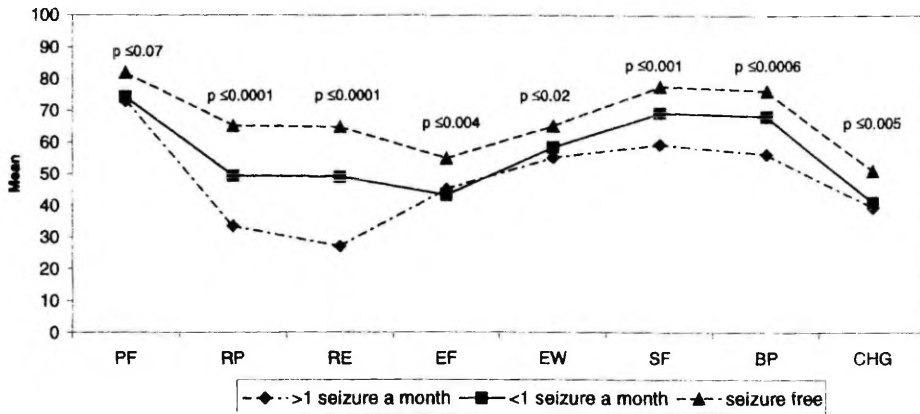Variance between seizure frequencies. Test of significance was Kruskal-Wallis one-way analysis of variance.

Fig. 4. Comparison of mean scores for the QOLIE-31 by seizure type.
Test of significance was Kruskal-Wallis one-way analysis of variance.
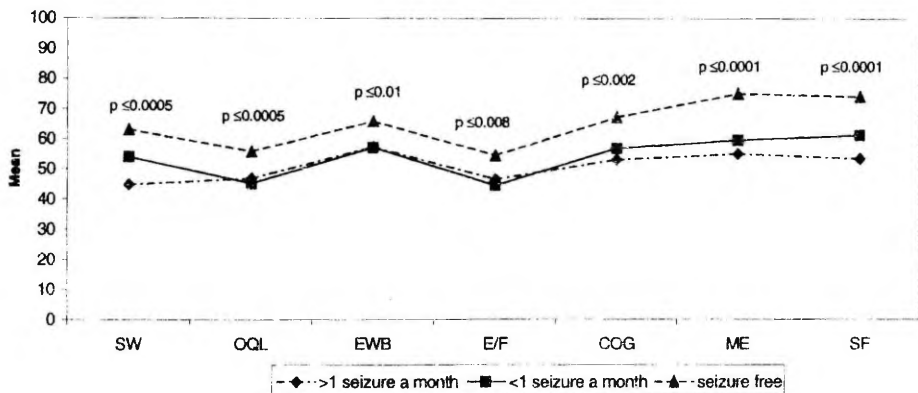
Fig. 5. Comparison of mean scores for the QOLIE-31 by seizure frequency.
* Test of significance was Kruskal-Wallis one-way analysis of variance.

7. Statistical methods

The data were analysed using statistical analysis package SPSS Professional Statistics[TM] 7.5 (SPSS Inc., 1997). Test of significance was one-way analysis of variance (ANOVA). Attention is drawn to results which differences were significant at the 5% level or less ($p \le 0.05$). The questionnaires were evaluated using the data completeness at an individual item and scale level, correlation between items and hypothesised scales, correlation between items and other scales, average inter-item correlation, internal-consistency reliability (Cronbach's α) and score distributions (floor and ceiling effects, skewness and kurto-

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sis). 95% confidence intervals (CI) were computed to define the range of variation around the mean. Construct validity was assessed in connection with seizure frequency and seizure type following hypotheses that patients with frequent seizures and patients with tonic-clonic or multiple seizure types would have poorer health status. To test for such comparisons between groups, Tukey's studentized range test was used for each variable.

RESULTS

1. Socio-demographic characteristics of the sample

The main data of the respondents from Tartu and Viljandi is given comparatively in **Table 12**. Unfortunately, when analysed separately, there were no remarkable statistically significant differences found either between the groups or with the factors. This is the reason why the results of the patients from two towns were summed up and interpreted together. The median age of the study population was 41 years (25th and 75th percentiles 29 and 57). The respondents of the study were divided into five age groups: 20–29 years — 54 (26.6%), 30-39 years — 42 (20.7%), 40–49 years — 35 (17.2%), 50–59 years — 28 (13.8%), and 60 years and older — 44 (21.7%). Men accounted for 48.8% (99). 82 (40.9%) were married or cohabiting, 84 (41.4%) were single, 21 (10.3%) were divorced and 15 (7.4%) were widowed. 90 (44.3%) had less than primary (lower than 8th grade) or primary education (8th or 9th grade), and 113 (55.7%) high school (11th or 12th grade) or university education. 67 (33%) were working full-time, 87 (41.9%) were un- or underemployed and 49 (24.1%) were retired or receiving disability pension. (**Table 13**) Only one person (0.5%) described his economic and financial status as very good, 17 (8.5%) — as good, 119 (59%) — as satisfactory, 53 (26.2%) — as moderately bad, 12 (5.9%) — as very bad. 71.4% (145) of respondents had never had a driving license, 17.2% (35) had a driving license and in 11.3% (23) the driving license was invalidated because of their epilepsy.

The median age of the control group was 40 (25th and 75th percentiles 27 and 56) years. 98 (49%) were men. 16 (8%) had less than primary education (lower than 8th level), 64 (32%) had primary education (8th or 9th level), 98 (49%) had high school education, and 11% had graduated from university.

Table 12. The main comparative results of the respondents from Tartu and Viljandi.

Parameter	Respondents from Tartu (total 122)		Respondents from Viljandi (total 81)	
	n	%	n	%
Median age	42 years		39 years	
Sex (M/F)	56/66	45.9/54.1	43/38	53.1/46.9
Marital status				
married/cohabiting	55	45.1	28	34.6
single	45	36.9	39	48.1
divorced	14	11.5	7	8.6
widowed	8	6.5	7	8.6
Employment status				
full-time	40	32.8	27	33.3
underemployed	45	36.9	20	24.7
unemployed	7	5.7	15	18.6
retired or receiving disablement pension	30	24.6	19	23.4
Education				
less than primary (lower than 8th grade)	8	6.6	14	17.3
primary (8th or 9th grade)	41	33.6	27	33.3
high school (11th or 12th grade)	60	49.2	33	40.7
university	13	10.7	7	8.6
Duration of epilepsy				
up to 1 year	6	4.9	5	6.2
2–5 years	22	18.0	23	28.4
6–10 years	22	18.0	24	29.6
11–20 years	29	23.8	15	18.5
over 20 years	43	35.3	14	17.3
Age at onset				
under 10 years	15	12.3	5	6.2
11–20 years old	38	31.1	30	37.0
21–30 years old	25	20.5	13	16.0
31–40 years old	17	13.9	19	23.5
41–50 years old	11	9.0	4	4.9
over 50 years old	16	13.1	10	12.3
Seizure type				
tonic-clonic only	47	38.5	37	45.7
tonic-clonic and others	51	41.8	10	12.3
others only	24	19.7	34	42.0
Seizure frequency status in the last year				
seizure free	39	32.0	30	37.0
<1 seizure a month	46	37.7	35	43.2
≥1 seizure a month	37	30.3	16	19.8

Parameter	Respondents from Tartu (total 122)		Respondents from Viljandi (total 81)	
	n	%	n	%
Medication				
free of medication	17	13.9	6	7.4
on AED treatment	105	86.1	75	92.6
Of those receiving AED medication				
on monotherapy	88	83.8	63	84.0
receiving 2 AEDs	11	10.5	11	14.7
receiving ≥3 AEDs	6	5.7	1	1.3
Type of drug				
carbamazepine	64	72.7	49	77.8
valproate	8	9.1	7	11.1
primidone	6	6.8	6	9.5
phenytoin	5	5.7	0	0
phenobarbital	3	3.4	1	1.6
bensobarbital	2	2.3	0	0
Side-effects of the AED therapy				
Yes	91	74.6	62	76.5
No	31	25.4	19	23.5
Number of reported side-effects				
One	16	17.6	5	8.1
Two	15	16.5	4	6.4
Three or more	60	65.9	53	85.5

Table 13. Socio-demographic characteristics of the study respondents.

Parameter	Study respondents	%
Age (median)	41 years	
Sex (M/F)	99/104	48.8/51.2
Marital status		
married/cohabiting	83	40.9
single	84	41.4
divorced	21	10.3
widowed	15	7.4
Employment status		
full-time	67	33.0
underemployed	65	31.9
unemployed	22	11.0
retired or receiving disablement pension	49	24.1
Education		
less than primary (lower than 8th grade)	22	10.8
primary (8th or 9th grade)	68	33.5
high school (11th or 12th grade)	93	45.8
university	20	9.9

2. Epilepsy characteristics of the sample

The main disease characteristics are presented in **Table 14**. The median age of the onset of epilepsy was 26.9 years, and the median duration of epilepsy was 11.3 years (25th and 75th percentiles 5.8 and 22.4). Patients were divided into five groups by duration of the disease and into six groups by age at onset of their epilepsy. 84 (41.4%) reported having only tonic-clonic seizures, 61 (30%) reported having both tonic-clonic and other types of seizures, and 58 (28.6%) reported having only other types of seizures. Almost a third (69, 34%) had been seizure-free in the last year, 81 (39.9%) had less than one seizure a month, and 53 (26.1%) had one or more seizures a month. Of those who had had at least one seizure in the past year (134 patients), 19 (14%) reported having serious injuries (burn, scald), 51 (38%) head injuries, 29 (22%) milder injuries or headache, 7 (5%) other injuries. More than a fifth (28, 21%) had not experienced any injuries. Those having seizures once or more in a month (χ^2=11.89, df=2, p=0.001) and those having multiple or generalised tonic-clonic seizure types (χ^2=9.94, df=2, p=0.009) were more likely to report a seizure-related injury. 15 (7.4%) described their seizures as very severe, 61 (30%) as severe, 84 (41.4%) as moderate, and 43 (21.2%) as light. There was a significant correlation with the subjective assessment about the severity of the seizures (those assessing their seizures as very severe or severe and those considering them moderate or light were counted together) with reported seizure-related injuries (χ^2=15.24, df=4, p=0.003). 180 (88.7%) were receiving AED treatment. 151 (83.9%) of them were receiving monotherapy. The majority (113, 74.8%) of those on monotherapy were receiving carbamazepine. The most commonly experienced side effects were non-specific: memory problems (31%), tiredness (25%), sleepiness (20%), headache (20%) and nervousness (20%). **(Table 15)** From those experiencing any of the symptoms associated with the AED treatment, the majority (113, 73.9%) reported having three or more. A third of subjects (50, 33%) reported no side effects. The majority of respondents (142, 78.8%) on AED treatment described their epilepsy as very or fairly well controlled by this, 38 (21%) stated that the level of control was unsatisfactory. Almost two fifths of respondents 74 (41.1%) receiving medication had changed it at least once in the past year; 51 (68.4%) had changed it once, 17 (22.8%) twice and 6 (8.8%) three or more times. 59 (79.3%) of those who had changed their medication once in the past year had changed it because of unsatisfactory control and 15 (20.7%) because of side effects. Compliance with medication: 101 (56%) of respondents said they never missed taking AEDs, 41 (23%) reported missing on average once a month, 25 (14%) reported missing once a week, and 13 (7%) more than once a week. 36 (17.7%) had some other disease or health problem in addition to epilepsy and 24 (11.8%) were receiving medical treatment because of these. The most common additional diseases were cardiovascular 14 (39%) and rheumatological 12 (33%), followed by the

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diseases of the lungs 5 (13.9%), endocrinological 3 (8.3%), gastrointestinal 1 (2.8%) and renal diseases 1 (2.8%).

Table 14. Disease characteristics of the study respondents.

Parameter	Study respondents	%
Duration of epilepsy (median)	11.3 years	
up to 1 year	11	5.4
2–5 years	45	22.2
6–10 years	46	22.7
11–20 years	44	21.7
over 20 years	57	28.1
Age at onset		
under 10 years	20	9.9
11–20 years old	68	33.5
21–30 years old	38	18.7
31–40 years old	36	17.7
41–50 years old	15	7.4
over 50 years old	26	12.8
Seizure type		
tonic-clonic only	84	41.4
tonic-clonic and others	61	30.0
others only	58	28.6
Seizure frequency status in the last year		
seizure free	69	34.0
<1 seizure a month	81	39.9
≥1 seizure a month	53	26.1
Medication		
free of medication	23	11.3
on AED treatment	180	88.7
Of those receiving AED medication		
on monotherapy	151	83.9
receiving 2 AEDs	22	12.2
receiving ≥3 AEDs	7	3.9
Type of drug		
carbamazepine	113	74.8
valproate	15	9.9
primidone	12	7.9
phenytoin	5	3.4
phenobarbital	4	2.7
bensobarbital	2	1.3

Table 15. Subjects' reports of AED side effects by type of the three most often used AEDs (number of subjects reporting side effects always, often, or sometimes in the last month; in patients receiving monotherapy only).

Reported side effect	CBZ n=113	VPA n=15	PRIM n=12	p-value*
Dizziness	12	0	2	NS
Tiredness	28	5	4	NS
Unsteadiness	16	0	4	0.02
Nausea/vomiting	7	0	1	NS
Skin itch, rash	11	1	3	NS
Sleepiness	26	4	2	NS
Mood changes	19	1	3	NS
Nervousness/agitation	26	3	0	NS
Headache	24	0	5	0.01
Shaky hands	12	3	1	NS
Weight gain	3	2	1	NS
Heart problems	18	0	4	0.03
Hair loss	6	1	0	NS
Difficulty in concentrating	18	3	1	NS
Memory problems	38	2	6	NS
Slurred speech	6	1	0	NS
Double/blurred vision	8	1	0	NS

CBZ-carbamazepine; VPA-valproate; PRIM-primidone.

* Test of significance was χ^2; NS-not significant.

3. Perceived stigma

More than half of all respondents (106, 52.4%) felt stigmatised by their epilepsy. 25 (24.7%) answered "yes" to all three items and this shows that they were highly stigmatised. Respondents were more likely to feel stigmatised if they had frequent seizures (χ^2=23.57, df=6, p<0.0001) or mixed seizure types (χ^2= 20.65, df=6, p<0.009). (**Table 16**) At the same time, only 76 (37.4%) considered their seizures very severe or severe. Those who had experienced seizures during the last year (χ^2=18.63, df=1, p<0.0001) and those who had tonic-clonic type of seizures only or together with other seizure types (χ^2=7.02, df=1, p<0.008) were more likely to score highly (to give two or three "yes" answers) on the stigma scale. Stigmatisation was more common among those having university or high school education (χ^2=12.89, df=6, p<0.05). No differences were found in scores on the stigma scale by sex, marital status, or employment status.

Table 16. Reported stigma by seizure type and frequency.

Parameter	Score on stigma scale			
	0	1	2	3
Seizure type				
Tonic-clonic only (n=84)	46.4%	27.5%	11.6%	14.5%
Tonic-clonic and other (n=61)	29.8%	27.7%	23.4%	19.1%
Other only (n=58)	65.4%	17.3%	13.5%	3.8%
χ^2=20.65, p<0.009				
Seizure frequency				
One or more a month (n=53)	25.6%	27.9%	27.9%	18.6%
Less than one a month (n=81)	45.6%	27.9%	11.8%	14.7%
None in past year (n=69)	68.8%	17.2%	12.1%	6.9%
χ^2=23.57, p<0.0001				

4. Employment status

A third of all respondents were working full-time. Employment status (working either full-time or being underemployed; those retired or receiving disability pension were excluded) was significantly related to age (χ^2=12.02, df=4, p=0.03), seizure frequency (χ^2=10.81, df=2, p=0.004), age at the onset of seizures (χ^2=15.13, df=5, p=0.01) and education (χ^2=11.38, df=3, p=0.01). 54 (62%) of those who were un- or underemployed named epilepsy as the significant reason for it. Respondents with frequent seizures were more likely to believe it (χ^2=11.03, df=2, p=0.001). During the last two years, 47 (29%) of respondents had changed jobs (meaning a change of workplace, not change of speciality or loss of job). Men (χ^2=7.07, df=1, p<0.003) and those with frequent seizures (χ^2=11.79, df=2, p<0.006) were more likely to do this. 74 (44%) said that they had been treated unfairly at work or when getting a job. There were significant interactions between this opinion and seizure frequency, type and education: respondents with frequent seizures (χ^2=16.26, df=2, p=0.0001), respondents having tonic-clonic or multiple seizure types (χ^2=8.94, df=1, p=0.002) and respondents who had lower than high school education (χ^2=7.32, df=1, p=0.007) were more likely to report this. Although it was not asked, several respondents commented on the fact that they had hidden their diagnosis of epilepsy from employers and colleagues because of the fear of discrimination and shame. Also, there was a significant interaction between full-time work and educational level (those retired or receiving a disablement pension were excluded): the higher the person's education, the more likely he or she was to be working full-time (χ^2=12.12, df=6, p=0.04).

5. Results of the RAND-36
(including comparison with the control group)

The results of the final models fitted to each RAND-36 domain score, including the factors that remain significant after controlling for the others, are shown in **Table 17**. Each multi-factor model is a main effect model (no significant interactions were found between the factors). Pairs of groups of significantly different factors were compared using Tukey HSD or Bonferroni's procedures. Scores of the RAND-36 domains were first compared in terms of the clinical variables. Significant differences were found for seizure frequency in all domains, except the Physical functioning domain. Seizure-free patients scored significantly higher than patients who had experienced seizures during the last year in the Role limitations — physical, Energy/fatigue, Bodily pain, and General health domains. The difference between those who had had seizures once or more in a month compared to those having seizures less often than once a month or not having seizures during the last year was significant in the Role limitations-emotional, Emotional well-being, and Social functioning domains.

In the Role limitations-physical domain, age, stigmatisation, stigma severity, and age at onset of epilepsy became significant after controlling for seizure frequency. Younger people were less likely to score low in this domain, and there were significant differences between the 20–29 and 30–39 age groups compared to people who belonged to the 60 years and over age group. Mean scores for this domain were significantly lower for those who were stigmatised, and for those who expressed very strong feelings of stigma (gave three "yes" answers on the stigma scale) compared to those who expressed less (one "yes" answer). Later age at onset was associated with lower scores, differences were significant between those for whom epilepsy had been diagnosed at the age of 41–50 or above 50 compared to those for whom it had been diagnosed at an age under 20.

In the Role limitations — emotional domain, mean scores were significantly lower for those who were stigmatised and for those who expressed very strong feelings of stigma (gave three "yes" answers on the stigma scale) compared to those who expressed themselves less strongly (one "yes" answer).

In the Energy/fatigue domain, employment status, duration of epilepsy, and age at onset of epilepsy were significant. In this domain, mean scores were significantly lower for those currently unemployed, in comparison to those who were in full-time or underemployed work, for those who had suffered from epilepsy for two to five, and six to ten years compared to those who had suffered longer and for those whose epilepsy had been diagnosed at the age of 41–50 or over 50 compared to those for whom it had been diagnosed at an age under 20 years.

Table 17. Results of the RAND-36 using analysis of variance models.

Domains	Factors	Mean square ratio	p-value
Physical functioning	Stigmatisation	4.78	0.03
	Age at onset	3.65	0.001
	Current age	4.39	0.001
Role limitations	Seizure frequency	9.27	0.0001
(physical problems)	Current age	3.54	0.02
	Stigmatisation	8.93	0.003
	Stigma severity	4.16	0.02
	Age at onset	3.15	0.01
Role limitations	Seizure frequency	13.89	0.0001
(emotional problems)	Stigmatisation	7.91	0.005
	Stigma severity	3.47	0.03
Energy/fatigue	Seizure frequency	24.20	0.0001
	Employment	3.26	0.02
	Duration of disease	3.27	0.02
	Age at onset	2.66	0.03
Emotional well-being	Seizure frequency	3.96	0.03
	Stigmatisation	4.27	0.04
	Duration of disease	3.27	0.02
Social functioning	Seizure frequency	11.88	0.0001
	Stigmatisation	6.98	0.01
	Stigma severity	8.83	0.0007
	Employment	23.85	0.0001
	Seizure type	5.88	0.003
	Age at onset	3.34	0.007
Bodily pain	Seizure frequency	7.76	0.0006
	Duration of disease	2.44	0.05
General health	Seizure frequency	5.36	0.005
	Age at onset	3.25	0.009
	Stigmatisation	4.69	0.03
	Stigma severity	3.82	0.03

In the Emotional well-being domain, those who were stigmatised had significantly lower scores than those who were not and of those who had suffered from epilepsy two to five years compared to those who had suffered more than twenty years.

In the Social functioning domain, stigmatisation, stigma severity, employment status, seizure type, and age at onset of seizures became significant. Significantly lower scores were obtained by those who were stigmatised, those who expressed very strong feelings of stigma (gave three "yes" answers) compared to those who did not feel this so strongly (one "yes" answer), those who were currently unemployed compared to those who were in full-time employment or underemployed, those who experienced either tonic-clonic or multiple seizure types compared to those who had only other types of seizures, and those

for whom epilepsy had been diagnosed at the age of 41–50 or over 50 compared to those for whom it had been diagnosed at an age under 20 years.

In the Bodily pain domain, lower scores were related to a shorter (2–5 years) rather than longer (11–20 and more than 20 years) duration of epilepsy.

In the General health domain, mean scores were significantly lower for those whose epilepsy had been diagnosed at the age of 41–50 or over the age of 50 compared to those for whom it had been diagnosed at under the age of 20. Those who were stigmatised also scored significantly lower than those who were not, and those who expressed very strong feelings of stigma (gave three "yes" answers) in comparison to those who did not (one "yes" answer).

In the Physical functioning domain, stigmatisation, age at onset, and current age were found to be significant. Mean scores in this domain were significantly lower for those who were stigmatised compared to those who were not and for those aged 60 years or older compared to those 20–29 years old. The overall pattern of variation in terms of age at onset was similar to that in the General health domain.

6. Results of the QOLIE-31

As with the RAND-36 questionnaire, scores of the QOLIE-31 domains were first compared in terms of the clinical variables. Significant differences were found for seizure frequency in all domains. The results of the final models after controlling for seizure status are shown in **Table 18**.

In the Seizure worry domain, seizure type, education, type of AED therapy, stigmatisation and stigma severity remained significant. Significantly lower scores were obtained by those who experienced either tonic-clonic or multiple seizure types compared to those who had only other types of seizures, those who had high school or university education compared to those who had primary or less than primary education, those who were on polytherapy compared to those on monotherapy, those who were stigmatised, and those who expressed very strong feelings of stigma (gave three "yes" answers) compared to those who did not (one "yes" answer).

In the Overall quality of life domain, seizure type, stigmatisation, age at onset, marital status, employment, type of AED therapy and AED side effects remained significant. Significantly lower scores were obtained by those who experienced either tonic-clonic or multiple seizure types compared to those who had only other types of seizures, those who expressed very strong feelings of stigma (gave three "yes" answers) compared to those who did not (one "yes" answer), those for whom epilepsy had been diagnosed at the age of 41–50 or above 50 compared to those for whom it had been diagnosed at an age under 20, those who were married or cohabiting compared to those who were single, those who were currently unemployed compared to those who were in full-time employment

Table 18. Results of the QOLIE-31 using analysis of variance models.

Domains	Factors	Mean square ratio	p-value
Seizure worry	Seizure frequency	25.46	0.0001
	Seizure type	4.26	0.03
	Education	2.45	0.04
	Type of AED therapy	3.89	0.005
	Stigmatisation	5.73	0.001
	Stigma severity	5.68	0.02
Overall quality of life	Seizure frequency	15.47	0.0001
	Seizure type	12.86	0.004
	Stigmatisation	8.35	0.007
	Age at onset	7.32	0.008
	Marital status	4.12	0.01
	Employment	3.68	0.03
	Type of AED therapy	3.53	0.03
	AED side effects	2.75	0.04
Emotional well-being	Seizure frequency	6.36	0.001
	Duration of epilepsy	4.25	0.003
	Employment	3.78	0.04
	AED side effects	2.74	0.05
Energy/fatigue	Seizure frequency	7.36	0.0007
	Age at onset	4.71	0.004
	Employment	4.24	0.02
	AED side effects	2.52	0.05
Cognitive function	Seizure frequency	9.36	0.0003
	Age at onset	4.71	0.006
	Education	4.42	0.009
	Type of AED therapy	3.59	0.01
	AED side effects	2.82	0.04
	Stigmatisation	2.63	0.04
Medication effects	Seizure frequency	6.47	0.003
	AED side effects	3.92	0.007
	Stigmatisation	3.54	0.03
	Stigma severity	2.94	0.05
Social functioning	Seizure frequency	15.63	0.0001
	Marital status	4.27	0.006
	Employment	5.76	0.005
	AED side effects	3.38	0.03
	Stigmatisation	3.41	0.03
	Stigma severity	3.35	0.05
Overall	Seizure frequency	11.24	0.0001
	Stigmatisation	4.67	0.03
	Stigma severity	4.83	0.01
	Age at onset	3.74	0.01
	AED side effects	3.95	0.05
	Type of AED therapy	3.48	0.05

or underemployed, those who were on polytherapy compared to those on mono-therapy, and those who stated having experienced side effects of the AEDs.

In the Emotional well-being domain, duration of epilepsy, employment, and AED side effects remained significant. Significantly lower scores were obtained by those who had suffered from epilepsy for two to five years compared to those who had suffered more than twenty years, those who were currently unemployed compared to those who were in full-time employment or underem-ployed, and those who stated having experienced side effects of the AEDs.

In the Energy/fatigue domain, age at onset, employment, and AED side effects remained significant. In this domain, scores were significantly lower for those whose epilepsy had been diagnosed at the age of 41–50 or over 50 compared to those for whom it had been diagnosed at an age under 20 years, for those who were currently unemployed compared to those who were in full-time employment or underemployed, and for those who stated having experienced side effects of the AEDs.

In the Cognitive functions domain, age at onset, education, type of AED the-rapy, AED side effects, and stigmatisation remained significant. Significantly lower scores were obtained by those for whom epilepsy had been diagnosed at the age of 41–50 or over 50 compared to those for whom it had been diagnosed at an age under 20 years, those who had had primary or less than primary education compared to those who had high school or university education, those who were on polytherapy compared to those on monotherapy, those who stated having experienced side effects of the AEDs and those who were stigmatised.

In the Medication effects domain, AED side effects, stigmatisation, and stigma severity remained significant. Significantly lower scores were obtained by those who stated having experienced side effects of the AEDs, those who were stigmatised, and those who expressed very strong feelings of stigma (gave three "yes" answers) compared to those who did not (one "yes" answer).

In the Social functioning domain, marital status, employment, AED side effects, stigmatisation, and stigma severity remained significant. Significantly lower scores were obtained by those who were single, divorced or widowed compared to those who were married, for those who were currently unemployed or retired compared to those who were in full-time employment or unde-remployed, those who stated having experienced side effects of the AEDs, those who were stigmatised, and those who expressed very strong feelings of stigma (gave three "yes" answers) compared to those who did not (one "yes" answer).

In the Overall score, stigmatisation, stigma severity, age at onset, AED side effects, and type of AED therapy remained significant. Significantly lower sco-res were obtained by those who were stigmatised, those who expressed very strong feelings of stigma (gave three "yes" answers) compared to those who did not (one "yes" answer), those for whom epilepsy had been diagnosed at the age of 41–50 or over 50 compared to those for whom it had been diagnosed at an age under 20 years, those who stated having experienced side effects of the AEDs, and those who were on polytherapy compared to those on monotherapy.

DISCUSSION

1. Study area and socio-demographic characteristics
of the study population

Our study focused on adults living in the community. To give a more extensive and accurate survey, the sample for the study was drawn from two Estonian towns differing from each other in several respects. One of them (Tartu) represented the country's urban society and the other (Viljandi), a mainly provincial and rural population. On January 1, 1997 the estimated prevalence ratio of active epilepsy in Tartu was 5.3 per 1,000 (Õun *et al.*, accepted for publication-b). To test the consecutiveness of the study the percentages of sex and age structure of the epileptic people in the present study were compared with the same data available about the epileptic people of Tartu. As shown in **Table 19**, there were no significant differences. When the data originating from two different towns was analysed separately, there were no remarkable statistically significant differences found either between the groups or with the factors except for the seizure frequency. That was possibly due to the too small groups of respondents.

Table 19. Comparison of sex and age structure of Tartu epileptic people and epileptic people of Tartu included in the present study.

Parameter	Among adults with epilepsy in Tartu		Among adults with epilepsy in Tartu in the present study		p-value*
	n	%	n	%	
Sex					
male	172	55.7	56	45.9	0.07
female	137	44.3	66	54.1	
Age groups					
20–29 years	53	17.2	26	21.3	0.3
30–39 years	74	23.9	27	22.1	0.7
40–49 years	70	22.6	24	19.7	0.5
50–59 years	54	17.5	20	16.4	0.8
≥60 years	58	18.8	25	20.5	0.7
Total	309	100.0	122	100.0	

* t-test

2. Treatment, sideeffects and seizure-related injuries.

The clinical characteristics of the present study were similar to most other series of prevalence cases of epilepsy (Forsgren, 1992; Joensen, 1986; Keränen, 1989). Most of the study respondents had generalised seizures with or without other seizure types, the average duration of the disease was 11 years and patients were predominantly on carbamazepine monotherapy. More than half of those who had experienced seizures during the last year reported having injuries related to them. Findings regarding the rate and severity of seizure-related injuries were slightly higher compared with the results of studies conducted in other countries (Baker *et al.*, 1997a; Buck *et al.*, 1997). Beran (1989) has pointed out that the purpose of treating epilepsy may not necessarily be that of seizure eradication but rather the maximal improvement of QOL for the patient. In comprehensive management, the treating physician must very seriously consider the influence of the therapy on the patients' QOL (Kugoh, 1996). 84% of the study respondents were receiving monotherapy. This was higher compared to the other studies (Jacoby *et al.*, 1996; Baker *et al.*, 1997a; Ribeiro *et al.*, 1998). The explanation is that all of the patients from Tartu were participating in an epidemiological survey and consulted by an epileptologist, which often resulted in the correction of medication. The number of untreated cases (11%) was not high and probably reflects insufficient compliance. However, AED prescription patterns had some distinctive features. Carbamazepine was a much more frequently reported drug than in other studies, while the percentage of those using valproate or phenytoin was lower. To surprise, two patients reported taking bensobarbital — a drug that is no longer officially used in Estonia. Significant numbers of study respondents (67%) reported side effects from the AEDs; the most commonly experienced side effects were non-specific. In the past year, 41% of respondents had changed their medication, at present 78% stated that the level of seizure control was satisfactory.

3. The problem of stigmatisation

The problem of stigmatisation has been projected in a number of studies as one of the most common social problems faced by persons with epilepsy (Baker *et al.*, 1996; Placencia *et al.*, 1995; Baker *et al.*, 1999; Jacoby, 1994; Baker *et al.*, 1997b). As stigmatisation is difficult to compare, the results were collated only with the results from the European study (Baker *et al.*, 1997a) where the same scale was used for measuring stigma. According to this, the highest proportions of stigmatised persons (over 60%) were found among the respondents from two highly developed countries, i.e. France and Germany. The study also included

respondents from Poland, the Czech Republic and Hungary, where the percentages of stigma were 32, 55 and 52, accordingly. According to this study, the levels of stigma among people with epilepsy were also high (52%) in spite of the fact that 40% of the study's respondents had less than one seizure a month and 34% had been seizure-free in the last year. The majority of patients stated that they were nevertheless satisfied with the current treatment and the percentage of stigmatisation in general and the percentage of severely stigmatised persons was high. The factors influencing the development and maintenance of stigma in different countries are diverse but in general, the higher percentage of stigmatisation could be a characteristic of Eastern European countries and could be the result of a general lack of knowledge and of indifference, since the individual's health and well-being were not valued, for a long period, due to the complicated political status. Respondents were more likely to feel stigmatised by epilepsy if they had frequent seizures or a combination of seizure types — findings that were in agreement with the results of other studies (Baker *et al.*, 1997a; Baker *et al.*, 1999; Jacoby, 1994; Jacoby *et al.*, 1996). Stigmatisation was more common among educated persons.

4. Employment

Unemployment and part-time employment, being much more frequent in the epilepsy population than in general, have been identified as being among the most serious problems facing people with epilepsy (Masland, 1985; Broughton *et al.*, 1984). The percentage of people working full-time and part-time was 65 in the present study; 11% were unemployed. This is not considered high because, according to the data of the labour force surveys of the Statistical Office of Estonia, the percentage of employees (both employed and underemployed) residing in Tartu and aged 20 years and more on January 1, 1998 was 63%, the unemployment rate was 9.5%, and 25.5% were pensioners receiving the state pension (Statistical Office of Estonia, 1997). Compared to the findings of a U.K. study by Jacoby *et al.* (1996) who found that the percentage of unemployed people was 10 and that of employed people was 35, the results indicate that the condition of our people with epilepsy is not much worse. At the same time, more than half of the study's respondents believed that they had employment problems caused by their disease. A little less than half stated that they were being treated unfairly at work. Perceived discrimination may not always correspond to real discrimination (Scambler and Hopkins, 1980). The findings of this study do not provide evidence of active discrimination against people with epilepsy. 55.7% of respondents had at least high school education and problems connected with unemployment or part-time employment, were not much expressed among this group. Not surprisingly,

seizure frequency was positively related to the unemployed and underemployed workers but no relationship could have been found with the type of seizures. The finding supports the data of previous research in which lower seizure frequency had been related to the greater likelihood of being employed (Rodin *et al.*, 1972; Scambler and Hopkins, 1980; Jacoby, 1995). The results of the study showed very clearly that there are a variety of reasons for the existence of the stigma. Although it has been found that unemployment and employment problems are on the whole the main source of the stigma (Collings, 1990c; Jacoby, 1994; Jacoby, 1995), the most educated respondents in the study, who had jobs, were even more stigmatised.

5. General health status assessed by the RAND-36

To assess general health status, a generic self-completed multidimensional instrument — the RAND 36-Item Health Survey 1.0 was used. This is developed as a measure of health status or health outcome for use in cross-sectional and longitudinal studies (König-Zahn *et al.*, 1997). Although the questionnaire has been quite widely used, it has been described that different ethnic or cultural groups may interpret same items of the questionnaire differently (Gilson *et al.*, 1980; Deyo, 1984). Different disease groups can also score too close to the bottom or top of the range, thus limiting the usefulness of a scale for comparing disease-burden profiles (McHorney *et al.*, 1994).

In general, the translation and pilot testing of the Estonian version demonstrated a satisfactory feasibility of the form and suggested that the response choices in the Estonian version were ordinal and comparable to the response choices in the U.S. version. The response rate was 78%. The results of the item descriptive statistics showed a high completeness of data (over 98.5% on the item level) and a good distribution across response choices on the scale levels. The application of the RAND-36 showed very good to satisfactory psychometric results in terms of scale characteristics with reliability coefficients above 0.70. The questionnaire has been criticised for its ceiling and floor effects (Jacoby *et al.*, 1999). In this study, high ceiling effects associated with most of the domains were found. For the epilepsy group both floor and ceiling effects were low for Emotional well-being, Vitality and General health. Floor effects in the epilepsy sample were negligible for six scales, ceiling effects for three — Emotional well-being, Vitality and General health. The construct validity of the scale was supported by the findings that those with frequent seizures did poorly compared to those who experienced infrequent seizures or were currently seizure-free. This expected finding was in accordance with other studies (Baker *et al.*, 1997a; Jacoby *et al.*, 1996; Ribeiro *et al.*, 1998; Malmgren *et al.*, 1997;

Devinsky and Cramer, 1997). Although the differences between seizure types were not significant in all the RAND-36 domains, there was a clear tendency towards a greater likelihood of lower scores in the case of patients suffering from generalised tonic-clonic seizures. Patients who experienced both genera- lised tonic-clonic and other types of seizures did poorly compared to the others, which was to be expected (Baker *et al.*, 1997a; Jacoby *et al.*, 1996; Devinsky and Cramer, 1997). Discriminant validity was highly acceptable. People with epilepsy had significantly lower scores than the controls in all domains. Though the emotional well-being of the study respondents was not much worse than that of the control group, their social functioning was significantly lower and limitations due to emotional problems were more expressed. The results of the European study had previously drawn attention to the fact that it was unclear why respondents with epilepsy scored relatively poorly on the domain concer- ned with physical function (Baker *et al.*, 1997a). Although current seizure acti- vity remained the most important predictor, there was a concomitant importance of socio-demographic variables (current age and employment status) to QOL. Older people and people who were currently unemployed were more likely to score lower. The other substantial disease characteristics in explaining the variation in the scores of several domains after controlling for seizure status were age at onset of epilepsy, duration of disease, and seizure type. Age at onset became significant in the case of Physical functioning, Role limitations — physical, Energy/fatigue, Social functioning, and General health. In all those domains, later age at onset was associated with lower scores. Dominian *et al.* (1963) have reported an association between depression and older age at onset, Jacoby *et al.* (1996) considered older age at onset to be implicated in feelings of depression and stigma. Duration of disease was significant in the case of Energy/fatigue, Emotional well-being and Bodily pain. Here, a shorter time of duration of epilepsy was related to lower scores. Seizure type became signi- ficant in relation to Social functioning — those who experienced either tonic- clonic or multiple seizure types scored significantly lower than those who had only other types of seizures. Jenkinson *et al.* (1993) mentioned that the instru- ment has its limitations — for instance containing no variable on sleep. However, it gives a good survey of the general health status of the people and enables an adequate health assessment comparison between the groups of patients with disease of varying severity.

6. Quality of life in epilepsy assessed by the QOLIE-31

The Estonian version of the QOLIE-31 showed psychometric properties com- parable to those of the American version, and thus may be used as a specific

measure of QOL in our population with epilepsy. The construct validity of the questionnaire was supported by the findings based on the values of the overall score that those with frequent seizures did poorly compared with those who experienced infrequent seizures or were currently seizure free. There was a clear tendency toward a greater likelihood of lower scores among patients with more frequent seizures. The overall score values of the three groups of patients with different seizure frequency were, statistically, significantly different between those who had not had seizures in the past year and those who had had seizures at least once a month or less often than once a month. Variance between seizure frequency statuses was statistically significant in all seven domains. The overall score of the QOLIE-31 was significantly different between all the three groups of seizure types: patients who had multiple seizure types had the lowest value, followed those who experienced generalised tonic-clonic seizures and those with other types only had the highest values. Variance between seizure types was statistically significant in four domains.

The most important predictor in assessing the QOL was seizure frequency. The other substantial disease characteristics after controlling for seizure status were seizure type, type of AED therapy, AED side effects, age at onset, and duration of epilepsy. Seizure type became significant in the case of Seizure worry and Overall quality of life. In both cases, people having generalised tonic-clonic seizures, either only or together with some other type of seizure, scored lower. Type of AED therapy became significant in relation to Seizure worry, Overall quality of life, Cognitive functions and the overall score. In all these cases, people receiving polytherapy had lower scores compared to these on monotherapy. People who stated experiencing AED side effects got lower values of the domains in Overall quality of life, Emotional well-being, Energy/fatigue, Cognitive function, Medication effects and in the overall score compared to those who reported no side-effects. Age at onset became significant in the case of Overall quality of life, Energy/fatigue, Cognitive function and in the case of overall score. In all those cases differences were significant between two groups of patients: lower scores were obtained by those for whom epilepsy had been diagnosed at the age of 41–50 or over 50 compared to those for whom it had been diagnosed at an age under 20 years. Duration of epilepsy remained significant only in the case of Emotional well-being where significantly lower scores were obtained by those who had suffered from epilepsy two to five years compared to those who had suffered more than twenty years. The other substantial socio-demographic variables included education, stigmatisation, stigma severity, marital status and employment. Education was significant in the case of two domains: Seizure worry and Cognitive function. In Seizure worry, lower scores had those who had higher education, while in Cognitive function domain, it was opposite: lower scores were obtained by those who had primary or less than primary education. Stigmatisation was significant in assessing Seizure worry, Cognitive function, Medication effects and Social functioning domains, and the overall score. In all

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cases lower values were obtained by those who were stigmatised. Stigma severity became significant in three domains (Seizure worry, Medication effects, Social functioning) and in the overall score. In all cases differences were significant between two groups: those who expressed very strong feelings of stigma (gave three "yes" answers) compared to those who did not (one "yes" answer). Marital status was significant in assessing Overall quality of life and Social function domains. In the first case, lower scores were obtained by those who were married or cohabiting compared to those who were single, in the second case, significantly lower scores were obtained by those who were single, divorced or widowed compared to those who were married. Employment became significant in four domains where being in a paid job was always associated with higher scores.

As the QOLIE-31 questionnaire is a relatively new measure, there is not much data about its use in the QOL studies. The averages for the Estonian patients of all domains were compared to the available data from USA (Devinsky *et al.*, 1995), Spain (Torres *et al.*, 1999) and Hungary (Lam *et al.*, 2001). (**Table 20**) The SDs did not show a significant difference between the groups. The overall scores of the scale were highest for the USA and Spain, followed by Estonia and Hungary. The values of the domains of the Estonian QOLIE-31 were significantly lower compared to three other countries in the Overall quality of life domain. In the Energy/fatigue domain, the average differed significantly only from the data from the USA and Spain. To surprise, in the Medication effects domain the average value of the Estonian epilepsy group was significantly higher compared to the same data from the USA and Hungary. That can be explained, at least partly, by the fact that the people with epilepsy from Tartu were during the epidemiological study consulted by a neurologist in terms of their treatment problems. The authors of the Hungarian study (Lam *et al.*, 2001) have explained their higher value in this domain compared to the USA by the different mental health expectations, the difference in the expected efficacy of treatment, the confidence in doctors and by the different circumstances and opportunities open to people from developed countries and from Eastern European countries. This may indicate that because of their disease our people judge themselves to be at a greater disadvantage with respect to their social status. This is why they have greater confidence in the doctors and the treatment. The averages of the domains of the Estonian QOLIE-31 were most similar to those of the Hungarian epilepsy group. Also, there was no statistically significant difference in the value of the overall score. The averages were generally lower (the negative judgement) compared to the American and Spanish data but they changed in parallel with it. The lower overall score compared to the data from the USA and Spain can be explained by the difference in economic and social status and by the difference in both the social judgement and ability to cope with the disease.

Table 20. Comparison of the mean scores of the QOLIE-31 domains of the respondents from USA, Spain, Hungary and Estonia.

Domains	Averages (SD) of the QOLIE-31 domains			
	USA (n=304)	Spain (n=252)	Hungary (n=170)	Estonia (n=203)
Seizure worry	58.29 (25.76)	51.47 (29.73)	53.95 (28.53)	54.67 (26.26)
Overall quality of life	67.17 (18.38)*	63.80 (16.95)*	55.45 (19.32)*	49.18 (17.59)
Emotional well-being	67.20 (19.28)*	61.78 (19.13)	58.28 (18.48)	60.14 (19.95)
Energy/fatigue	55.30 (21.10)*	60.89 (20.27)*	49.68 (17.68)	48.40 (20.17)
Cognitive function	59.96 (22.76)	60.32 (23.80)	59.26 (20.23)	59.41 (23.75)
Medication effects	55.34 (30.52)*	60.30 (29.10)	57.39 (31.13)*	63.64 (27.70)
Social functioning	67.25 (26.88)	66.44 (27.96)	56.88 (23.60)*	63.54 (25.08)
Overall score	62.87 (16.31)*	61.77 (17.33)*	56.45 (16.50)	57.38 (18.50)

* The means different from the corresponding results of the Estonian epilepsy group at 0.05 significance level (t-test).

Also, the results the QOLIE-31 of the patients from USA, Hungary and Estonia, who were seizure free, were compared. (**Table 21**) The same tendency was found when comparing the results of the QOLIE-31 according to seizure frequency (and severity). The Estonian seizure free patients rated their Overall quality of life as being much lower than American and Hungarian patients; the Medication effects domain was rated higher. The averages of the other domains were in the middle, being higher than the same values of Hungary and lower than the averages given by the American patients. Although when comparing the data it was not possible to calculate statistical significance, the averages of the seizure free patients reflected the same tendency as shown by the whole groups of respondents with epilepsy in **Table 20**. In brief, one can say that our people with seizure free epilepsy suffer more from prejudices than seizure free patients in the USA.

Table 21. Comparison of the mean scores of the QOLIE-31 of seizure free patients from USA, Hungary and Estonia.

Domains	Seizure free		
	USA	Hungary	Estonia
n(%)=	21 (6%)	50 (29%)	69 (34%)
Seizure worry	74.90	53.78	63.12
Overall quality of life	72.00	62.24	55.73
Emotional well-being	73.40	59.92	65.91
Energy/fatigue	63.00	47.86	54.42
Cognitive function	70.75	62.10	67.27
Medication effects	56.80	59.58	75.08
Social functioning	77.70	65.74	74.07

CONCLUSIONS

1. The research took place in 1997 through 1998 and followed an epidemiological survey of epilepsy in Tartu. The study was based on the analysis of data collected from a sample of 203 patients, aged 20–72 years, from Tartu and Viljandi County. All the respondents from Tartu and the problematic cases from Viljandi County included in the study were re-examined at least once to specify the type of their seizures and that excludes cases with provoked and acute symptomatic seizures.

2. A profound translation and psychometric testing phase preceded the inclusion of the RAND-36 and QOLIE-31 questionnaires in the research. It showed that both of them were reliable and valid descriptive health status measures for the Estonian epilepsy population.

3. 74% of study respondents had less than one seizure a month, of these 34% had been seizure-free in the last year. 78% of the patients stated being satisfied with the current treatment. Despite this the stigmatisation in general (52.4%) and the percentage of severely stigmatised (24.7%) was high. Being aware of the limitations to the generalisability of the study in the interpretation of the results, due to a relatively small and somewhat biased sample size; it can be quite clearly said that one of the main problems of epileptic people in Estonia is their perception of stigmatisation.

4. Although the percentage of full-time and underemployed people in the study was not lower than in the general population, more than half of the respondents believed that they had employment problems caused by their epilepsy. A little less than half stated that they were being treated unfairly at work.

5. The characteristics describing the disease, its medication and complications were generally in accordance with the data from other countries, and also marital and educational status (except when assessing the stigmatisation) were not statistically significant.

6. People with epilepsy had significantly lower scores than the controls in all domains of the RAND-36. Though the emotional well-being of the study respondents was not much worse than that of the control group, their social functioning was significantly lower and limitations due to emotional problems more expressed. Although current seizure activity remained the most important predictor, there was a concomitant importance of socio-demographic variables (current age and employment status) to the scores of domains of the RAND-36. The other substantial disease characteristics, in explaining the variation in the scores of several domains after controlling for seizure status, were age at onset of epilepsy, duration of disease, and seizure type.

7. The most important predictor in assessing the QOL with the QOLIE-31 was seizure frequency. The other substantial disease characteristics after controlling for seizure status were seizure type, type of AED therapy, AED side effects, age at onset, and duration of epilepsy. The socio-demographic variables influencing the averages of the domains included education, stigmatisation, stigma severity, marital status and employment. On the basis of the averages of the domains the Estonian people with epilepsy rated their Overall quality of life as the lowest and the average of the Medication effects domain was higher then expected. The results of the QOLIE-31 were comparable with those obtained in other countries. The values of the domains were generally lower than in developed countries (USA, Spain) and similar to those given in another Easten European country (Hungary).

8. The findings of this study confirm that remarkable psychosocial problems accompany the diagnosis of epilepsy. The study demonstrated QOL decreases in subjects with epilepsy.

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SUMMARY IN ESTONIAN

Epilepsiahaigete elukvaliteet Eestis

Sissejuhatus

Epilepsia on krooniline haigus, mille korral normaalse neuroloogilise funkt-siooniga perioodid vahelduvad harvade, lühikeste hoogude-perioodidega. Mit-mete krooniliste haiguste puhul esinev haigusnähtude avaldumise ootamatus, mis tekitab inimeses pideva kindlusetustunde, on epilepsia puhul eriti väljendunud. Epilepsia tõttu suuremal või vähemal määral esile kerkivad psühhosotsiaalsed probleemid kaaluvad sageli üles hoogude ja nende raviga seotud probleemid. Stigma (sisemise häbitunde või märgistatuse) tunnetamine võib muuta inimese iseloomu nii, et tal tekivad tõsised suhtlemisprobleemid, mis omakorda tekitavad raskusi ja langetavad motivatsiooni toimetulekuks ühiskonnas. Uuringutega on esile tõstetud mitmeid erilist tähelepanu väärivaid valdkondi (Baker *et al.*, 1997a). Epilepsiaga isikutel on tihti vähenenud enesest lugupidamine, sagedamini kui rahvastikus keskmiselt esineb neil ärevushooge ja depressiooni. Nende hulgas tuleb keskmisest sagedamini ette töötust või tööga alahõivatust, samuti on selles inimgrupis suurem sotsiaalne isolatsioon ja madalam abielus olevate inimeste protsent. Epidemioloogiliste uuringute järgi alluvad 70–80%-l epilepsiaga inimestest hood hästi antiepileptilisele (AE) ravile (Sander, 1993) ning nende puhul epilepsia otseselt elukvaliteeti alandada ei tohiks. Ülejäänud 20–30% puhul, kelle hood on kroonilised ja alluvad raskesti ravile, on olukord tunduvalt komplitseeritum. Teistes riikides läbiviidud uurin-gud on selgelt näidanud, et suhe epilepsia raskuse ja selle mõju vahel elu-kvaliteedile on kompleksne ja selle hindamisel tuleb arvesse võtta mitmeid erinevaid faktoreid, kaasa arvatud patsiendi enda arvamus (Jacoby *et al.*, 1996).

Uuringu eesmärgid

1. Kontrollida epilepsiahaigete elukvaliteedi uuringus kasutatavate mujal välja-töötatud küsimustike RAND-36 (RAND 36-Item Health Survey 1.0) ja QOLIE-31 (Quality of Life Inventory in Epilepsy-31, versioon 1.0) vastu-võetavust, usaldusväärsust ja valiidsust Eesti inimestel.
2. Uurida epilepsia ja selle ravi mõju tööhõivele ning epilepsiaga sageli kaasneva stigma ulatust patsientide hulgas.
3. Kirjeldada ülalmainitud küsimustike abil suuremas osas kahest Eesti linnast pärit epilepsiaga patsientide üldist tervislikku seisundit ja hinnata nende elukvaliteeti.

4. Leida ja analüüsida seoseid epilepsia kliiniliste näitajate ja epilepsiahaigete elukvaliteedi vahel.
5. Leida ja analüüsida seoseid patsientide demograafiliste näitajate ja elukvaliteedi vahel.

Patsiendid ja meetodid

Uuring toimus aastatel 1997–98 ning hõlmas 203 epilepsiaga inimest Tartust ja Viljandimaalt. Algandmed patsientide kohta pärinesid Tartus varem läbiviidud epidemioloogilise uuringu tulemustest ning Viljandis kohaliku epilepsiaühingu (Viljandimaa Epilepsia Ühing) nimekirjadest. Kliinilised andmed täpsustati kasutades Viljandi maakonnahaigla ja polikliiniku ning Tartu Maarjamõisa Haigla ja polikliiniku meditsiinilist dokumentatsiooni. Kõik inimesed, kelle puhul epilepsia anamnees ning kliinilised andmed (peamiselt hoo tüüp) jäid ebaselgeks, kutsuti kordusvastuvõtule. Käesolev uuring hõlmas 20-aastaseid ja vanemaid epilepsiaga inimesi, kel oli esinenud vähemalt kaks provotseerimata epileptilist hoogu, neist vähemalt üks viimase viie aasta jooksul.

Uuringu eelselt viidi läbi küsimustike tõlkimine eesti keelde, nende valideerimine ning pilootuuring 30 Tartu linna epilepsiaga inimese hulgas, mis näitas, et küsimustikud olid üldiselt mõistetavad ning inimestele kergesti täidetavad. Võrdlemaks üldist tervislikku seisundit peegeldava küsimustiku tulemusi, moodustati vanuse, soo ja haridustaseme poolest sarnane 200 inimesest koosnev kontrollgrupp. Et hinnata epilepsia mõju patsientide üldisele tervislikule seisundile ja elukvaliteedile, saadeti kõigile uuringus osalejatele posti teel küsimustik, mis sisaldas peale ülalnimetatud skaalade ka küsimusi demograafiliste andmete, majandusliku toimetuleku, hoogude, hoogudega seotud vigastuste, AE ravi kõrvaltoimete, raviga rahulolu, ravi muutuste, ravimreziimi järgimise, kaasuvate haiguste, tööhõive ja sellega seotud probleemide, stigma tunnetamise ning autojuhilubade olemasolu kohta. Täidetud küsimustikud tagastas 78% inimestest.

Elukvaliteedi uuringu tulemuste analüüsile eelnes RAND-36 ja QOLIE-31 küsimustike reliaabluse (usaldatavuse) ja valiidsuse (kehtivuse) kontroll.

Uuringu peamised tulemused

Hoogude sageduse ning valdkondade keskmiste väärtuste vahel ilmnes statistiliselt oluline seos: need, kel esines hooge sagedamini, said nii RAND-36 kui QOLIE-31 kõigis valdkondades vähem punkte (madalam elukvaliteet) võrreldes nendega, kel esines hooge harvemini. Samuti oli täheldatav (kuigi mitte kõigi valdkondade puhul statistiliselt oluline) seos hoogude tüübi ning valdkondade keskmiste väärtuste vahel: patsiendid, kel esinesid generaliseeritud toonilis-kloonilised hood, andsid valdkondade hindamisel madalamaid punkte.

Uuringugrupi keskmine vanus oli 41 aastat. Uuringus osalejad jagati viide vanusegruppi: 20–29a. —54 (26.6%), 30–39a. — 42 (20.7%), 40–49a. — 35 (17.2%), 50–59a. — 28 (13.8%), ning 60a. ja vanemad — 44 (21.7%) inimest. Vastanutest 48.8% (99) olid mehed. 82 (40.9%) oli abielus või vabaabielus, 84 (41.4%) vallalised, 21 (10.3%) lahutatud ja 15 (7.4%) lesed. 90 (44.3%) omas algharidust (8 või 9 klassi) ning 113 (55.7%) kesk-või kõrgharidust. 67 (33%) töötas täiskohaga, 87 (41.9%) oli alahõivatud või töötud, 49 (24.1%) vanadus-või invaliidsuspensionil. Ainult üks vastanutest (0.5%) pidas oma majandus-likku seisundit väga heaks, 17 (8.5%) — heaks, 119 (59%) — rahuldavaks, 53 (26.2%) — halvaks, 12 (5.9%) — väga halvaks. 11.3%-l (23 inimesel) oli juhi-loa kehtivus katkestatud epilepsia tõttu. Vastanute keskmine vanus epilepsia diagnoosimisel oli 26.9 aastat, epilepsia kestus keskmiselt 11.3 aastat.

84 (41.4%) uuringus osalejal oli esinenud ainult toonilis-kloonilist tüüpi hooge, 61 (30%) – nii toonilis-kloonilisi kui muud tüüpi hooge ning 58 (28.6%) ainult muud tüüpi hooge. Viimasel aastal ei olnud hooge esinenud umbes kol-mandikul (69, 34%), 81 (39.9%) isikul oli hooge harvemini kui kord kuus ja 53 (26.1%) kord või sagedamini kuus. AE ravi sai 180 vastanut (88.7%), neist monoteraapiat 151 (83.9%). Enamus neist, kes said monoteraapiat, tarvitas karbamasepiini (113, 74.8%), ülejäänuid raviti valproaadi, primidooni, fenü-toiini, fenobarbitaali ning bensobarbitaaliga. AE ravi kõrvaltoimeid kaebas 153 (75%) vastanut, neist enamusel (113, 73.9%) esines kolm või enam sümptomit. Kõige sagedamini esinevad kõrvaltoimed olid mittespetsiifilised: mäluprob-leemid (31%), väsimus (25%), unisus (20%), peavalu (20%) ja närvilisus (20%). Enam kui pooltel nendest, kel oli viimase aasta jooksul hooge esinenud (134 patsienti), oli esinenud ka neist tingitud vigastusi: 19 (14%) tõsisemaid vigastusi (põletusi, sügavaid sisselõikeid, luumurde), 51 (38%) pea vigastusi, 29 (22%) kergemaid vigastusi või peavalu. Vigastusi ei esinenud ligikaudu viien-dikul (28, 21%) vastanutest. Suurema tõenäosusega esines hoogudega seotud vigastusi neil, kel oli hooge kord või sagedamini kuus (χ^2=11.89, df=2, p=0.001), ja neil, kel esinesid generaliseeritud toonilis-kloonilised või segatüüpi hood (χ^2=9.94, df=2, p=0.009). Oma hooge hindas väga rasketeks 15 (7.4%) vastanut, 61 (30%) rasketeks, 84 (41.4%) keskmisteks ja 43 (21.2%) kergeteks. Esines statistiliselt oluline korrelatsioon hoogude raskuse subjektiivse hinda-mise ja hoogudega seotud vigastuste vahel (χ^2=15.24, df=4, p=0.003). Enamus AE ravi saavatest vastanutest (142 isikut ehk 78.8%) oli oma praeguse raviga täielikult või enam-vähem rahul, 38 (21%) oli ravi suhtes rahulolematu. Kahel viiendikul (74 vastanul ehk 41.1%-l) neist, kes said ravi, oli seda viimase aasta vältel muudetud: 51 juhul (68.4%) oli muudetud üks kord, 17 (22.8%) kaks ja 6 (8.8%) kolm või enam korda. Neist, kelle ravi viimase aasta jooksul oli muude-tud vähemalt korra, oli 59 (79.3%) seda tehtud ravi ebapiisavuse ja 15 (20.7%) kõrvaltoimete tõttu. Ravimrežiimi järgimine: 101 patsienti (56%) ei olnud kor-dagi unustanud AE tablette võtta, 41 (23%) unustas umbes korra kuus, 25 (14%) umbes korra nädalas ja 13 (7%) sagedamini kui korra nädalas. Kaasuvaid

kroonilisi haigusi esines 36 (17.7%) vastanul ja 24 (11.8%) tarvitasid nende tõttu ka pidevalt ravimeid. Kõige sagedasemad kaasuvad kroonilised haigused olid südamehaigused — neid esines 14 isikul (39%) ning luu- ja liigeshaigused — 12 vastanul (33%).

Hoolimata sellest, et 78.8% patsientidest oli enam-vähem rahul oma praeguse raviga, oli stigmatiseeritute üldprotsent (52.4) ja raskelt stigmatiseeritute protsent (24.7) siiski kõrge. Stigma tunnetamise raskus sõltus hoogude tüübist ja sagedusest: need, kel hooge esines sagedamini (χ^2=23.57, df=6, p<0.0001) ja neil, kel esinesid segatüüpi hood (χ^2= 20.65, df=6, p<0.009), tunnetasid stigma suurema tõenäosusega, samuti olid nad suurema tõenäosusega raskelt stigmatiseeritud. Stigmatiseeritust esines rohkem nende hulgas, kes omasid kesk-või kõrgharidust (χ^2=12.89, df=6, p<0.05). Täiskohaga töötas kolmandik vastanutest. Neist, kes olid tööga alahõivatud või töötud, pidas 54 (62%) inimest selle peamiseks põhjuseks epilepsiat. Viimase kahe aasta jooksul oli töökohta vahetanud 47 (29%) vastanut. Pisut vähem kui pooled uuringus osalenutest (74 isikut, 44%) tunnistasid, et neid on nende haiguse tõttu tööle võtmisel või töö juures koheldud ebaõiglaselt. Hoogude sageduse ja tööga alahõivatuse ning töötuse vahel leiti positiivne korrelatsioon. Statistiliselt oluline seos esines ka täiskohaga töötamise ja haridustaseme vahel: mida kõrgemat haridust isik omas, seda suurema tõenäosusega töötas ta täiskohaga (χ^2=12.12, df=6, p=0.04). Täiskohaga töötavate ja alahõivatute protsent oli käesolevas uuringus 64, töötuid oli 11%. Mujal maailmas tehtud analoogiliste uuringutega võrreldes oli täiskohaga töötavate ning alahõivatute epilepsiaga inimeste protsent kõrgem (Jacoby et al., 1996). Samal ajal uskusid enam kui pooled uuringus osalenutest, et neil on nende haiguse tõttu probleeme tööhõivega.

Nii RAND-36 kui QOLIE-31 analüüsimisel osutusid mõlemaid kirjeldavad näitajad erinevate valdkondade puhul väga headeks kuni rahuldavateks. Reliaabluse näitajad olid üle 0.70. Konstruktiivvaliidsust toetasid tulemused, mille järgi need, kel esinesid sagedased hood hindasid valdkondi madalamalt kui need, kel hood esinesid harvem. Samasuunaline tendents esines seoses hoogude tüübiga: need, kel esinesid generaliseeritud toonilis-kloonilised hood hindasid valdkondi madalamalt kui need, kel seda tüüpi hooge ei esinenud. Uuringus osalejad said võrreldes kontrollgrupiga kõigis RAND-36 valdkondades vähem punkte, mis näitab, et nad pidasid oma tervist ja sellest tulenevat elukvaliteeti halvemaks. Suurimad erinevused ilmnesid nelja valdkonna puhul: sotsiaalne tegevus, füüsilisest tervisest tingitud piirangud, emotsionaalsetest probleemidest tingitud piirangud, üldine tervis. RAND-36 erinevate valdkondade hindamist mõjutavatest näitajatest osutusid olulisteks hoogude sagedus, hoo tüüp, vanus epilepsia diagnoosimisel, epilepsia kestus, stigmatiseeritus, stigma raskus, isiku vanus ja tööhõive. QOLIE-31 erinevate valdkondade keskmised näitajad olid seotud hoogude sageduse, hoo tüübi, AE ravi tüübi, AE kõrvaltoimete esinemise, vanusega epilepsia diagnoosimisel, epilepsia kestuse, stigmatiseerituse, stigma raskuse, haridustaseme, perekonnaseisu ja tööhõivega. Kui QOLIE-31 abil saadud tulemusi võrreldi USA-s (Devinsky et al., 1995),

Hispaanias (Torres *et al.*, 1999) ja Ungaris (Lam *et al.*, 2001) sama küsimustiku abil läbiviidud uuringute andmetega ilmnes, et Eesti andmed olid kõige enam sarnased Ungari vastavate tulemustega. Tulemused olid madalamad, kui USA-s ja Hispaanias läbiviidud uuringutes. Antud uuringus osalejad hindasid üldist elukvaliteeti iseloomustavat valdkonda oluliselt madalamalt kui teiste maade vastanud, samas oli ravi mõju käsitlevat valdkonda iseloomustav keskmine väärtus oluliselt kõrgem kui sama näitaja USA ja Hispaania uuringutes.

Järeldused

1. Uuring toimus aastatel 1997–1998 ning hõlmas 203 epilepsiaga isikut vanuses 20–72 aastat Tartust ja Viljandimaalt. Kõik Tartust pärit uuringus osalejad ning probleemsemad Viljandimaalt pärit patsiendid olid uuringu käigus kontrollitud hoogude tüübi suhtes, mis välistas juhud, mille korral oli tegemist provotseeritud või ägedate sümptomaatiliste epileptiliste krambihoogudega.

2. Uuringu küsimustike (RAND-36 ja QOLIE-31) kasutusele võtmisele ning tulemuste interpreteerimisele eelnes nende põhjalik tõlkimisprotsess ja hindamine. Mõlemad küsimustikud osutusid antud populatsiooni seisundi kirjeldamisel usaldusväärseks ning valiidseks.

3. 74%-l uuringus osalejatest esines hooge harvemini kui kord kuus, 34% olid viimase aasta jooksul olnud hoovabad. 78% olid rahul oma praeguse AE raviga. Sellele vaatamata oli nii stigmatiseeritute üldprotsent (52.4) kui raskelt stigmatiseeritute protsent (24.7) kõrged. Vaatamata sellele, et uuringugrupp ei olnud väga suur ning saadud tulemused võivad peegeldada vaid teatud osa epilepsiahaigete arvamust, saab üsna kindlalt väita, et stigmatiseeritus on Eestis üheks epilepsiaga inimeste peamiseks probleemiks.

4. Kuigi täiskohaga töötavate ja alahõivatud inimeste osakaal ei olnud antud uuringu andmetel madalam kui rahvastikus üldiselt, arvas üle poolte osalejatest, et neil on epilepsia tõttu probleeme tööhõivega. Pisut alla poolte tunnistas, et neid on nende haiguse tõttu tööl koheldud ebaõiglaselt.

5. Haiguse ja selle raviga seotud kliinilisi aspekte kirjeldavad näitajad ei erinenud üldiselt teistes maades läbiviidud uuringute andmetest. Statistiliselt olulisi erinevusi ei ilmnenud ka perekonnaseisu ning haridustaseme osas.

6. Epilepsiaga inimesed said kõigi RAND-36 valdkondade hindamisel madalama keskmise väärtuse võrreldes kontrollgrupiga. Kuigi uuringus osalejate emotsionaalne seisund ei erinenud palju kontrollgrupi omast, oli nende sotsiaalne tegevus oluliselt häiritud ning emotsionaalsetest probleemidest tingitud piirangud enam väljendudnud. Kuigi hoogude sagedus osutus kõige olulisemaks faktoriks, omasid RAND-36 valdkondade keskmiste väärtuste hindamisel tähtsust ka mõningad demograafilised näitajad — vanus ja tööhõive. Haigusega seotud näitajatest osutusid peale hoogude sagedusega

arvestamist olulisteks vanus esimese epileptilise hoo ajal, epilepsia kestus ja hoo tüüp.

7. Elukvaliteedi hindamisel QOLIE-31 abil osutus hoogude sagedus samuti kõige olulisemaks faktoriks. Lisaks sellele olid olulised ka epilepsiaga seotud näitajad — hoo tüüp, AE ravi tüüp, AE ravi kõrvaltoimed, vanus esimese epileptilise hoo ajal ning epilepsia kestus. Demograafilistest näitajatest olid olulised haridus, stigmatiseeritus, stigma raskus, perekonnaseis ja tööhõive. Valdkondade keskmiste alusel otsustades andsid Eesti epilepsiaga inimesed kõige madalamaid punkte üldist elukvaliteeti puudutavatele küsimustele, oodatust mõnevõrra kõrgemalt hinnati ravi mõju. Võrreldes QOLIE-31 valdkondade tulemusi mujal maailmas läbiviidud uuringutega ilmnes, et keskmised olid üldiselt madalamad kui arenenud maades (USA, Hispaania), kuid sarnased teises Ida-Euroopa riigis (Ungari) läbiviidud uuringu tulemustega.

8. Antud uuringutulemused kinnitavad, et epilepsiaga kaasnevad olulised psühhosotsiaalsed probleemid, mis alandavad elukvaliteeti.

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ELUKVALITEET EPILEPSIA KORRAL

Kuupäev …………..

Nimetähed: …………………..…   Haridus:…………………………….
Sünniaeg: …………………….   Amet:…………………………………...
Vanus: …………….
Sugu: M N
Perekonnaseis……………………….

1. Hoogude sagedus: a) kord või sagedamini kuus
   b) harvemini kui üks kord kuus
   c) pole esinenud viimase aasta jooksul
2. Hoogudega seotud vigastused viimase aasta jooksul:
   a) tõsisemad vigastused: põletused, suuremad marrastused,
      sügavad sisselõiked, luumurrud
   b) keelde hammustamine, hammaste vigastusedvõi tugev peavalu
   c) kergemad vigastused (kergemad marrastused, verevalumid jne)
      või kerge peavalu
   d) muud vigastused ……………………………………………
   e) vigastusi pole esinenud
3. Kui hoog tingib teadvusekaotuse, kas enne seda esineb nn hoiatavaid nähte, mis
   võimaldavad Teil end vigastuste eest kaitsta? (Kui teadvusekaotust ei esine või hood
   tekivad ainult magades, märkige c))
   a) mitte iialgi
   b) mõnikord
   c) peaaegu alati või alati
4. Kui sageli olete hoo korral kukkunud maha?
   a) peaaegu alati või alati
   b) sageli
   c) vahete-vahel
   d) mitte iialgi
5. Kui kaua võtab peale hoogu aega, kuni Te olete jälle teadvusel ja aktiivne?
   a) alla 1 min
   b) 1-10 min
   c) 10 min -1 tund
   d) 1-3 tundi
   e) üle 3 tunni
6. Palun iseloomustage lühidalt oma hooge (mis juhtub Teiega hoo ajal – mida Te ise
   tunnete, kuidas on Teie hooge kirjeldanud pealtnägijad): …………………………
   ………………………………………………………………………………………
   ………………………………………………………………………………………
   ………………………………………………………………………………………
   ………………………………………………………………………………………
7. Kui vana Te olite, kui Teil hood esmakordselt tekkisid? ………………………….
8. Millal esines viimane hoog (märkige ligikaudne kuupäev)? ……………………...
9. Kas Teil on hoo ajal esinenud uriinipidamatust?
   a) peaaegu alati või alati

b) sageli

c) vahete-vahel

d) mitte kunagi

10. Kas hoo ajal on esinenud järgmisi nähte:

a) ümbritsevaid inimesi tõsiselt häirivat automaatset tegevust (nt. karjumine, sihitult ringi hulkumine, lahti riietumine)

b) kergeid automaatseid liigutusi või võpatusi

c) pole esinenud

11. Kuidas Te ise hindaksite oma hooge: a) väga rasked b) rasked c) keskmised
d) kerged

12. Milliseid epilepsiavastaseid ravimeid Te praegu tarvitate (nimi + annus):
....

13. Kas Teil on viimase kuu aja jooksul esinenud epilepsiavastaste ravimite tarvitamisest tingitud kõrvalnähte? Kui on, siis palun märkige kõrvaltoime taha ka number, mis näitab, kui sageli antud kõrvaltoime on esinenud: 1 – kogu aeg või peaaegu kogu aeg, 2 – mõnikord, 3 – harva.

pearinglus... b) väsimus... c) tasakaaluhäired... d) iiveldus, oksendamine...e) nahasügelus, -lööve... f) kõhulahtisus...g) unisus... h) unetus...

i) meeleolumuutused... j) närvilisus, ärevus... k) rahutus... l) peavalu... m) käte värisemine... n) kõrvetised... o) kehakaalu muutused... p) isu muutused... r) tursed... s) kaebused südame poolt... t) surenenud karvakasv... u) juuste väljalangemine... v) kontsentreerumishäired... õ) mäluprobleemid... ä) raskusi selgelt mõtlemisega... ö) raskusi rääkimisel... ü) kahekordne või hägune nägemine... x) muud kõrvalnähud...

y) kõrvalnähte pole esinenud

14. Kuidas Te olete rahul oma praeguse raviga (nii hoogude kontrolli kui kõrvaltoimete talutavuse osas): a) täielikult rahul

b) enam-vähem rahul

c) pisut rahulolematu, võiks olla parem

d) ei ole rahul

15. Kas Teie epilepsiavastast ravi on viimase aasta vältel muudetud? a) jah b) ei
Kui jah, siis mitu korda? .....

Kas ravi muudeti selle ebapiisavuse või kõrvaltoimete tõttu? (Palun tõmmake joon õigele vastusele alla)

16. Kui regulaarselt olete Te viimase kuu aja jooksul tarvitanud epilepsiavastaseid ravimeid? a) pole kordagi unustanud tablette võtta

b) olen unustanud võtta tablette umbes korra kuus

c) olen unustanud võtta tablette umbes korra nädalas

d) olen unustanud võtta tablette sagedamini kui korra nädalas

17. Kaasuvad kroonilised haigused (juhul, kui neid esineb):
....
....

18. Teised pidevalt tarvitatavad ravimid:
....
....

19. Kas Te töötate täiskohaga? a) jah b) ei
Kui Te olete töötu või tööga alakoormatud, kas selle põhjuseks on ka epilepsia?
a) jah b) ei

20. Kas Te olete viimase kahe aasta jooksul vahetanud töökohta?
a) jah b) ei

21. Kas Teid on Teie epilepsia tõttu kunagi tööle võtmisel või töö juures koheldud ebaõiglaselt? a) jah b) ei

22. Majanduslik toimetulek: a) väga hea
                            b) hea
                            c) rahuldav
                            d) halb
                            e) väga halb

23. Juhiload: a) pole kunagi olnud
             b) kehtivus katkestatud epilepsia tõttu
             c) on

24. Kas Teil on vahel tunne, et Teie epilepsia tõttu:
    - teised inimesed tunnevad end Teiega ebamugavalt? a) jah b) ei
    - teised inimesed on kohelnud Teid alaväärsetena? a) jah b) ei
    - teised inimesed on eelistanud Teid vältida? a) jah b) ei

25. Umbes mitu korda olete Te viimase aasta jooksul käinud arsti juures? (märkige arv) ..... Sellest mitu korda epilepsia tõttu? .....

26. Milliseid ja mitu korda järgnevatest analüüsidest ja uuringutest on Teile viimasel aastal tehtud: a) vere analüüs....b) EEG.... c) kompuutertomograafia....
d) magnetresonantstomograafia....Neist milliseid ja mitu korda epilepsia tõttu?
....

27. Umbes mitu korda olete viimase aasta jooksul arsti poole pöördunud hoogudest tingitud vigastuste tõttu? (märkige arv) .... Kui Teil on esinenud tõsisemaid vigastusi, palun märkige ära protseduurid, mis Teiega on tehtud (nt. haavapuhastus, -õmblus, luumurru lahastamine, tekkinud tüsistused, ka haiglaravi ja selle päevade arv).
....
....
....

28. Sellele küsimusele vastamine ei ole kohustuslik.
Teie arvamus nii selle kui ülejäänud küsimustike kohta (kas küsimused olid arusaadavad, kas Teil tekkis vastamisega mõnele neist probleeme). Kui Teil on esinenud muid probleeme seoses epilepsiaga, mida eelnevad küsimused ei kajastanud piisavalt, võiksite neid siin kirjeldada. Rõhutame veelkord, et uuring on mõeldud epilepsiaga inimeste probleemide välja selgitamiseks ning vastuste analüüsimisel on Teie anonüümsus tagatud.

....
....
....
....
....
....
....
....

QUALITY OF LIFE IN EPILEPSY

Date ....

Initials: ....   Education: ....………….…..
Date of birth: ....   Profession: ....
Age: ....
Sex: M F
Marital status: ....

1. Seizure frequency status: a) once or more in a month
                        b) less often than once a month
                        c) not at all in the past year
2. Injuries associated with seizures during the past year:
a) serious injuries: seizure-related burns or scalds, large excoriations, deep cuts, fractures
b) bitten tongue, dental injuries or severe headaches
c) milder injuries (small excoriations, suffusions, etc) or mild headaches
d) any other injuries ....
e) no injuries
3. If the seizure causes loss of conciousness, is there a warning long enough for you to protect yourself? (If there is no loss of conciousness or seizures occur only while asleep, mark c)
                   a) never
                   b) sometimes
                   c) nearly always or always
4. How often have you fallen to the ground during a seizure?
                   a) nearly always or always
                   b) often
                   c) occasionally
                   d) never
5. How long is it until you are really back to normal consciousness and active after the seizure?
                   a) less than 1 minute
                   b) between 1 and 10 minutes
                   c) between 10 minutes and 1 hour
                   d) between 1 and 3 hours
                   e) more than 3 hours
6. Please, characterise briefly your seizures (what happens with you during a seizure – what do you feel, how have your seizures been characterised by the eyewitnesses):
....
....
....
....
7. How old were you at the time of the first seizure? ....
8. When did you have the last seizure (approximate date)? ....
9. How often have you been incontinent of urine during a seizure?
                   a) nearly always or always

b) often

c) occasionally

d) never

10. Do the following events have occurred during a seizure:

a) seriously disruptive automatisms (e.g. shouting, wandering, undressing)

b) mild automatisms or focal jerking

c) none

11. How would you rate your seizures: a) very severe b) severe c) medium
d) light

12. What kind of antiepileptic drugs are you taking ? (name + dose):

…………………………………………………………………………………..

13. Have you experienced any of the symptoms associated with the antiepileptic drug treatment during the past month? Please, mark behind the side-effect you have had the number showing how often the symptom has been a problem: 1 – always or often, 2 – sometimes, 3 – infrequently.

a) dizziness… b) tiredness… c) unsteadiness… d) nausea, vomiting…

e) skin itch, rash… f) diarrhoea… g) sleepiness… h) insomnia… i) mood changes…

j) nervousness, agitation… k) restlessness … l) headache… m) shaky hands…

n) heartburn… o) weight changes… p) changes in appetite… r) oedemas…

s) heart problems… t) increased growth of hair… u) loss of hair…

v) difficulty in concentrating… õ) memory problems… ä) difficulty in thinking clearly…   ö) slurred speach… ü) double or blurred vision… x) other symptoms

………………………………………………. y) side-effects have not occurred

14. How satisfied are you with your current treatment (also with the control of the seizures and the tolerance of the side-effects):

a) absolutely satisfied

b) almost satisfied

c) a little bit unsatisfied, could be better

d) not satisfied at all

15. Has your antiepileptic treatment been changed during the past year? a) yes b) no

If yes, then how many times? …..

Has the treatment been changed because of its insufficiency or side-effects?

(Please, underline the right answer)

16. How regularly have you been taking your antiepileptic drugs during the last month?   a) I have never missed taking my antiepileptic drugs

b) I have missed to take them less than once a month

c) I have missed to take them less than once a week

d) I have missed to take them more often than once a week

17. Additional chronical illnesses (in case you are having any):

……………………………………………………………………………………………

……………………………………………………………………………………………

18. Other constantly used medication(s):

……………………………………………………………………………………………

……………………………………………………………………………………………

19. Do you work full-time?   a) yes   b) no

If you are un- or underemployed, do you consider epilepsy as a reason for it?

a) yes   b) no

20. Have you changed a job during the last two years?

a) yes   b) no

21. Have you been treated unfairly at work or when applying for a job because of epilepsy? a) yes b) no

22. Economical and financial status:

> a) very good
> b) good
> c) satisfactory
> d) moderately bad
> e) very bad

23. Driving-license:

> a) never had one
> b) invalidated because of epilepsy
> c) having a driving license

24. Have you felt that because of your epilepsy:

- other people have been uncomfortable with you?   a) yes   b) no
- other people have treated you as inferior?   a) yes   b) no
- other people have preferred to avoid you?   a) yes   b) no

25. About how many times during the past year have you visited your doctor? (mark the number) ...... Of this, how many times because of epilepsy? ......

26. What kind of and how many of the following analyses have been done to you during the last year: a) blood test.... b) EEG.... c) CT.... d) MRI.... . Of them, which ones and how many times because of epilepsy?

....

27. About how many times have you visited your doctor because of the seizure-related injuries during the last year? (mark the number).....If you have had serious injuries, please, mark the procedures that have been done to you (e.g. cleaning of the wound, suture of the wound, application of a splint due to fracture, complications, also hospital treatment and the number of days)

....
....
....

28. Answering to this question is not obligatory.

We would like to know your opinion about this as well as about the other questionnaires (were the questions understandable, did you have problems in answering to any of the questions, your opinion about the importance of the study). In case you have had any other problem related to your epilepsy that were not sufficiently covered with the questions, you could describe them here. We would emphasise once more that the study is meant to explore the problems of the people with epilepsy and when analysing the answers your anonymity is guaranteed.

....
....
....
....
....
....
....
....

RAND 36-küsimuseline tervisliku seisundi ülevaade, versioon 1.0

Küsimustik

1. Üldiselt öeldes, kas Teie tervis on:

<div style="text-align:center">tõmmake ring ümber ainult
ühele vastusevariandi numbrile</div>

Suurepärane	1
Väga hea	2
Hea	3
Rahuldav	4
Halb	5

2. Milline on Teie tervislik seisund **praegu võrreldes olukorraga aasta tagasi**?

<div style="text-align:center">tõmmake ring ümber ainult
ühele vastusevariandi numbrile</div>

Palju parem kui aasta tagasi	1
Mõnevõrra parem kui aasta tagasi	2
Umbes sama kui aasta tagasi	3
Veidi halvem kui aasta tagasi	4
Palju halvem kui aasta tagasi	5

Alljärgnevalt on toodud igapäevased füüsilist koormust pakkuvad tegevused. Kas Teie praegune **tervislik seisund piirab Teil** nende toimingute sooritamist? Kui jah, siis kui palju?

tõmmake igas reas ainult ühele vastusevariandi numbrile ring ümber

	Jah, piirab palju	Jah, piirab veidi	Ei, üldse ei piira
3. **Suurt füüsilist koormust** pakkuvad tegevused nagu jooksmine, raskete esemete tõstmine, pingeline sporditegevus	1	2	3
4. **Keskmist füüsilist koormust** pakkuvad tegevused nagu söögilaua liigutamine, tolmuimeja kasutamine, kerge võimlemine, lehtede riisumine	1	2	3
5. Poekottide tõstmine või kandmine	1	2	3
6. **Mitme** trepivahe üles kõndimine	1	2	3
7. **Ühe** trepivahe üles kõndimine	1	2	3
8. Painutamine, põlvitamine, kummardumine	1	2	3
9. **Rohkem kui 1 kilomeetri** kõndimine	1	2	3
10. **500 m** kõndimine	1	2	3
11. **100 m** kõndimine	1	2	3
12. Enda pesemine ja riietumine	1	2	3

Kas Teil on **viimase nelja nädala jooksul** ette tulnud allpool loetletud probleeme oma töö või muude igapäevaste toimingute juures **tingituna Teie kehalisest tervisest**?

tõmmake igas reas ainult ühele vastusevariandi numbrile ring ümber

	Jah	Ei
13. Olite sunnitud vähendama töö ja teiste toimingute jaoks planeeritud **aega**?	1	2
14. **Saavutasite vähem** kui Teile oleks meeldinud?	1	2
15. Olite võimeline sooritama **ainult teatud** töid ja toiminguid?	1	2
16. Oli **raskusi** töö ja teiste toimingute tegemisel (näiteks seetõttu, et see nõudis lisapingutust) ?	1	2

Kas Teil on **viimase nelja nädala jooksul** ette tulnud oma **emotsinaalse seisundi** (näiteks olite depressioonis või ärevil) tõttu tööl või muude igapäevaste toimingute juures allpool loetletud probleeme?

	Jah	Ei
17. Olite sunnitud vähendama töö ja teiste toimingute jaoks planeeritud **aega**?	1	2
18. **Saavutasite vähem** kui Teile oleks meeldinud?	1	2
19. Ei teinud oma töid või toiminguid nii **hoolikalt** kui tavaliselt?	1	2

20. Kui palju **viimase nelja nädala jooksul** on Teie kehaline tervis või emotsionaalsed probleemid häirinud Teie normaalset seltskondlikku tegevust perekonna, sõprade, naabrite või kolleegidega?

<div align="right">

tõmmake ring ümber ainult
ühele vastusevariandi numbrile

Üldse mitte	1
Veidi	2
Mõõdukalt	3
Üsna palju	4
Väga palju	5

</div>

21. Kui palju **füüsilist** valu tundsite Te **viimase nelja nädala jooksul**?

<div align="right">

tõmmake ring ümber ainult
ühele vastusevariandi numbrile

Üldse mitte	1
Väga vähe	2
Vähe	3
Mõõdukalt	4
Palju	5
Väga palju	6

</div>

22. Kui palju segas **valu viimase nelja nädala jooksul** Teid oma igapäevase töö juures (nii väljaspool kodu kui ka koduste tööde juures)?

<div align="right">

tõmmake ring ümber ainult
ühele vastusevariandi numbrile

Üldse mitte	1
Veidi	2
Mõõdukalt	3
Üsna palju	4
Väga palju	5

</div>

Järgnevad küsimused puudutavad Teie enesetunnet ja seda, kuidas Teil on läinud, **viimase nelja nädala jooksul**.
Igale küsimusele andke vastus, mis kõige täpsemalt kirjeldab, kuidas Te ennast tundsite.
Kui tihti Te **viimase nelja nädala jooksul**...

tõmmake igas reas ainult ühele
vastusevariandi numbrile ring ümber

	Kogu aeg	Suurema osa ajast	Sageli	Vahel	Harva	Üldse mitte
23....tundsite end särtsakalt?	1	2	3	4	5	6
24....olite väga närviline?	1	2	3	4	5	6
25....olite nii suures masenduses, et miski ei suutnud Teid lohutada?	1	2	3	4	5	6
26....olite rahulik?	1	2	3	4	5	6
27....tundsite ennast täis energiat?	1	2	3	4	5	6
28....olite rõhutud ja kurb?	1	2	3	4	5	6
29....olite kurnatud?	1	2	3	4	5	6
30....olite õnnelik?	1	2	3	4	5	6
31....olite väsinud?	1	2	3	4	5	6

32. Kui suure osa ajast **viimase nelja nädala** jooksul segasid **kehaline tervis** või **emotsionaalsed probleemid** Teie seltskondlikku tegevust (nt. sõprade ja sugulaste külastamist jms.)?

tõmmake ring ümber ainult
ühele vastusevariandi numbrile

Pidevalt	1
Suurema osa ajast	2
Vahel	3
Harva	4
Üldse mitte	5

Kui suurel määral on iga järgnev väide Teie suhtes ÕIGE või VALE?

tõmmake igas reas ainult ühele
vastusevariandi numbrile ring ümber

	Väga õige	Enamasti õige	Ei tea	Enamasti vale	Väga vale
33.Mulle näib, et ma jään haigeks kergemini kui teised inimesed	1	2	3	4	5
34.Ma olen niisama terve kui teisedki	1	2	3	4	5
35.Ma arvan, et mu tervis halveneb edaspidi	1	2	3	4	5
36.Minu tervis on suurepärane	1	2	3	4	5

RAND 36-ITEM HEALTH SURVEY 1.0

QUESTIONNAIRE ITEMS

1.   In general, would you say your health is:

(Circle One Number)

Excellent.. 1

Very good 2

Good 3

Fair.. 4

Poor 5

2.   **Compared to one year ago,** how would you rate your health in general now?

(Circle One Number)

Much better now than one year ago 1

Somewhat better now than one year ago................................. 2

About the same.. 3

Somewhat worse now than one year ago................................. 4

Much worse now than one year ago.. 5

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(Circle One Number on Each Line)

		Yes, Limited a Lot	Yes, Limited a Little	No, Not Limited at All
3.	**Vigorous activities,** such as running, lifting heavy objects, participating in strenuous sports............................	1	2	3
4.	**Moderate activities,** such as moving a table, pushing a vacuum cleaner, bowling, or playing golf........................	1	2	3
5.	Lifting or carrying groceries	1	2	3
6.	Climbing several flights of stairs..	1	2	3
7.	Climbing one flight of stairs..	1	2	3
8.	Bending, kneeling, or stooping	1	2	3
9.	Walking more than a mile...	1	2	3
10.	Walking several blocks..	1	2	3
11.	Walking one block	1	2	3
12.	Bathing or dressing yourself..	1	2	3

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(Circle One Number on Each Line)

		Yes	No
13.	Cut down the amount of time you spent on work or other activities..	1	2
14.	Accomplished less than you would like............................	1	2
15.	Were limited in the kind of work or other activities.............	1	2
16.	Had difficulty performing the work or other activities (for example, it took extra effort)...	1	2

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(Circle One Number on Each Line)

		Yes	No
17.	Cut down the amount of time you spent on work or other activities	1	2
18.	Accomplished less than you would like............................	1	2
19.	Didn't do work or other activities as carefully as usual.......	1	2

20. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

(Circle One Number)

Not at all...	1
Slightly	2
Moderately	3
Quite a bit...	4
Extremely..	5

21. How much bodily pain have you had during the past 4 weeks?

(Circle One Number)

None..	1
Very mild...	2
Mild..	3
Moderate...	4
Severe..	5
Very severe.......................................	6

22. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

(Circle One Number)

Not at all	1
A little bit	2
Moderately	3
Quite a bit	4
Extremely	5

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks . . .

(Circle One Number on Each Line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
23. Did you feel full of pep?	1	2	3	4	5	6
24. Have you been a very nervous person?	1	2	3	4	5	6
25. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
26. Have you felt calm and peaceful?	1	2	3	4	5	6
27. Did you have a lot of energy?	1	2	3	4	5	6
28. Have you felt downhearted and blue?	1	2	3	4	5	6
29. Did you feel worn out?	1	2	3	4	5	6
30. Have you been a happy person?	1	2	3	4	5	6
31. Did you feel tired?	1	2	3	4	5	6

32. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

(Circle One Number)

All of the time	1
Most of the time	2
Some of the time	3
A little of the time	4
None of the time	5

- 10 -

How TRUE or FALSE is each of the following statements for you?

(Circle One Number on Each Line)

		Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
33.	I seem to get sick a little easier than other people	1	2	3	4	5
34.	I am as healthy as anybody I know	1	2	3	4	5
35.	I expect my health to get worse.	1	2	3	4	5
36.	My health is excellent	1	2	3	4	5

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1700 Main Street, PO Box 2138
Santa Monica, CA 90407-2138

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ELUKVALITEET EPILEPSIA KORRAL
QOLIE-31 *(Versioon 1.0)*

KÜSIMUSTIK PATSIENDILE

Kuupäev __ / __ / __ /
     päev kuu aasta

Nimi ....

SISSEJUHATUS

Selles küsimustikus esitatakse Teile küsimusi Teie tervise ja igapäevaste tegevuste kohta. Palun vastake **igale küsimusele**, märkides ära vastav number (1, 2, 3, …).

Kui Te ei ole päris kindel, kuidas küsimusele vastata, andke sobivaim ligilähedane vastus ja kirjutage lehe servale selgitav märkus.

Kui vajate küsimustiku lugemisel või täitmisel kellegi kõrvalabi, paluge, et keegi Teid aitaks.

1. **Kuidas Te hindate oma elukvaliteeti laias plaanis?**

(Märkige alloleval skaalal üks arv)


```
 10   9   8   7   6   5   4   3   2   1   0
```
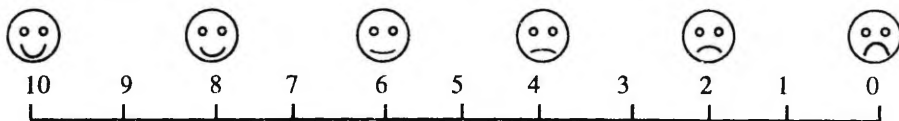
Parim võimalik
elukvaliteet

Halvim võimalik
elukvaliteet
(sama halb või halvem
oleks olla surnud)

Neis küsimustes käsitleme seda, kuidas Te end **TUNNETE** ja kuidas Teil on läinud **viimase 4 nädala** jooksul. Palun andke igale küsimusele vastus, mis Teie seisundile kõige enam vastas.

Kui tihti **viimase 4 nädala** jooksul ...

(Märkige igas reas üks arv ringiga)

	Kogu aeg	Suurema osa ajast	Sageli	Mõnikord	Harva	Üldse mitte
2. ... tundsite end särtsakalt?	1	2	3	4	5	6
3. ... olite Te väga närviline?	1	2	3	4	5	6
4. ... olite nii löödud, et miski ei suutnud Teid lohutada?	1	2	3	4	5	6
5. ... olite Te rahulik ja tasakaalukas?	1	2	3	4	5	6
6. ... olite Te täis energiat?	1	2	3	4	5	6
7. ... olite Te tujutu ja kurb?	1	2	3	4	5	6
8. ... olite Te kurnatud?	1	2	3	4	5	6
9. ... olite Te õnnelik?	1	2	3	4	5	6
10. ... olite Te väsinud?	1	2	3	4	5	6
11. ... olite Te mures järgmise hoo tekkimise pärast?	1	2	3	4	5	6
12. ... oli Teil raskusi probleemide kallal töötamisel või nende lahendamisel (nt. plaanide tegemisel, otsuste vastu võtmisel, uute asjade õppimisel)	1	2	3	4	5	6

13. … olite Te oma tervisliku seisundi tõttu piiratud sotsiaalse tegevuse ja ettevõtmiste osas (nt. sõprade või lähedaste külastamine)	1	2	3	4	5	6

14. Milline oli Teie **ELUKVALITEET viimase 4 nädala** jooksul (s.t. kuidas Teil on läinud)?

Märkige üks arv ringiga
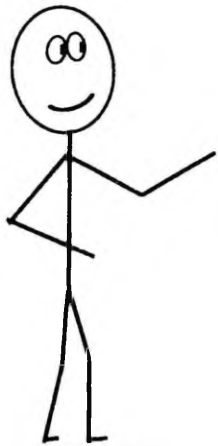
Väga hea: parem ei saagi olla	**1**
Üsna hea	**2**
Nii hea kui halb	**3**
Üsna halb	**4**
Väga halb: halvem ei saagi olla	**5**

Järgmine küsimus puudutab **MÄLU**.

(Märkige ringiga üks arv)

	Jah, palju	Jah, mõningal määral	Ainult vähesel määral	Ei, üldse mitte
15. Kas Teil on olnud viimase 4 nädala kestel probleeme mäluga?	1	2	3	4

Märkige üks arv, iseloomustamaks seda, **kui sageli** viimase 4 nädala jooksul on Teil olnud probleeme *meenutamisega* või **kui sageli** on probleemid mäluga seganud Teie normaalset tööd või elu.

	Alati	Enamasti	Kaunis sageli	Mõnikord	Harva	Mitte kunagi
16. Oli Teil probleeme meenutamaks asju, mida Teile oli öeldud?	1	2	3	4	5	6

Järgmised küsimused käsitlevad võimalikke probleeme, mis Teil võivad esineda seoses **KONTSENTREERUMISEGA**. Märkige üks arv, iseloomustamaks seda, **kui sageli viimase 4 nädala** jooksul on Teil olnud probleeme kontsentreerumisega või **kui sageli** on need probleemid seganud Teie tööd või elu.

	Alati	Enamasti	Kaunis sageli	Mõnikord	Harva	Mitte kunagi
17. Oli Teil probleeme lugemisele kontsentreerumisega?	1	2	3	4	5	6
18. Oli Teil probleeme kontsentreerumisega ühe asja tegemisele korraga?	1	2	3	4	5	6

Järgmised küsimused puudutavad probleeme, millised võivad olla seotud kindlate **TEGEVUSTEGA**. Märkige üks arv, iseloomustamaks seda, **kui palju** on Teie epilepsia või epilepsiavastased ravimid **viimase 4 nädala** jooksul põhjustanud Teile probleeme järgmiste tegevuste juures.

	Väga palju	Palju	Veidi	Väga vähe	Üldse mitte
19. Vaba aja veetmine (nt. hobid, väljas käimine)	1	2	3	4	5
20. Auto-, mootorratta juhtimine	1	2	3	4	5

Järgmised küsimused püüavad välja selgitada Teie **SUHTUMIST** oma **hoogudesse**.

(Märkige igas reas ringiga üks arv)

	Suur hirm	Mõõdukalt hirmu	Vähe hirmu	Üldse mitte hirmu
21. Kui suur on Teil hirm hoo tekke ees järgneva kuu jooksul	1	2	3	4

	Muretsen palju	Vahete-vahel muretsen		Ei muretse üldse
22. Kas Te muretsete selle pärast, et võite end hoo ajal vigastada?	1	2		3

	Väga mures	Mõõdukalt mures	Pisut mures	Üldse mitte mures
23. Kui mures Te olete selle üle, et hoog järgmise 4 nädala jooksul asetab Teid piinlikku olukorda või tekitab Teile kaaskodanikega muid probleeme?	1	2	3	4
24. Kui mures Te olete selle üle, et kui Te pidevalt tarvitate epilepsia-vastaseid ravimeid, võivad need Teie tervisele halvasti mõjuda?	1	2	3	4

Märkige iga järgneva probleemi kohta skaalal 1 kuni 5 üks arv, mis näitab, **kui väga Te selle all kannatate**, kusjuures 1 = ei kannata üldse ja 5 = kannatan väga (erakordselt).

25. Haigushood	1	2	3	4	5
26. Mäluprobleemid	1	2	3	4	5
27. Piirangud töös	1	2	3	4	5
28. Piirangud sotsiaalsetes suhetes	1	2	3	4	5
29. Epilepsiavastaste ravimite kehalised kõrvaltoimed	1	2	3	4	5
30. Epilepsiavastaste ravimite psüühilised kõrvaltoimed	1	2	3	4	5

31. Kui heaks või halvaks hindate Te oma tervist? Allpool kujutatud skaalal on parim kujuteldav terviseseisund 100 juures ja halvim kujuteldav terviseseisund 0 juures. Palun märkige skaalal ristiga, kuidas Te oma tervist hindate. **Sellele küsimusele vastates palun hinnake epilepsiat osana oma üldisest tervisest.**

100 = parim kujuteldav
         terviseseisund
90
80
70
60
50
40
30
20
10
0 = halvim kujuteldav
       terviseseisund
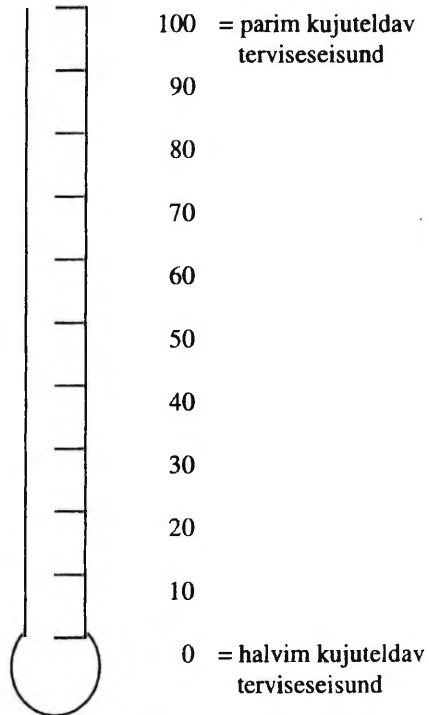
14. How has the **QUALITY OF YOUR LIFE** been during the **past 4 weeks** (that is, how have things been going for you)?

(Circle
one
number)

Very well: could hardly be better	1
Pretty good	2
Good & bad parts about equal	3
Pretty bad	4
Very bad: could hardly be worse	5

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The following question is about **MEMORY**.

(Circle one number)

	Yes, a great deal	Yes, somewhat	Only a little	No, not at all
15. In the past 4 weeks, have you had any trouble with your memory?	1	2	3	4

Circle one number for **how often** in the **past 4 weeks** you have had trouble *remembering* or **how often** this memory problem has interfered with your normal work or living.

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
16. Trouble remembering things people tell you	1	2	3	4	5	6

The following questions are about **CONCENTRATION** problems you may have. Circle one number for **how often** in the **past 4 weeks** you had trouble concentrating or **how often** these problems interfered with your normal work or living.

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
17. Trouble concentrating on reading	1	2	3	4	5	6
18. Trouble concentrating on doing one thing at a time	1	2	3	4	5	6

The following questions are about problems you may have with certain **ACTIVITIES**. Circle one number for **how much** during the **past 4 weeks** your epilepsy or antiepileptic medication has caused trouble with . . .

	A great deal	A lot	Somewhat	Only a little	Not at all
19. Leisure time (such as hobbies, going out)	1	2	3	4	5
20. Driving	1	2	3	4	5

The following questions relate to the way you **FEEL** about your seizures.

(Circle one number on each line)

		Very fearful	Somewhat fearful	Not very fearful	Not fearful at all
21.	How fearful are you of having a seizure during the next month?	1	2	3	4

		Worry a lot	Occasionally worry	Don't worry at all
22.	Do you worry about hurting yourself during a seizure?	1	2	3

		Very worried	Somewhat worried	Not very worried	Not at all worried
23.	How worried are you about embarrassment or other social problems resulting from having a seizure during the next month?	1	2	3	4
24.	How worried are you that medications you are taking will be bad for you if taken for a long time?	1	2	3	4

For each of these **PROBLEMS**, circle one number for **how much they bother you** on a scale of 1 to 5 where 1 = Not at all bothersome, and 5 = Extremely bothersome.

		Not at all bothersome				Extremely bothersome
25.	Seizures	1	2	3	4	5
26.	Memory difficulties	1	2	3	4	5
27.	Work limitations	1	2	3	4	5
28.	Social limitations	1	2	3	4	5
29.	Physical effects of antiepileptic medication	1	2	3	4	5
30.	Mental effects of antiepileptic medication	1	2	3	4	5

31. How good or bad do you think your health is? On the thermometer scale below, the best imaginable state of health is 100 and the worst imaginable state is 0. Please indicate how you feel about your health by circling one number on the scale. **Please consider your epilepsy as part of your health when you answer this question.**

```
100 = Best Imaginable
      Health State

 90

 80

 70

 60

 50

 40

 30

 20

 10

  0 = Worst Imaginable
      Health State
```
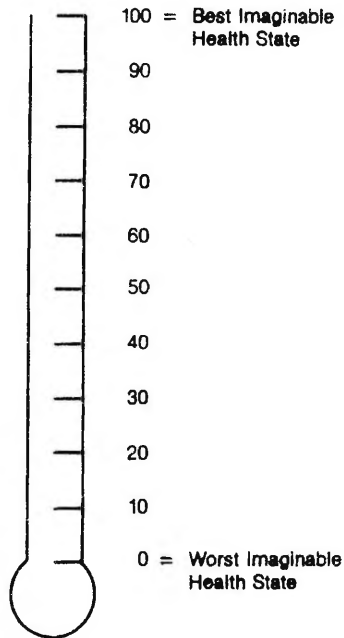
PUBLICATIONS

QUALITY OF LIFE IN EPILEPSY
QOLIE-31 *(Version 1.0)*

Patient Inventory

Today's Date ___ / ___ / ___

Patient's Name _____

Patient's ID# _____

Gender: ☐ **Male** ☐ **Female**   **Birthdate** ___ / ___ / ___

INSTRUCTIONS

This survey asks about your health and daily activities. **Answer every question** by circling the appropriate number (1, 2, 3 . . .).

If you are unsure about how to answer a question, please give the best answer you can and write a comment or explanation in the margin.

Please feel free to ask someone to assist you if you need help reading or marking the form.

1.   Overall, how would you rate your quality of life?

(Circle one number on the scale below)


```
  ☺        ☺        ☺        ☹        ☹        ☹

 |   |    |    |    |    |    |    |    |    |    |
 10   9    8    7    6    5    4    3    2    1    0
```
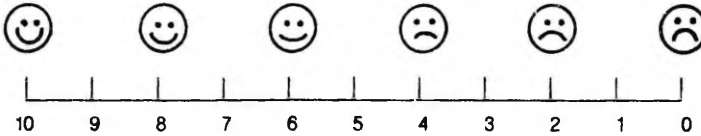
Best Possible   Worst Possible
Quality of Life   Quality of Life

                                                     (as bad as or
                                                      worse than
                                                      being dead)

These questions are about how you **FEEL** and how things have been for you during the **past 4 weeks**. For each question, please indicate the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks**...

(Circle one number on each line)

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
2.	Did you feel full of pep?	1	2	3	4	5	6
3.	Have you been a very nervous person?	1	2	3	4	5	6
4.	Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
5.	Have you felt calm and peaceful?	1	2	3	4	5	6
6.	Did you have a lot of energy?	1	2	3	4	5	6
7.	Have you felt downhearted and blue?	1	2	3	4	5	6
8.	Did you feel worn out?	1	2	3	4	5	6
9.	Have you been a happy person?	1	2	3	4	5	6
10.	Did you feel tired?	1	2	3	4	5	6
11.	Have you worried about having another seizure?	1	2	3	4	5	6
12.	Did you have difficulty reasoning and solving problems (such as making plans, making decisions, learning new things)?	1	2	3	4	5	6
13.	Has your health limited your social activities (such as visiting with friends or close relatives)?	1	2	3	4	5	6

Täiskasvanute elukvaliteet epilepsia korral

Marju Rätsepp Andre Õun Sulev Haldre
Ain-Elmar Kaasik

epilepsia, stigma, hoo raskus, tervisega seotud elukvaliteet, elukvaliteedi hindamise vahendid, elukvaliteedi uuringud

Inimesi, kellel esineb epilepsia, on läbi aegade peetud "ebasoovitavalt erinevateks" (*an undesired differentness*) (15). Epilepsia ei ole pidev seisund. See on haigus, mille korral normaalse neuroloogilise funktsiooniga perioodid vahelduvad harvade lühikeste hoogude-perioodidega. Mitme kroonilise haiguse puhul esinev haigusnähtude avaldumise ootamatus, mis tekitab inimeses pideva kindlusetustunde, on epilepsia puhul eriti ilmekalt väljendunud.

Haiguse raskus ja prognoos on varieeruvad ning hood selle välise ilminguna ettearvamatud. Epilepsia tõttu suuremal või vähemal määral esile kerkivad psühhosotsiaalsed probleemid kaaluvad sageli üles hoogude ja nende raviga seotu. Kliiniliste nähtude ja sotsiaalse tähenduse tõttu võib epilepsia inimese elukvaliteedile avaldada märkimisväärset mõju (2, 3).

Stigma olemus. E. Goffman defineerib stigma (kr. *stigma* — arm, märk) sisemise häbitundena, mis võib muuta inimese iseloomu nii, et tal tekivad tõsised suhtlemisprobleemid, mis omakorda tekitavad raskusi ja langetavad motivatsiooni toimetulekuks ühiskonnas (15). Stigma kujunemisel näevad nii E. Goffman kui ka H. Becker olulist osa ühiskonnas valitseval üldisel suhtumisel inimestesse, kes on millegi poolest erinevad, ning nende suh-

tes kehtestatud reeglites ja piirangutes (4, 15). Kuid nagu väidavad mitmed autorid, on stigma tekkeks eelkõige vajalik see, et inimene tunneks, et ta on mingil põhjusel sunnitud ühiskondliku arvamusega arvestama, s.t. selle teataval määral omaks võtma (27).

E. Goffman leiab, et stigma väljendub erinevalt inimestel, kelle haigussümptomid on kõigile nähtavad ja esinevad pidevalt, võrreldes nendega, kelle haigus avaldub episoodiliselt ning võib neid asetada ootamatutesse olukordadesse. Viimati mainitute puhul tekitab neile enim probleeme see, et nad peavad pidevalt kontrollima, mida, millal ja kellele oma seisundist rääkida ja mida varjata (15). Selline olukord võib tekitada pideva ärevus- ja stressiseisundi. G. L. Albrecht ja kaasautorid väidavad, et kord juba tekkinud stigmast ei olegi täielikult võimalik vabaneda ning seetõttu peavad nad seisundit pöördumatuks (1). G. Scambler rõhutab stigma olemasolu just epilepsia korral (24).

Uuringutega on esile tõstetud mitmeid erilist tähelepanu väärivaid valdkondi (6, 8, 16). Epilepsiaga isikutel on tihti vähenenud enesest lugupidamine (5), sagedamini kui rahvastikus keskmiselt esineb neil ärevust ja depressiooni (7). Nende hulgas tuleb suhteliselt sageli ette töötust või tööga alahõivatust (14), samuti on suurem sotsiaalne isolatsioon ja väiksem abielus olevate inimeste protsent (2, 12).

Epidemioloogilised uuringud on näidanud, et 70—80%-l epilepsiahaigetest alluvad hood hästi epilepsiavastasele ravile (23), ning on tõendeid, et nende puhul epilepsia otseselt elukvaliteeti ei alanda (17). Ülejäänud 20—30% puhul, kelle hood on kroonilised ja ravile raskesti alluvad, on olukord tunduvalt komplitseeritum. Siiani tehtud uuringud on selgelt näidanud, et suhe epilepsia raskuse ja tema mõju vahel elukvaliteedile on kompleksne ning selle hindamisel tuleb arvesse võtta erinevaid tegureid, kaasa arvatud patsiendi

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enda arvamus, tema haiguse raskus ja selle ravi (22).

Tervisega seotud elukvaliteet. Tervis on Maailma Tervishoiuorganisatsiooni defineerituna täieliku füüsilise, vaimse ja sotsiaalse heaolu seisund, mitte lihtsalt haiguse puudumine (11). H. Schipper ja kaasautorid on kirjeldanud tervisega seotud elukvaliteeti (*health-related quality of life*) krooniliste haiguste korral kui haiguse ja selle ravi funktsionaalset efekti patsiendile, tunnetatuna tema enda poolt (26). Mõiste on laiem kui üksikute selle alla kuuluvate komponentide summa, sest sellega tähistatakse sünergiat erinevate valdkondade vahel ja erinevusi, mis on tingitud olukordadest ja patsiendipoolsest suhtumisest. Definitsioone kombineerides võib öelda, et meditsiin püüab lisada elule aastaid, samal ajal kui inimloomus tahaks lisada aastatele elu. Leitakse, et elukvaliteedi uurimisel tuleks peatähelepanu koondada sellele, kuidas inimene ise oma seisundit hindab, arvestamata, mida näitavad kliinilised uuringud ja analüüsid (11).

Elukvaliteedi uuringud epilepsia korral. Üks esimesi, kes uuris elukvaliteedi spetsiifilisi aspekte epilepsia korral, oli J. Collings (3). Ta hindas patsientide eneseväärikust, eluga rahulolu, sotsiaalseid ja isikutevahelisi suhteid, üldist tervist, probleemide üle muretsemise määra ja üldist heaolu, kasutades erinevaid psühhomeetrilisi vahendeid. Tulemused näitasid märkimisväärseid eneseninnangu vastuväärikivusi. Kui remission viis ravi lõpetamiseni, siis psühhosotsiaalne seisund mõningal määral paranes. A. Jacoby ja kaasautorid, kasutades viit standardset psühhomeetrilist testi, hindasid patsiente, kellel ei olnud hooge tekkinud mitme aasta vältel. Nad leidsid, et neil, kelle epilepsiavastane ravi jätkus, esines märgatavalt rohkem stressi kui neil, kelle ravi oli lõpetatud (19).

G. Scambler ja A. Hopkins, hinnates piiranguid sotsiaalsetes suhetes, kirjeldasid erinevust tõelise ja tunnetatud stigma vahel (25). Patsiendi eneseninnang leiti olevat heas korrelatsioonis üldise tervisega seotud elukvaliteediga. Epilepsiahaiged said märgatavalt vähem punkte eneseväärikuse, eluga rahulolu, sotsiaalsete probleemidega toimetuleku, füüsiliste sümptomite ning murede ja emotsioonide tasakaalustamise osas kui kontrollrühma patsiendid. Hoogude esinemissagedus ei olnud kõige tähtsam sotsiaalse stressi näitaja, kuigi parem kontroll hoogude üle oli korrelatsioonis üldise heaoluga (25).

Nii arst kui ka patsient koondavad oma tähelepanu tavaliselt hoogude sagedusele ja raskusele. Eesmärk pärast diagnoosi määramist ja ravi alustamist on hoogudest vabanemine. Kahjuks korduvad need 70%-l komplekssete partsiaalsete hoogudega täiskasvanuist ravile vaatamata (20). Komplekssed partsiaalsed hood on epileptilised hood, mille aluseks olev aju bioelektrilise aktiivsuse ülemäärane tõus algab hemisfääri ühes osas. Need hood kulgevad teadvushäiretega, mille väljenduseks on reageerimatus välistele ärritajatele ja automatismide avaldumine (näiteks suu matsutamine, huulte lakkumine, sõrmede keerutamine, vahel ka eesmärgistatud tegevus). Kuigi isik on hoo ajal ärkvel, esineb tal toimunu suhtes hiljem tihti amneesia.

Edasi sõltub ravi korrigeerimine suuresti patsiendist endast. Arst võib ravi muuta vastusena selle patsiendi ohtratele kaebustele, kel esinevad harvad hood, kuid mitte muuta ravi teise sama hoogude arvuga patsiendi puhul, kes peab oma seisundit rahuldavaks. Sageli hindavad sama tüüpi epilepsiahoogudega isikud, kellel hood alluvad ka ravile sarnaselt ja kes taluvad ka ravi kõrvaltoimeid sarnaselt, epilepsia mõju oma igapäevaelule täiesti erinevalt, sõltuvalt sellest, mida kumbki enda jaoks piiranguna tunnetab (11).

Epilepsiahoo raskuse hindamine.
Epilepsia korral põhineb haiguse raskuse hindamine tavaliselt hoogude sageduse arvestamisel, kuid hoogude arvu ja nende tagajärgede vahel ei pruugi olla selget vastavust. Isikutel, kellel esineb refraktaarne (ravile allumatu) epilepsia, võib hoogude raskus olla tähtsam psühhosotsiaalse heaolu determinant kui hoogude sagedus. Samal ajal, kui isiku puhul, kellel esinevad kerged hood, võib suurimaks probleemiks olla hoopis epilepsia diagnoos ise (28). Samuti ei pruugi hoogude tüüp haiguse raskust peegeldada.

Näiteks võib lihtne partsiaalne hoog (epilepsiahoog, mille aluseks olev aju bioelektrilise aktiivsuse ülemäärane tõus algab hemisfääri ühes osas ning mis ei põhjusta teadvushäiret) nähtava ja kontrollimatu motoorse komponendiga olla inimesele subjektiivselt häirivam kui kerge teadvuse hägunemise ja aeglaselt kulgev kompleksne partsiaalne hoog, mis jääb kõrvalseisjaile märkamatuks (9).

Hoo raskuse hindamine annab lisainformatsiooni ka neil juhtudel, kui sama hoogude sageduse juures muutub nende kvaliteet, näiteks ilmnevad muutused automatismide (sihipäratu, kontrollimatu, tahtliku juhtimiseta toimuv (automaatne) liigutus või liigutuste kompleks) raskuses, esineb vähem kukkumisi ja vigastusi hoo ajal, kiirem taastumine vms. (21).

Hoogude raskuse ja elukvaliteedi hindamise skaalad. Hoogude raskuse hindamiseks on kasutatud erinevaid skaalasid, kuid laialdaselt ei ole neist levinud ükski. Iga skaala abil on võimalik koguda teatav punktisumma, mille abil hinnatakse seisundit seoses hoogude sagedusega kindlaks määratud perioodi vältel. Ameerika Ühendriikides riiklikult finantseeritava sõjaveteranide tervishoiuorganisatsiooni epilepsiauuringute grupi poolt väljatöötatud hoogude sageduse ja raskuse hindamise skaala (*The Vete-*

rans Affairs (VA) Seizure Frequency and Severity Scale) on kasutusel kliinilistes katsetes, et dokumenteerida nii hoogude arvu kui ka tüüpi.

Inglismaalt pärit Chalfondi hoogude skaala (*The Chalfont Seizure Scale*) ning selle lühendatud ja lihtsustatud variant — NHS3 (*The National Hospital Seizure Severity Scale*) — koondavad tähelepanu hoogude objektiivsete parameetrite registreerimisele. Neid skaalasid täidab arst, kes küsitleb patsienti ja võimaluse korral ka hoogu pealtnäinud isikut. Liverpooli skaala (*The Liverpool Scale*) kujutab endast küsimustikku, mis põhineb patsiendi tunnetatud epilepsia mõju ning hooaegsete ja -järgsete nähtude arvestamisel (21).

Küllaltki laialdaselt kasutusel olev 36-punktiline üldise tervisega seotud elukvaliteedi hindamise küsimustik SF-36 (*The RAND 36 Item Health Survey (Short Form-36)*) on tuletatud pikemast uurimisvahendist, mille on välja töötanud Ameerika Ühendriikide (Santa Monica, CA) RAND-i instituudi teadlased. See vahend hõlmab küsimusi, mis puudutavad selliseid valdkondi nagu sotsiaalne tegevus, depressiooni olemasolu ja sügavus, füüsilise aktiivsuse tase jne., et peegeldada igapäevast toimetulekut (11). O. Devinsky ja kaasautorid on selle põhjal välja töötanud uue küsimustiku, mis võimaldab hinnata patsientide seisundit pärast epilepsia tõttu rakendatud kirurgilist ravi (13).

1990-ndate aastate algul alustas RAND-i epileptoloogidest ja sotsioloogidest koosnev uurimismeeskond (*The QOLIE (Quality of Life in Epilepsy) Development Group*) uue, laiahaardelisema epilepsiaspetsiifilise uurimisvahendi väljatöötamist. Töö tulemusena valmis kolm küsimustikku, mida esmakordselt tutvustati Ameerika Epilepsia Ühingu (*The American Epilepsy Society*) koosolekul 1992. aastal. Need küsimustikud on: QOLIE-89 (hõlmab 17 valdkonda, mis si-

3.

saldavad 89 küsimust), QOLIE-31 (7 valdkonda, 31 küsimust) ja QOLIE-10 (10 küsimust). Kaks esimest küsimustikku on mõeldud ravimite või kirurgilise ravi mõju hindamiseks ning erinevate patsientiderühmade võrdlemiseks, kolmas on mõeldud kasutamiseks kliinilises praktikas, et valgustada probleeme, mis ei pruugi vestluse käigus ilmsiks tulla (10).

QOLIE-31 küsimustik on kasutusel ka TÜ Närvikliinikus käimasolevas Tartu linna täiskasvanud epilepsiahaigete elukvaliteedi uuringus. Selle vahendi abil on võimalik hinnata järgmisi valdkondi: üldine elukvaliteet, energia, emotsionaalne heaolu, mure hoogude pärast, kontsentratsioonivõime, töö ja sotsiaalse tegevusega toimetulek, mälu, ravi mõju igapäevaelule ja üldine tervis (13).

Suuremad maailmas läbiviidud epilepsiahaigete elukvaliteedi uuringud. 15 Euroopa riigis, millest suurima vastajate arvuga olid Suurbritannia, Prantsusmaa, Madalmaad ja Saksamaa, esines uuringu andmeil 5200 täiskasvanud epilepsiahaigest rohkem kui ühel kolmandikul hooge kord või sagedamini kuus. Viiendik tundis, et nende hood ei olnud raviga hästi kontrollitud. 38%-l ei olnud viimasel aastal hooge esinenud. Epilepsiavastast ravi sai 96%, 47% monoteraapiana (neist 53% karbamasepiini, 33% valproaati, 25% fenütoiini ja 14% fenobarbitaali). 36% tarvitas kahte preparaati, 13% kolme või enamat ravimit. Ravist tingitud kõrvaltoimeid esines palju, sagedamateks olid väsimus, mäluprobleemid ja kontsentreerumisraskused. Kõrvaltoimeid ei esinenud 12%-l. Umbes pooled tundsid end epilepsia tõttu stigmatiseeritutena. Küsimusele, kui väga nad oma epilepsia pärast muret tunnevad, vastas 48%, et nad muretsevad väga palju või palju; üldse ei muretsenud 15% (3).

Võrdlusena toodud meie poolt Tartu linna 30 epilepsiahaige hulgas korraldatud pilootuuringu andmeil esines hooge kord või sagedamini kuus 27%-l; viimase aasta jooksul ei olnud hooge esinenud 33%-l. Kõikidest vastanutest sai epilepsiavastast ravi 93%, neist monoteraapiana 77%; kaks preparaati 7%, kolm või enam preparaati 10%. Erinevusi ilmnes konkreetsete ravimite tarvitamise osas: monoteraapiana sai karbamasepiini 65%, valproaati 9%, primidooni 22% ja bensonaali 4%. Kõrvaltoimetena toodi kõige enam esile peavalu, unisust ja südamekaebusi. Pooled vastanuist tundsid väga või mõõdukalt muret selle üle, et kui nad kestvalt tarvitavad ravimeid, siis võivad need neile halvasti mõjuda.

Pisut varem Suurbritannias ligikaudu 1000 epilepsiahaige hulgas korraldatud uuring näitas, et kui isikute hulgas, kelle epilepsia oli remissioonis, esines ärevust 13%-l ja depressiooni 4%-l, siis sagedate hoogudega isikute hulgas vastavalt 44% ja 21%. Sagedate hoogudega isikud (need, kellel esines hooge kord või sagedamini kuus) hindasid epilepsia mõju igapäevaelule väga suureks või suureks 2—3 korda sagedamini. 62% tundis end epilepsia tõttu stigmatiseerituna, võrreldes 40%-ga, kel esines hooge harvemini kui kord kuus, ja 25%-ga, kellel viimase aasta jooksul hooge ei ole esinenud. Psühhosotsiaalsele staatusele kõige tugevamat mõju avaldavaks näitajaks oli hoogude sagedus.

Ärevuse astmega korreleerusid epilepsia kestus ja naissugu, depressiooniga epilepsia kestus, vanus epilepsia avaldumisel ja praegune vanus. Stigmat tunnetasid oluliselt rohkem need, kellel epilepsia oli alanud vanemas eas. Mis puutus haiguse remissiooni ja psühhosotsiaalse staatuse suhtesse, siis kõik psühhosotsiaalset staatust iseloomustavad näitajad, v.a. rahulolu materiaalse kindlustatuse üle, olid paremad neil, kellel epilepsia oli remissioonis (18).

Meie pilootuuringu andmeil tegid hoogudest tingitud sotsiaalsed probleemid

väga või mõõdukalt muret 57%-le küsitletuist. Piirangute tõttu sotsiaalsetes suhetes kannatas 63%, samal ajal kui epilepsia mõju vaba aja veetmisele pidas suureks või väga suureks ainult 13%.

Üksikasjalikumaid järeldusi tegemata võib öelda, et ka meie ühiskonnas on probleemid selles valdkonnas suured ning vajavad esmalt täpsemat väljaselgitamist. Uuringute alusel tehtud kokkuvõtetes rõhutatakse seda, et epilepsiahaigete elukvaliteedi parandamise võtmeks on hoogude üle parema kontrolli saavutamine ja samal ajal epilepsiavastasest ravist tingitud kõrvaltoimete vähendamine, samuti epilepsia tõttu tunnetatud stigma vähendamine nii epilepsiaga isikute kui ka ühiskonna teadlikkuse tõstmise kaudu (3, 18).

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Summary

The quality of life of adults in case of epilepsy. Epilepsia is a stigmatising disorder and available evidence suggests that its diagnosis can have important psychosocial consequences and severely reduce the quality of an individual's everyday life. This is a review of the literature of the nature of stigma and the quality of life in epilepsy. Different scales to evaluate the seizure severity and health-related quality of life are described. Also brief information about the findings from the recent largest studies investigating the quality of life in epilepsy as compared to the results of the pilot-study we conducted is given.

II

EPILEPSIA MÕJU ISIKU PSÜHHOSOTSIAALSELE ADAPTATSIOONILE

Marju Rätsepp

Tartu Ülikooli närvikliinik

Epilepsia piirdub suuremal osal juhtudest harvaesinevate, lühiaegsete, iselõppevate hoogudega. Sellele vaatamata tunnevad selle haigusega inimesed end igapäevaelus stigmatiseeritutena (ehk "märgistatutena"). Käesoleva uuringu üheks eesmärgiks oli epilepsia mõju hindamine isiku psühhosotsiaalsele adaptatsioonile. Uuring haaras 90 Tartu linnas elavat epilepsiaga isikut. Umbes kolmandikul vastanutest esines hooge kord või sagedamini kuus. Üle poolte tunnistasid, et neid on nende haiguse tõttu tööle võtmisel või töö juures koheldud ebaõiglaselt. Üle poolte tundsid end epilepsia tõttu stigmatiseeritutena. Uuring näitas, et epilepsia mõju oma igapäevaelule hindasid suurimaks need, kel esinesid sagedased hood, ja need, kel esinesid generaliseeritud toonilis-kloonilised hood koos mingit muud tüüpi hoogudega. Parema psühhosotsiaalse adaptatsiooni ja toimetuleku saavutamisel on meditsiinilisest seisukohast oluline eelkõige parema kontrolli saavutamine hoogude üle. Lisaks on oluline nii ühiskonna teadlikkuse kui epilepsiaga isikute eneseteadvuse tõstmine.

SISSEJUHATUS

Termin "epilepsia" tuleneb kreeka sõnast, mis tähendab "kinni haarama", "oma valdusesse võtma" või "ülemvõimu omama". Antiikkreeklased viitasid epilepsiale kui "pühale haigusele" ning pidasid seda põdevaid inimesi jumala poolt väljavalituiks. Hiljem on suhtumine epilepsiasse muutunud, epilepsiahoogudes on nähtud deemonliku hõlmatuse väljendust. Tänaseni on see haigus paljudes ühiskondades jäänud suures osas valesti mõistetuks (13). Epilepsia on haigus. mille korral normaalse neuroloogilise funktsiooniga perioodid vahelduvad harvade. lühikeste hoogude-perioodidega. Mitmete krooniliste haiguste puhul esinev haigusnähtude avaldumise ootamatus, mis tekitab inimeses pideva kindlusetustunde, on epilepsia puhul eriti ilmekalt väljendunud. Haiguse raskus ja prognoos on varieeruvad ning hood selle välise ilminguna ette ennustamatud. Epilepsia on oma olemuselt stigmatiseeriv, mis tähendab, et sellega kaasnevad psühhosotsiaalsed probleemid kaaluvad sageli üles kliinilised probleemid. Goffman defineerib

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stigma (kr. *stigma* – arm, märk) sisemise häbitundena, mis võib muuta inimese iseloomu nii, et tal tekivad tõsised suhtlemisprobleemid, mis omakorda tekitavad raskusi ja langetavad motivatsiooni toimetulekuks ühiskonnas (11). Stigma kujunemisel näevad nii Goffman kui Becker olulist rolli ühiskonnas valitseval üldisel suhtumisel inimestesse, kes on millegi poolest erinevad, ning nende suhtes kehtestatud reeglites ja piirangutes (3, 11). Scambler rõhutab stigma olemasolu just epilepsia korral (18). Uuringutega on esile tõstetud mitmeid erilist tähelepanu väärivaid valdkondi (5, 7, 12). Epilepsiaga isikutel on tihti vähenenud enesest lugupidamine (4), sagedamini kui rahvastikus keskmiselt esineb neil ärevust ja depressiooni (6). Nende hulgas tuleb suhteliselt sageli ette töötust või tööga alahõivatust (10), samuti on suurem sotsiaalne isolatsioon ja madalam abielus olevate inimeste protsent (1, 9). Epidemioloogilised uuringud on näidanud, et 70-80%-l epilepsiaga inimestest alluvad hood hästi antiepileptilisele ravile (17) ning nende puhul ei tohiks epilepsia otseselt elukvaliteeti alandada (13). Goodridge ja Shorvon leidsid oma uuringus, et ainult 20%-l patsientidest esines krooniline, ravimresistentne epilepsia. Jacoby jt, hinnates patsiente, kellel ei olnud hooge esinenud mitme aasta vältel, leidsid, et neil, kelle epilepsiavastane ravi jätkus, esines märgatavalt rohkem stressi võrreldes nendega, kelle ravi oli lõpetatud (15). Nii arst kui patsient koondavad oma tähelepanu tavaliselt hoogude sagedusele ja raskusele. Eesmärk pärast diagnoosi püstitamist ja ravi alustamist on hoogudest vabanemine. Kuid sageli hindavad isikud sama tüüpi hoogudega, mis alluvad ka ravile sarnaselt, ja kes taluvad ravi kõrvaltoimeid sarnaselt, epilepsia mõju oma igapäevasele elule täiesti erinevalt, sõltuvalt sellest, mida kumbki isik tunnetab enda jaoks piiranguna (8).

UURINGU EESMÄRK

Meie poolt läbiviidava uuringu üheks eesmärgiks oli uurida epilepsia ja selle ravi mõju epilepsiaga isikute üldisele elukvaliteedile, sealhulgas ka psühhosotsiaalsele adaptatsioonile.

MEETODID

Uuring hõlmas 90 Tartu linnas elavat epilepsiaga isikut vanuses 16-89 eluaastat, kes omasid vähemalt algkooli tasemel lugemis- ja kirjutamisoskust. Algandmed patsientide kohta pärinesid eelnevalt läbi viidud epidemioloogilise uuringu materjalidest. Antud uuringusse kuuluvatel isikutel oli esinenud vähemalt 2 provotseerimata hoogu, neist vähemalt üks ligikaudu viimase viie aasta jooksul. Uuringu käigus täitsid kõik selles osalejad küsimustiku hoogudesse puutuvate kliiniliste näitajate ja demograafiliste andmete kohta kas neuroloogi vastuvõtule tulles või kodus, vastates posti teel saadetud ankeedile. Stigma tunnetamise hindamiseks kasutasime 3-küsimuselist skaalat, mille igale küsimusele sai anda "jah" või "ei"

vastuse. Stigma olemasolu ja raskust hindasime "jah"-vastuste summa alusel. Pat-
sientidel tuli vastata järgmistele küsimustele: kas Teil on vahel tunne, et Teie
epilepsia tõttu teised inimesed tunnevad end Teiega ebamugavalt; on kohelnud
Teid alaväärsetena; on eelistanud Teid vältida.

TULEMUSTE ANALÜÜS

Uuringus osalejate demograafilised ja kliinilised näitajad (tabel 1, 2).

Tabel 1. Vastanute tähtsamate demograafiliste näitajate võrdlus.

PARAMEETER	UURINGUS OSALEJAD	%
Vanus (keskmine)	42;5 a	
M/N	41/49	45,6/54,4
Perekonnaseis:		
abielus/vabaabielus	39	43,3%
vallaline	33	36,7%
lahutatud	11	12,2%
lesk	7	7,8%
Tööhõive:		
töötab täiskohaga	30	33,3%
töötu või alahõivatud	32	35,6%
pensionil	9	10,0%
invaliidsuspensionil	14	21,1%
I gr	1	3,4%
II gr	24	82,8%
III gr	4	13,8%
Haridus:		
alla 8 klassi	5	5,6%
8 või 9 klassi	29	32,2%
kesk- või keskeriharidus	45	50,0%
kõrgem	11	12,2%
Autojuhiload		
olemas	12	13%
kehtivus katkestatud epilepsia tõttu	11	12%
ei ole	67	75%

Tabel 2. Vastanute tähtsamate hoogudega seotud näitajate võrdlus.

PARAMEETER	UURINGUS OSALEJAD	%
Vanus epilepsia diagnoosimisel (keskmine)	26,9 a	
Epilepsia kestus (keskmine)	17,2	
Hoogude sagedus viimase aasta jooksul:		
pole esinenud	29	32,60%
harvemini kui 1 kord kuus	32	36,0%
kord või sagedamini kuus	28	31,5%
Epilepsia diagnoositud		
kuni 5a tagasi	19	21,30%
kuni 10a tagasi	14	15,70%
kuni 20a tagasi	22	24,70%
üle 20a tagasi	34	38,30%
Vanus esimese hoo ajal		
kuni 10a	8	9%
11-20a	30	33,70%
21-30a	20	22,50%
31-40a	12	13,50%
41-50a	9	10,10%
üle 50a	10	11,20%
Neist, kes viimase aasta jooksul olid olnud		
hoovabad, esines viimane hoog		
kuni 2a tagasi	29	32,10%
2-5a tagasi	51	57,10%
üle 5a tagasi	10	10,70%

Oma hooge hindas ise väga rasketeks 10%, rasketeks 31,1%, keskmisteks 37,8% ja kergeteks 21,1%. Ilmnes statistiliselt oluline seos: need, kel esines hooge sagedamini, pidasid neid ka raskemateks.

Kõikidest vastanutest sai antiepileptilist ravi 88,9%, neist ühte ravimit tarvitas 76,7%.

Tööhõive ja sotsiaalne seisund

Neist, kes olid tööga alahõivatud või töötud, pidas 63% selle põhjuseks ka epilepsiat. Statistiliselt oluline seos ilmnes siin hoogude sagedusega. Viimase kahe aasta jooksul oli töökohta vahetanud 32% vastanutest. Ka siin ilmnes oluline seos hoogude sagedusega. Küsimusele, kas neid on kunagi epilepsia tõttu tööle võtmisel

või töö juures koheldud ebaõiglaselt, vastas jaatavalt 55,4%. Statistiliselt oluline seos ilmnes täiskohaga töötamise ja hoogude sageduse vahel: need, kel esines hooge sagedamini, töötasid väiksema tõenäosusega täiskohaga. Samuti ilmnes oluline seos hariduse ja täiskohaga töötamise vahel: mida kõrgem oli haridus, seda suurema tõenäosusega töötas isik täiskohaga.

Stigma tunnetamine

51% vastanutest tundis end epilepsia tõttu stigmatiseerituna, 14% vastas "jah" kõigile kolmele küsimusele, mis näitab, et nad tunnetasid seda väga tugevalt. Stigma tunnetamine sõltus hoogude tüübist: suurema tõenäosusega tundsid end stigmatiseerituna need, kel esinesid generaliseeritud toonilis-kloonilised hood koos mingit muud tüüpi hoogudega, samuti tunnetasid nad suurema tõenäosusega stigma tugevamini. Statistiliselt olulist seost hoogude sagedusega tõestada ei õnnestunud, kuid ilmnes selge tendents stigma tunnetamise tõenäosuse suurenemisele sagedamini esinevate hoogude korral (tabel 3).

Tabel 3. Stigma tunnetamine hoogude sageduse alusel.

Parameeter	Tunnetatud stigma			
	0	1	2	3
Hoogude sagedus:				
kord või sagedamini kuus (%)	41,2	36,7	16,6	5,5
harvemini kui kord kuus (%)	50,0	15,0	10,0	25,0
pole esinenud viimase aasta jooksul (%)	57,9	15,8	15,8	10,5
Kõik vastanud (%) (=100%)	49	23	14	14

Stigmat tunnetasid suurema tõenäosusega enam need, kes hindasid oma hooge rasketeks või väga rasketeks; lisaks võis täheldada statistiliselt olulist seost mitmete teiste näitajatega (tabel 4). Stigma tunnetamise raskus sõltus ka epilepsia kestusest: kui neist, kes tundsid end stigmatiseeritutena ja kellel epilepsiat oli diagnoositud kuni 5a tagasi ning kuni 10a tagasi, vastas kolmele stigma tunnetamist näitavale küsimusele "jah" 0%, siis nende gruppides, kellel epilepsiat oli diagnoositud 20a ja üle 20a tagasi, olid need protsendid vastavalt 25 ja 46 (p=0,03).

Tabel 4. Stigma tunnetamise seos erinevate näitajatega.

Näitaja	p*
Stigma	
Subjektiivne hinnang hoogudele	0,03
Hirm järgmise hoo ees järgneva 4 nädala jooksul	<0,001
Mure hoo tõttu piinlikku olukorda sattumise pärast järgneva 4 nädala jooksul	<0,001
Mure ravimite ebasoovitavate kõrvaltoimete avaldumise pärast kestval kasutamisel	0,01
Arvamus, et töötuse või tööga alakoormatuse põhjuseks on ka epilepsia	0,009
Arvamus, et epilepsia tõttu on neid kunagi tööle võtmisel või töö juures koheldud ebaõiglaselt	0,03

*Seoste olulisuse tõenäosuse leidmisel on kasutatud hii-ruutu.

DISKUSSIOON

Antud uuring käsitles epilepsia mõju inimeste psühhosotsiaalsele adaptatsioonile. Et kõik uuringus osalejad olid epidemioloogilise uuringu käigus juba eelnevalt läbi vaadatud, siis on põhjust arvata, et vastasid eelkõige need, kes tunnetasid oma haigusest tulenevaid probleeme kõige tugevamini ning seega peegeldab uuring eelkõige nende seisukohti. Monoteraapiat sai 76,7%, mis on tunduvalt kõrgem võrreldes mujal läbi viidud uuringutega (2, 14, 16), kuid ilmselt oli see tingitud sellest, et valitud uuritavate gruppi oli tihti spetsialistide poolt läbi vaadatud ning ravi korrigeeritud. On rõhutatud, et kroonilist haigust põdevate inimeste puhul on oluline mitte ainult see, et nad oleksid sümptomitevabad, vaid et nad elaksid nii normaalset elu kui võimalik (19). Meie poolt uuritud isikutest 32,6%-l ei olnud viimase aasta jooksul hooge esinenud ja 36%-l tuli neid ette harvemini kui kord kuus. Seega tuleb arvesse eeskätt toimetulek ravist tingitud probleemide ja epilepsiast põhjustatud psühhosotsiaalsete probleemidega. Epilepsia mõju oma igapäevasele elule hindasid suurimaks need, kel esinesid sagedased hood, ja need, kel esinesid generaliseeritud toonilis-kloonilised hood koos mingit muud tüüpi hoogudega. End rohkemal või vähemal määral stigmatiseeritutena tundis 51% vastanutest. Nende isikute hulgas, kel generaliseeritud hooge ei esinenud, ja nende, kel viimase aasta jooksul hooge ei olnud esinenud, oli end stigmatiseeritutena tundvate isikute protsent väikseim. Stigma tunnetamisega kaasnes suurema hirmu tundmine ootamatute hoogude ees ja hirm sattuda seetõttu piinlikku olukorda ning muretsemine selle üle, et kestval tarvitamisel võivad antiepileptilised ravimid halvasti mõjuda. Kõige halvemaks hindasid oma elukvaliteeti 41-50-aastased alla

8 kl haridusega lahutatud või lesestunud isikud, kel hood esinesid kord või sage-
damini kuus. Üksikuid inimesi (vallalised, lahutatud või lesed) oli kokku 56,7%.
Töötuid või tööga alahõivatuid oli 35,6%, neist 63% pidas selle põhjuseks ka
epilepsiat. Üle poolte märkisid, et neid on nende haiguse tõttu tööle võtmisel või
töö juures koheldud ebaõiglaselt. Tulemuste alusel võib väita, et parema psühho-
sotsiaalse adaptatsiooni saavutamisel on oluline hoogude sageduse langetamine, mil-
le aluseks on korrigeeritud antiepileptiline ravi võimalikult minimaalsete kõrval-
toimetega. Hoogude vähenemisega on otseselt seotud stigma tunnetamise nõrge-
nemine ja toimetulek probleemidega. Rõhutamist väärib aga see, et võrdselt olu-
line on nii ühiskonna teadlikkuse kui epilepsiaga isikute eneseteadvuse tõstmine.

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III

Felt stigma and impact of epilepsy on employment status among Estonian people: exploratory study

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This article examines the impact of epilepsy and its treatment on employment status and the extent of stigma among patients with epilepsy.

Clinical and demographic data concerning patients examined during a recent epidemiological survey were obtained from medical notes and postal self-completed questionnaires.

Information was collected from 90 patients aged 16–70 years. A third of the respondents had been seizure-free during the last year. Thirty-nine percent were working full-time, 24% were working part-time and 11% were unemployed. Sixty-three percent from those working part-time or unemployed considered their epilepsy to be a significant reason for this. Overall, 55.4% believed they had been treated unfairly at work or when trying to get a job. Fifty-one percent of respondents felt stigmatized by epilepsy, 14% of them highly so.

The level of employment among epileptic people was not lower than in the general population. The percentage of stigmatization in general and the percentage of the severely stigmatized was as high or even higher than in other studies. Occurrence of stigma and its severity depended first and foremost on the type of seizures. The frequency of seizures was not clearly related to this.

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Key words: epilepsy; stigmatization; employment status; Estonia.

INTRODUCTION

Several investigators have discovered psychological and social problems among people with epilepsy. Living with epilepsy necessitates paying attention to more than seizures. Though being episodic, they impact on a wide range of daily activities and feelings. The misunderstanding and the resulting social stigma surrounding epilepsy can often cause more suffering than the seizures themselves. Patients with epilepsy often feel stigmatized by their condition[1–3]. Felt stigma has been described as the shame associated with being epileptic and a source of unhappiness[3]. Different authors have stressed that in order for stigma to exist, individuals must accept their devaluation[4]. A person's own reaction to having a seizure disorder is even considered the most significant factor in adjustment[5]. The perception of stigma can reduce motivation for work and social activity[6]. Nowadays, it has become relatively common to have patients make a judgement about their medical care[7]. It means they must have the courage to express their opinion and to show their dissatisfaction. Individuals with epilepsy often have problems with employment[8, 9], although there is evidence that when seizures are well-controlled and uncomplicated by any other handicap they do not generally experience problems[10]. Part-time employment and unemployment have been identified as two very serious problems among people with epilepsy[5], being closely connected to overall well-being[11, 12]. Many investigators have studied the problems accompanying epilepsy, however data from Eastern European countries are scarce.

Estonia is a newly independent state, re-established after the collapse of the Soviet Union which geographically is positioned in Eastern Europe on the Baltic Sea coast. Today, of the 1.5 million people who live in Estonia, 64.6% are ethnic Estonians. Among other nationalities, Russians represent the largest figure (about 28.5%). The Russian-speaking population is not evenly distributed throughout the country[13].

Southern Estonia is focused on Tartu, the historic university town and the country's second largest city. Being the intellectual and educational centre of Estonia, Tartu demonstrates quite typical demographic characteristics for Estonia with the exception that the percentage of the Russian-speaking population is lower than in Estonia in general.

The present report is a preliminary study and the first in its field in our country. The aim of the study was to examine the impact of epilepsy and its treatment on employment status and the extent of stigma among individuals with epilepsy, focusing on the following questions: What is the current treatment status? How many people feel stigmatized by their epilepsy? What is the relationship between feelings of stigma and the main clinical characteristics describing seizures? Do the feelings of stigmatization make it more difficult to perceive the psychosocial problems connected to epilepsy and employment status? What is the current employment status of the respondents? To what extent is it affected by their disease? Had there been any occasions when people had been treated unfairly at work because of their epilepsy?

SUBJECTS AND METHODS

The research took place between 1997 and 1998 and followed an epidemiological survey of epilepsy in the city of Tartu, Estonia. The epidemiological survey included persons who were residents of Tartu and were aged 19 and over, and had before or within the course of 01/01/1991–01/01/1996 had at least two unprovoked epileptic seizures, at least one of them within the previous 5 years. Data collection for epidemiological study consisted of two parts: data registration from a multi-source medical register review and data registration from a personal case re-examination. Case records of patients treated in the University Hospital, Outpatients' Clinics, physicians offices, emergency rooms and the electroencephalograpic laboratory with a diagnosis of epilepsy, convulsions, syncope, amnestic attacks and abnormal involuntary movements were reviewed and invitations for re-examination were sent to the suitable persons. Over the last 2 years, all the patients were re-examined at least once by a neurologist to specify the type of their seizures. This present study was based on the analysis of data collected from a sample of 90 patients, in the 16–70 year age group. The patients were picked out randomly from the preliminary lists of the epidemiological study leaving out the *people who were not capable of understanding Estonian (mostly the Russian-speaking people)* because there were not any sufficiently well translated and validated questionnaires available for them. All patients gave their consent to participate in the research and the project was approved by the Ethics Committee of the University of Tartu. All of the respondents had *at least* a basic education level with sufficient ability to read and write, and were capable of understanding and completing the questionnaires. Clinical information, if needed, was abstracted once again from medical notes and during the personal re-examination of subjects. Abstracted information used in the study related to the etiology of epilepsy, classification of seizure type and current antiepileptic drug (AED) therapy. To evaluate the impact of epilepsy on employment status and perceived stigma, the patients were sent a questionnaire through the mail. Following the example of other quality-of-life studies conducted among epileptic people[10, 14–16], the questionnaire employed a combination of open questions together with a previously translated and validated scale (The Stigma of Epilepsy Scale). In addition, single items were included which referred specifically to feelings of stigmatization in the areas of employment (Table 1). The questionnaire contained a number of questions covering the following issues. (1) Demographic characteristics: information was obtained about subjects' sex, age, marital and employment status, and education level. (2) Economical and financial status: patients were asked to state whether they considered it to be 'very good', 'good', 'satisfactory', 'moderately bad', or 'very bad'. (3) Seizure frequency: patients were asked whether they had had one or more seizures in a month, less than one a month, or not at all in the past year. (4) Previous research has shown that patients' perception of the severity of their seizure disorder may be more important than seizure frequency in determining their psychological and social well-being[17]. Therefore, subjects were asked to assess their seizures as 'very severe', 'severe', 'medium', or 'light'. (5) AED treatment and side effects: patients were asked about the AED they were taking and about the experienced side effects during the past month, as well about the satisfaction with the current treatment and about the changes in AED medication in the past year. (6) Compliance with medication: patients were asked to state whether they never missed taking their AEDs, missed less than once a month, missed less than once a week, or missed more than once a week. According to other studies, correlations between patient reports and objective methods has been shown to be high[14]. (7) Perceived stigma was measured with a three-item Stigma Scale, developed originally for stroke[18], which was adapted for epilepsy and is already used in other quality-of-life studies[14, 15]. Respondents with epilepsy had to state whether they; (a) felt that other people were uncomfortable with them, (b) treated them as inferior, or (c) preferred to avoid them. Each of the three items required a yes/no response. An individual's score was the sum of the 'yes' responses and the higher the score,

the greater the perception of stigma was. The scale was translated into Estonian by two independent native Estonian speakers with an excellent knowledge of English. The translators then met to discuss and agree upon a common version of the questionnaire. Subsequently, the common version was evaluated by another native Estonian speaker in terms of conceptual equivalence, linguistic performance and clarity. The agreed upon Estonian form was then backtranslated into English and rated. If modifications were necessary, the re-formulation in the Estonian version was performed. The internal consistency of the scale was examined using Cronbach's alpha and found to be acceptable ($\alpha = 0.71$)[19]. The evidence for the construct validity of the scale was supported by the data received following the hypotheses that patients with frequent seizures and mixed seizure types would score positively on the scale. (8) The impact of epilepsy on employment history—those currently in part-time employment or unemployed—were asked whether the reason for it was their epilepsy, whether they had changed jobs in the preceding 2 years because of epilepsy and whether they had been treated unfairly at work because of epilepsy. Each of the items required a yes/no response.

When analysing the data, the unemployed and part-time employed were counted together because it is not common in our country to work part-time since it causes serious financial difficulty in coping with everyday life. Patients were divided into three groups by seizure type (as having only tonic–clonic, only other types, or both tonic–clonic and other types) and frequency (based on seizure occurrence occurring once or more a month, less than once a month, or not at all in the past year).

Statistical methods

The data were analysed using the statistical analysis package SPSS Professional Statistics[TM] 7.5[20]. Tests of significance were χ^2 (chi-squared) and Spearman's rank correlation. Attention is drawn to results where differences were significant at the 5% level or less ($P \leq 0.05$). To test the reliability of the Stigma scale, Cronbach's alpha was used[19].

Response to the study

Questionnaires to be completed individually were mailed to 110 patients, of whom 78 replied—a response rate of 71%. After sending a reminder, 16 patients returned their questionnaires. From all the questionnaires returned, 19 appeared to be unusable: in six of them more than 10% of the questionnaire was left unanswered, three were sent back with a note that

the person was dead, five with a note that the person no longer lived at the address, five because the persons were not capable of understanding the questions due to mental disability. The rest of the questionnaires were considered usable and were included in the study. In addition, 15 patients filled in the questionnaires while visiting their neurologist at the Outpatients' Clinic.

RESULTS

Demographic and clinical characteristics of the study population

The study included 90 persons with epilepsy. Sociodemographic characteristics of the sample are presented in Table 2. Of the sample, 45.6% (41 persons) were men. The median age of respondents was 42.5 years. Forty-three point three percent (39) were married or cohabiting, 36.7% (33) reported being single, 12.2% (11) were divorced and 7.8% (7) widowed. Thirty-eight point nine percent (35) were working full-time, 24% (22) were working part-time and 11% (10) were unemployed. Fifteen point six percent (14) were receiving disablement pension. Twenty-two percent (20) of respondents were aged 60 years or older and 10% (9) were receiving the state pension. Five point six percent (5) had less than primary education (lower than the 8th level), 32.2% (29) had primary education (8th or 9th level), 50% (45) had high school education (11th or 12th level) and 12.2% (11) had graduated from university.

Table 1: Coverage of the questionnaire.

1. Demographic details
     Sex and age
     Marital status
     Employment status
     Educational level
2. Self-assessed economical and financial status
3. Disease characteristics
     Seizure frequency
4. Self-assessed seizure severity
5. Antiepileptic treatment
     Current medication
     Associated side effects
     Changes in AED medication
6. Compliance with medication
7. Perceived stigma
     Stigma of Epilepsy Scale
8. Impact of epilepsy on employment history
     Part-time employment or unemployment
     A job change
     Unfair treatment

Table 2: Socio-demographic characteristics of respondents.

Parameter	Study respondents	%
Age (median)	42.5 years	
Sex (male)	41	45.6
Marital status		
married/cohabiting	39	43.3
single	33	36.7
divorced	11	12.2
widowed	7	7.8
Employment status		
full-time	35	38.9
part-time	22	24.0
unemployed	10	11.0
retired	9	10.0
receiving disablement pension	14	15.6
Education		
less than primary (lower than 8th level)	5	5.6
primary (8th or 9th level)	29	32.2
high school (11th or 12th level)	45	50.0
university	11	12.2

Table 3: Disease characteristics of respondents.

Parameter	Study respondents	%
Duration of epilepsy (median)	17.2 years	
Seizure type		
tonic–clonic only	36	40.0
tonic–clonic and others	36	40.0
others only	18	20.0
Seizure frequency status in the last year		
seizure-free	30	33.3
<1 seizure a month	32	35.6
≥1 seizure a month	28	31.1
Seizure onset		
5 years ago	19	21.3
10 years ago	14	15.7
up to 20 years ago	22	24.7
more than 20 years ago	35	38.3
Medication		
free from medication	11	12.2
on AED treatment	79	87.7
For those receiving AED medication		
on monotherapy	61	77.2
receiving 2 AEDs	5	6.3
receiving ≥3 AEDs	13	16.5
Type of drug on monotherapy		
carbamazepine	49	80.0
valproate	5	8.2
primidone	5	8.2
bensobarbital	2	3.3

The results of the underlying epidemiological study are as yet not fully published. Therefore, we found it necessary to give more detailed information about the clinical characteristics of the epilepsy of the study respondents. The main disease characteristics are presented in Table 3.

Twenty-two persons (24.4%) reported some other chronic disease in addition to epilepsy, 12 persons (13.6%) constantly used medications because of their condition. One point one percent (2) described their economic and financial status as very good; 6.7% (6), good; 51.7% (46), satisfactory; 30.3% (27), quite bad; 10.2% (9), very bad. Subjectively, 10% of respondents considered their seizures very severe, 31.1% severe, 37.8% medium, and 21.1% light. There was a significant interaction between the severity of seizures and seizure type: those experiencing generalized tonic–clonic seizures were more likely to evaluate their seizures severe or very severe ($\chi^2 = 12.8$, $P = 0.04$). A significant interaction between the seizure frequency and seizure severity was revealed: the more frequently the seizures occurred, the more severe they were considered ($\chi^2 = 6.02$, $P = 0.03$). Of all subjects receiving AEDs 27.8% reported no side effects. Compliance with medication was quite good: 52% (43) of respondents said they never missed taking AEDs, 21% (17) reported missing on an average once a month, 17% (14) reported missing once a week, and 10% (8) more than once a week.

Twenty-five point five percent of respondents were completely satisfied with the current treatment, 51% were fairly satisfied, 17.6% were somewhat unsatisfied, and 5.9% stated that the level of control was unsatisfactory. There was a weak statistically significant relation with the seizure frequency (Spearman's rho = −0.34, $P = 0.02$): those having seizures more often were more likely to feel dissatisfaction.

Foury-three point one percent of all respondents had changed their AED medication in the past year: 47% had changed it once, 31.3% twice, and 7.8% three or more times. Sixty-six point five percent had changed it because their seizures were poorly controlled, 19.5% because of associated side effects.

Perceived stigma

Of the respondents, 51% felt stigmatized by their epilepsy: 14% answered 'yes' to all three items and this shows that they were highly stigmatized. The perception of stigma depended on seizure type: persons having tonic–clonic and other types of seizures were more likely to feel stigmatized ($\chi^2 = 5.02$, $P = 0.05$); in addition, they were more likely to score highly on the stigma scale ($\chi^2 = 4.27$, $P = 0.04$). We could not point out a statistically significant interaction between perceived stigma and seizure frequency ($P = 0.3$) but there was a clear tendency to a higher significance of feeling stigmatized when having more frequent seizures. However, the severity of stigmatization was not related to this (Table 4).

Table 4: Reported stigma by seizure type and frequency.

Parameter	Score on stigma scale			
	0	1	2	3
Seizure type				
Tonic–clonic only ($n = 36$)	47.8%	30.4%	8.7%	13.0
Tonic–clonic and other ($n = 36$)	40.9%	18.2%	18.2%	22.7%
Other only ($n = 18$)	66.7%	16.7%	16.7%	0
$\chi = 5.02, P = 0.05$				
Seizure frequency				
One or more a month ($n = 28$)	41.2%	41.2%	12.1%	5.5%
Less than one a month ($n = 32$)	50.0%	15.0%	10.0%	25.0%
None in past year ($n = 30$)	57.9%	15.8%	15.8%	10.5%
$\chi = 4.07, P = 0.3$				

Figures in brackets are the numbers on which percentages are calculated.

Those who considered their seizures to be more severe had a greater likelihood of feeling stigmatized ($\chi^2 = 6.7, P = 0.03$). In addition, those people who had more fear of having a seizure during the next month ($\chi^2 = 18.4, P < 0.001$), worry more about embarrassment resulting from having a seizure ($\chi^2 = 16.3, P < 0.001$), and also about the adverse effects of AED medication if taken for a long time ($\chi^2 = 8.0, P = 0.01$) were more likely to feel stigma. The same features concerned those who believed that epilepsy was one of the main reasons of their part-time employment or unemployment ($\chi^2 = 7.0, P = 0.009$), and that they had been treated unfairly when seeking a job or at work ($\chi^2 = 4.5, P = 0.03$).

Employment and social status

A third of all respondents were working full-time. From those being in part-time employment or unemployed, 63% believed the significant reason for this was their epilepsy. Respondents with frequent seizures were more likely to believe this (Spearman's rho = 0.5, $P = 0.003$). During the last 2 years, 32% of respondents had changed their jobs (meaning changing their working place, not a change of speciality or losing a job). In this situation, the respondents with frequent seizures were more likely to do this (Spearman's rho = 0.6, $P = 0.05$). Fifty-five point four percent said that they had been treated unfairly at work or when applying for a job. There was a significant interaction between employment status and seizure frequency: those having frequent seizures were more likely to be in part-time employment or unemployed (Spearman's rho = 0.3, $P = 0.02$) (Table 5). There was also a significant interaction between full-time working and education: the higher the education was, the more likely the person would be working full-time ($\chi^2 = 13.3, P = 0.03$). To explore the correlation we reassessed the role of seizure characteristics and

stigma after adjustment for levels of education. However, since we found no significant interactions at the 5% level, we are unable to construct a corresponding model.

DISCUSSION

The aim of the study was to describe some aspects of the psychosocial status of epileptic patients and to analyse how they are affected by their disease. Despite the relatively small sample size, the findings from this study give preliminary information and further outlines for investigation about the situation of people with epilepsy in a country in transition, such as Estonia at the current moment of time. On 1 January, 1996, the estimated crude prevalence ratio of active epilepsy in Tartu was 4.1 per 1000[21]. When comparing the percentages of sex and age structure of the epileptic people of the present study with the epileptic people of Tartu and the general population of the city there were no significant differences so we would consider our study consecutive (Table 6). The clinical characteristics were similar to most other series of prevalence cases of epilepsy[22–24]. Most of the study respondents had generalized seizures with or without other seizure types and were predominantly on carbamazepine monotherapy. The average duration of the disease was 17 years. Of the respondents, 68.9% had been seizure-free during the last year or had had less than one seizure a month which points to a rather efficient antiepileptic drug control. Compared with other studies, the disease status was quite satisfactory and the number of patients receiving monotherapy was higher[10, 14, 15, 25]. The explanation is that all of them were earlier consulted by an epileptologist which often resulted in a correction of medication. To review the economical and financial status of the respondents, their own opinion was asked. According to this, 59.5% valued it as very good, good or satisfactory, and 40.5%

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Table 5: Reported problems with employment by seizure frequency.

	Seizure frequency		
	One or more a month	Less than one a month	None in past year
Believed the significant reason for being in part-time employment or unemployed was their epilepsy $n = 20$	45% (9)	35% (9)	20% (4)
Had changed their job $n = 29$	52% (15)	27% (8)	21% (6)
Part-time unemployment or unemployed $n = 32$	50% (16)	31% (10)	19% (6)

Figures in brackets are the numbers on which percentages are calculated.

Table 6: Comparison of sex and age structure of Tartu epileptic people and epileptic people of the present study.

Parameter	Among epileptic people of Tartu		Among epileptic people of the present study		
	n	%	n	%	P
Sex					
male	172	55.7	41	45.6	0.09
female	137	44.3	49	54.4	
Age groups					
16–19 years			2	2.2	
20–29 years	53	17.2	23	25.6	0.08
30–39 years	74	23.9	15	16.7	0.15
40–49 years	70	22.6	17	18.9	0.46
50–59 years	54	17.5	13	14.4	0.49
≥60 years	58	18.8	20	22.2	0.51
Total	309	100.0	90	100.0	

as bad or very bad. Correspondingly, more than half of the study population copes with everyday needs. This pattern is presumably similar to that of the general population. The present study did not confirm the fact that the rates of marriage are significantly lower among people with epilepsy than in general which has been reported[11, 14, 26]. Despite the fact that more than 75% of the patients confirmed being satisfied with the current treatment, the percentage of stigmatization in general and the percentage of severely stigmatized was as high or even higher than in other studies[10, 14]. Fifty-one percent of the respondents felt stigmatized by their epilepsy, 14% of them highly. The perception of stigma depended on seizure type: persons having tonic–clonic and other types of seizures were more likely to score high on the stigma scale. Of subjects reporting frequent seizures, 58.8% felt stigmatized by their epilepsy, as compared with 50% of those having seizures less than once a month and with 42% of those having none in the past year. This is much higher compared with the work of Jacoby et al.[15] who found corresponding percentages of 62, 40 and 25, and with the study by Baker et al.[14] who reported on their results as 67%, 48% and 37%. We speculate that the higher percentage of stigmatization could be a characteristic of Eastern European countries and could be the result of a general lack of knowledge and indifference, as due to their complicated political status, an

individual's health and well-being was not valued for a long period. The finding also confirms the fact that the feeling of stigma was not clearly related to seizure frequency. Several authors have shown how epilepsy affects people's perceptions of themselves and their overall well-being[4, 11]. In our study, a very clear relationship between stigmatization and problem perception was found. This emphasizes the importance of reducing stigma in order to improve the overall health-related quality of life.

In Estonia, the pension age (age for retiring) is 65 years. But it is very common to continue working to obtain the same salary as it makes it easier financially to cope with life. In our study, only nine persons stated they were retired, meaning that they were only receiving the state pension. The percentage of full-time and part-time employed people in the present study was 62.9, 11% were unemployed. Compared to the findings of a UK study by Jacoby[15], who found that the percentage of unemployed people was 10 and that of employed people was 35, the results indicate that the condition of our epileptic people is better. The employment status of the study respondents was compared with the published data on the inhabitants of Tartu[27]. According to the data of the labour force surveys of the Statistical Office of Estonia, on 1 January, 1998, the percentage of employed people (including those employed part-time) among inhabitants of Tartu aged 20

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IV

M. Herodes, A. Õun, S. Haldre, A.-E. Kaasik.
Epilepsy in Estonia: a quality-of-life study.
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Epilepsy in Estonia: A Quality-of-Life Study

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Summary: *Purpose:* To study the impact of epilepsy and its treatment on people with epilepsy in Estonia and to analyze how it is affected by the characteristics of epilepsy.

Methods: Clinical and demographic data about patients were obtained from medical notes and mailed self-completed questionnaires (including the RAND 36-Items Health Survey 1.0 (RAND-36)).

Results: Information was collected from 203 patients aged 20–74 years, who all had active epilepsy. A third of the respondents had been seizure free during the last year. Eighty-four percent were receiving monotherapy. More than half of respondents felt stigmatized by epilepsy, 24.7% of them highly so. A third were working full-time, 31.9% were underemployed workers, and 11%, unemployed. Sixty-two percent of these same unemployed or underemployed workers considered their epilepsy to be a significant reason for this situation. Overall,

44% believed they had been treated unfairly at work or when trying to get a job. Study respondents scored lower in all domains on the RAND-36 than did persons from the control group. The biggest differences were found in five domains: Social functioning, Role limitations–physical, Role limitations–emotional, General health, and Vitality.

Conclusions: The clinical characteristics of this study were similar to those of most other series of prevalence cases of epilepsy. The level of employment among persons with epilepsy was not lower than that in the general population. The percentage of stigmatization was high. There were significant differences in the way respondents scored on the stigma scale and on the RAND-36 domains when measuring their health status, depending above all on seizure frequency and type. **Key Words:** Epilepsy—Quality of life—Stigmatization—RAND-36—Estonia.

Although it is a universal brain disorder, epilepsy is often misunderstood. It is now widely acknowledged that people with epilepsy are as likely to be distressed by social and cultural problems as they are by continuing seizures, and that epilepsy has profound physical, psychological, and social consequences (1). Although current seizure frequency is one of the most important predictors showing the efficacy of treatment, it is not the only measure, especially from the patient's viewpoint, commonly used in clinical studies of new antiepileptic drugs (AEDs) (2). The effect of any disease is determined by several factors, including underlying biology, as well as host factors, and available medical interventions, but also by the attitudes and reactions of the surrounding society (3). Several studies have used health-related quality of life in epilepsy as an outcome measure and have also used it to give a broader measure of the burden of the disease (4). Quality of life is difficult to define but might be said to reflect functions in three main areas: physical, social, and psychological (1). Devinsky and Cramer (5) stated that the essence of quality of life

is the balance between patients' perceived and desired status. It also is defined by how well one is able to function and how one feels about one's daily life (6), on the assumption that aspects of functional health status have an impact on quality of life. Although no definitive consensus has been reached concerning the essential nature of quality of life, there is some agreement that general health status is one of its main components (7). A variety of instruments are available to evaluate the perception of health in the general population. One of these, which also is among the most widely used questionnaires, is the RAND 36-Item Health Survey 1.0. It is a brief and intensively tested instrument that was derived from longer instruments developed by RAND researchers (Santa Monica, CA, U.S.A.) for the Medical Outcome Study (MOS) and the Health Insurance Experiment (8) to assess health status. The purposes and methods of the RAND study have been fully summarized (9,10). The RAND 36-Item Health Survey 1.0 items are identical to the MOS 36-item short-form health survey (MOS SF-36) described by Ware and Sherbourne (9). They were adapted from longer instruments completed by patients participating in the MOS (11). The conceptual framework is based on the multidimensional World Health Organization definition of health (12). Although the

RAND version has a slightly different scoring method, it allows users of the MOS SF-36 and RAND-36 to relate their findings (9).

Because of the emphasis on the phenomenologic experience of the individual, it is necessary that quality of life be determined from the patient's subjective viewpoint, the physician's viewpoint being deliberately excluded, as self-reports are the primary method of assessing it (6) because, with very few exceptions, evaluations conducted by physicians tend to concentrate primarily on seizure management, leaving all else as secondary features (13). It has become relatively common to have patients make a judgment about their medical care (14). This means they must have the courage to express their opinion and show their dissatisfaction. There is a growing awareness of the psychosocial implications of epilepsy. People with epilepsy face social disadvantages not shared by those with other chronic diseases. Psychiatric problems, particularly anxiety, depression, and loss of self-esteem are common among people with epilepsy (15–26). Most patients feel that a prospective employer's knowledge of a diagnosis of epilepsy will make it more difficult for them to get a job (27). Information on these issues has come mainly from developed countries (26,28–33). Very few studies originate from developing countries (34–37). and there is clearly a lack of documented evidence regarding the impact of epilepsy in Eastern Europe (38,39).

Estonia, which is located in Eastern Europe on the coast of the Baltic Sea, regained its independence after the collapse of the Soviet Union. Today 64.6% of the 1.5 million people living in Estonia are ethnic Estonians. Among other nationalities, Russians represent the largest group (~28.5%). The Russian-speaking population is not evenly distributed throughout the country (40). Southern Estonia revolves around Tartu, the historic university town and the country's second largest city. Tartu, the intellectual and educational center of Estonia, demonstrates relatively typical demographic characteristics for Estonia, with the exception that the percentage of the Russian-speaking population is lower than that in Estonia as a whole. Viljandi County, with a population of 62,336 (41), is considered to be first in the country in terms of the level of development of agriculture, and is located in south-central Estonia. The administrative center of the county is the town of Viljandi, which is situated 81 kms from Tartu.

This report is a comprehensive study of what it is like to have epilepsy in our society. It was conducted to pursue the following objectives: (a) to describe the quality of life for epilepsy patients on the grounds of perceived health status and possible stigma accompanying epilepsy and to analyze how it is affected by the characteristics of epilepsy; and (b) to analyze how quality of life is affected

by the sociodemographic characteristics of epilepsy patients, with emphasis on their current employment status.

METHODS

Design and study sample

The research took place in 1997 through 1998 and followed an epidemiologic survey of epilepsy in the city of Tartu, Estonia. The epidemiologic survey included persons who were residents of Tartu, were aged 20 years and older, and had before or during the period from January 1, 1991, through January 1, 1996, had at least two unprovoked epileptic seizures, at least one of them within the previous 5 years. Data collection for the epidemiologic study consisted of two parts: data registration from a multisource medical register review and data registration from a personal case reexamination. Case records of patients treated at the University Hospital, Outpatients' Clinics, physicians' offices, emergency rooms, or the electroencephalographic laboratory with a diagnosis of epilepsy, convulsions, syncope, amnestic attacks, or abnormal involuntary movements were reviewed, and invitations for reexamination were sent to the relevant persons. During the last 2 years, all the patients were reexamined at least once by one of the authors to specify the types of their seizures.

Our study focused on the analysis of data collected from a sample of 203 patients in the 20- to 74-year age group. The patients were selected at random from the preliminary lists of the epidemiologic study conducted in Tartu, excluding people who were not capable of understanding Estonian (mostly Russian speakers) because no sufficiently well translated and validated questionnaire was available. In Viljandi, primary information about people with epilepsy was gathered through the local epilepsy support group, and clinical information was abstracted from medical notes held in the County Hospital and Outpatients' Clinic register. To evaluate the accuracy of diagnoses, the problematic cases were investigated by one of the authors and reexamined if necessary. All patients gave their consent for participation in the research, and the project was approved by the Ethics Committee of the University of Tartu. In addition, a control group of 200 healthy subjects corresponding in age, sex, and educational level was randomly selected from among the patients receiving treatment from dentists at the University's Dental Clinic. All of the respondents possessed at least a basic education with sufficient ability to read and write, and were capable of understanding and completing the questionnaires.

Measures

Clinical information, if needed, was abstracted, once again, from medical notes and during the personal reexamination of subjects. Abstracted information used in the study related to the etiology of epilepsy, classification of

seizure type, and current AED therapy. To evaluate the impact of epilepsy on employment status and perceived stigma, the patients were sent a questionnaire by mail. Following the example of other quality of life studies conducted among persons with epilepsy (26,42–44), the questionnaire used a combination of open questions with two previously translated and validated scales (The Stigma of Epilepsy Scale and the RAND 36-Item Health Survey 1.0). In addition, single items that referred specifically to feelings of stigmatization in the area of employment were used. The questionnaire contained a number of scales and questions covering the following issues:

1. Demographic characteristics: information was obtained about subjects' sex, age, marital and employment status, and educational level;

2. Economic and financial status: patients were asked to state whether they considered it to be "very good," "good," "satisfactory," "moderately bad, or "very bad";

3. Seizure frequency: patients were asked whether they had had seizures once or more in a month, less often than once a month, or not at all in the past year;

4. Injuries associated with seizures: subjects who had had at least one seizure in the past year were asked whether they had had a burn or scald, a head injury, milder injuries (including dental injuries), any other injuries (unspecified), or no injuries;

5. History of the epilepsy: patients were asked about age at first attack;

6. Previous research has shown that patients' perception of the severity of their seizure disorder may be more important than seizure frequency in determining their psychological and social well-being (45). Therefore subjects were asked to assess their seizures as "very severe," "severe," "medium," or "light";

7. AED treatment and side effects: patients were asked about the AED they were taking and about the experienced side effects during the past month, as well as about satisfaction with the current treatment and about changes in AED medication in the past year;

8. Compliance with medication: patients were asked to state whether they never missed taking their AEDs, missed less often than once a month, missed less often than once a week, or missed more often than once a week. According to other studies, correlations between patient report and objective method have been shown to be high (43);

9. Perceived stigma was measured with a three-item scale developed originally for stroke (46), adapted

for epilepsy and already used in other quality-of-life studies (26,43). Respondents with epilepsy stated whether they felt that other people (a) were uncomfortable with them, (b) treated them as inferior, or (c) preferred to avoid them. Each of the three items required a yes/no response. An individual's score was the sum of the "yes" responses, and the higher the score, the greater was the perception of stigma. The scale was translated into Estonian by two independent native Estonian speakers with an excellent knowledge of English. The translators then met to discuss and agree on a common version of the questionnaire. Subsequently the common version was evaluated by another native Estonian speaker in terms of conceptual equivalence, linguistic performance, and clarity. The agreed Estonian form was then translated back into English and rated. If modifications were necessary, reformulation was performed in the Estonian version. The internal consistency of the scale was examined using Cronbach's alpha and found to be acceptable (alpha = 0.71) (47). The evidence for the construct validity of the scale was supported by the data received following the hypotheses that patients with frequent seizures and mixed seizure types would score positively on the scale;

10. The impact of epilepsy on employment history: those currently un- or underemployed were asked whether this was caused by their epilepsy, whether they had changed jobs in the preceding 2 years because of epilepsy, and whether they had been treated unfairly at work because of epilepsy. Each of the items required a yes/no response. Patients were divided into three groups by seizure type (as having only tonic–clonic, only other types, or both tonic–clonic and other types) and frequency (based on seizure occurrence once or more a month, less often than once a month, or not at all in the past year);

11. Health status: respondents were asked to complete a comprehensive generic health status measure, the RAND 36-Item Health Survey 1.0 (RAND-36) (48), which consisted of eight multiitem variables: physical functioning (PF), 10 items; social functioning (SF), two items; role limitations due to physical problems (RP), four items; role limitations due to emotional problems (RE), three items; mental health (MH), five items; energy and vitality (VT), four items; bodily pain (BP), two items; and general perception of health (GH), five items. There is a further unscaled single item on changes in respondents' health over the past year (CHG). The scale was translated into Estonian as described in the Stigma scale. The RAND-36

questionnaire took ~5 min to complete. As indicated in standard RAND-36 scoring algorithms, for each variable item scores were coded, summed, and transformed onto a scale from 0 (worst possible health state measured by the questionnaire) to 100 (best possible health state). Missing value rates for the items were low and did not exceed 1.5% for any item of the eight scales. Internal-consistency reliabilities (Cronbach's alpha) met the level acceptable for group comparisons (>0.70) across all scales ranging from 0.75 to 0.92. Scaling assumptions were tested in two ways. Corrections, between items and hypothesized scales, were substantial within each scale and reached the level of >0.40 in all instances, supporting the reliability of the RAND-36 scales in both groups. In the epilepsy group, the lowest median item-total correlation was 0.53 for general health, and the highest, 0.84 for bodily pain. Discriminant validity was considered acceptable when these correlations exceeded all correlations between items and other scales. All of the eight scales in both groups passed this test level. The validity of the RAND-36 was assessed using discriminant techniques. The RAND-36 ability to distinguish between a high and a low symptom load was determined through assessment by seizure type and frequency. Discriminative power was examined by comparing the RAND-36 score profiles of the healthy respondents and respondents with epilepsy. A subsequent methodologic article will examine in detail the psychometric properties of the RAND-36 in this sample of people with epilepsy.

Statistical methods

The data were analyzed using the statistical analysis package SPSS Professional Statistics 7.5 (49). Tests of significance were χ^2 (chi square) and one-way analysis of variance (ANOVA). Attention is drawn to results in which differences were significant at the 5% level or less ($p \le 0.05$). To examine the correlations between different characteristics concerning employment and stigma, we performed a multivariate analysis of the data, but because we found no significant interactions at the 5% level, we were unable to construct corresponding models. Cronbach's alpha was used to test the reliability of the scales. To assess the influence of patient characteristics on quality of life (RAND-36) domains, the effects of the clinical variables (seizure frequency, type of seizures, age at onset, duration of disease), stigmatization and its severity, and sociodemographic variables (age, sex, educational level, employment status, marital status) on each domain total score were studied, using multifactor ANOVA models. Preliminary analyses were carried

out to investigate which of the clinical variables predominated. At each stage, factors found to be no longer significant after adjusting for the remainder were excluded. The final model includes only the factors that contributed significantly in predicting the domain score. To determine significant differences between pairs of groups, the Tukey HSD procedure or Bonferroni's method was used (50).

Response to the study

In Tartu, questionnaires to be completed individually were mailed to 110 patients, of whom 78 replied, a response rate of 71%. After sending a reminder, 16 more patients returned their questionnaires. Of all the questionnaires returned, 19 appeared to be unusable: in six cases, >10% of the questionnaire was left unanswered; three were sent back with a note that the person was deceased; five, with a note that the person no longer lived at the address; five, because the person was incapable of understanding the questions because of mental disability. The remaining questionnaires were considered usable and were included in the study. In addition, 15 patients completed the questionnaires while visiting their neurologist at the Outpatients' Clinic. One hundred twenty-two of the questionnaires appeared usable.

In Viljandi, questionnaires were mailed to 120 patients, of whom 85 replied. After being sent a reminder, 10 more patients returned their questionnaires. Eighty-one of the returned questionnaires appeared usable.

RESULTS

Sociodemographic characteristics of sample

The median age of the study population was 41 years (25th and 75th percentiles 29 and 57). The respondents of the study were divided into five age groups: 20–29 years, 26.6%; 30–39 years, 20.7%; 40–49 years, 17.2%; 50–59 years, 13.8%; and 60 years and older, 21.7%. Men accounted for 48.8%. Of the respondents, 40.9% were married or cohabiting, 41.4% were single, and 10.3% were divorced; 44.3% had less than primary (lower than eighth grade) or primary education (eighth or ninth grade), and 55.7%, high school (11th or 12th grade) or university education. Thirty-three percent were working full-time, and 41.9% were un- or underemployed; 0.5% described their economic and financial status as very good; 8.5%, as good; 59%, as satisfactory; 26%, as moderately bad; 6%, as very bad (Table 1).

The median age of the control group was 40 (25th and 75th percentiles 27 and 56) years. Forty-nine percent were men. Eight percent had less than primary education (lower than eighth grade level), 32% had primary education (eighth or ninth grade level), 49% had a high school education, and 11% had graduated from university.

TABLE 1. *Sociodemographic characteristics of respondents*

Parameter	Study respondents	%
Age (median)	41 yr	
Sex (M/F)	99/104	48.8/51.2
Marital status		
Married/cohabiting	82	40.9
Single	84	41.4
Divorced	21	10.3
Widowed	15	7.4
Employment status		
Full-time	67	33.0
Underemployed	65	31.9
Unemployed	22	11.0
Retired or receiving disability pension	49	24.1
Education		
Less than primary (lower than 8th grade)	22	10.8
Primary (8th or 9th grade)	68	33.5
High school (11th or 12th grade)	93	45.8
University	20	9.9

Disease characteristics of the sample

The median age of the onset of epilepsy was 26.9 years, and the median duration of epilepsy was 11.3 years (25th and 75th percentiles 5.8 and 22.4). Patients were divided into five groups by duration of the disease and into six groups by age at onset of the epilepsy. Of patients, 41.4% reported having only tonic–clonic seizures, 30% reported having both tonic–clonic and other types of seizures, and 28.6% reported having only other types of seizures. Almost a third (34%) had been seizure free in the last year; 39.9 had less than one seizure a month; and 26.1% had one or more seizures a month. Of those who had had at least one seizure in the past year (134 patients), 14% reported having serious injuries (burn, scald); 38%, head injuries; 22%, milder injuries or headache; and 5%, other injuries. More than a fifth (21%) had not experienced any injuries. Those having seizures once or more in a month ($\chi^2 = 11.89$; df = 2; p = 0.001) and those having multiple or generalized tonic–clonic seizure types ($\chi^2 = 9.94$; df = 2; p = 0.009) were more likely to report a seizure-related injury. Of these, 7.4% described their seizures as very severe; 30%, as severe; 41.4%, as moderate; and 21.2%, as light. There was a significant correlation with the subjective assessment about the severity of the seizures (those assessing their seizures as very severe or severe and those considering them moderate or light were counted together) with reported seizure-related injuries ($\chi^2 = 15.24$; df = 4; p = 0.003). Of the 88.7% who were receiving AED treatment, 83.9% were receiving monotherapy. The majority (74.8%) of those receiving monotherapy were receiving carbamazepine (CBZ). The most commonly experienced side effects were memory problems (31%), tiredness (25%), sleepiness (20%), headache (20%), and nervousness (20%). A third (33%) of subjects reported no side effects. The majority of respondents (78%) receiving AED treatment described their epilepsy

as very or fairly well controlled by this; 21% stated that the level of control was unsatisfactory. Almost two fifths (41.3%) of those receiving medication had changed it at least once in the past year; 68.4% had changed it once; 22.8%, twice; and 8.8%, three or more times. Of those who had changed their medication once in the past year, 79.3% had changed it because of unsatisfactory control and 20.7% because of side effects. For compliance with medication, 56% of respondents said they never missed taking AEDs, 23% reported missing on average once a month, 14% reported missing once a week, and 7%, more than once a week. Some (17.7%) had some other disease or health problem in addition to epilepsy; 11.8% were receiving medical treatment because of these. The most common additional diseases were diseases of the heart (39%) and joints (33%). The results of the underlying epidemiologic study conducted in Tartu have not yet been published in full. We therefore found it necessary to provide more detailed information about the clinical characteristics of the epilepsy of the study respondents. The main disease characteristics are presented in Table 2.

TABLE 2. *Disease characteristics of respondents*

Parameter	Study respondents	%
Duration of epilepsy (median)	11.3 yr	
≤1 yr	11	5.4
2–5 yr	45	22.2
6–10 yr	46	22.7
11–20 yr	44	21.7
>20 yr	57	28.1
Age at onset		
<10 yr	20	9.9
11–20 yr	68	33.5
21–30 yr	38	18.7
31–40 yr	36	17.7
41–50 yr	15	7.4
>50 yr	26	12.8
Seizure type		
Tonic–clonic only	84	41.4
Tonic–clonic and others	61	30.0
Others only	58	28.6
Seizure frequency status in the last year		
Seizure free	69	34.0
<1 seizure a month	81	39.9
≥1 seizure a month	53	26.1
Medication		
Free of medication	23	11.3
AED treatment	180	88.7
Of those receiving AED medication		
Monotherapy	151	83.9
Receiving 2 AEDs	22	12.2
Receiving ≥3 AEDs	6	3.3
Type of drug		
Carbamazepine	113	74.8
Valproate	15	9.9
Primidone	12	7.9
Phenytoin	5	3.4
Phenobarbital	4	2.7
Bensobarbital	2	1.3

TABLE 3. *Reported stigma by seizure type and frequency*

Parameter	Score on stigma scale			
	0	1	2	3
Seizure type				
Tonic–clonic only (n = 84)	46.4%	27.5%	11.6%	14.5%
Tonic–clonic and other (n = 61)	29.8%	27.7%	23.4%	19.1%
Other only (n = 58)	65.4%	17.3%	13.5%	3.8%
χ^2 = 20.65, p < 0.009				
Seizure frequency				
One or more a month (n = 53)	25.6%	27.9%	27.9%	18.6%
Less than one a month (n = 81)	45.6%	27.9%	11.8%	14.7%
None in past year (n = 69)	68.8%	17.2%	12.1%	6.9%
χ^2 = 23.57, p < 0.0001				

Figures in brackets are the numbers on which percentages are calculated.

Perceived stigma

More than half of all respondents (52.4%) felt stigmatized by their epilepsy; 24.7% answered "yes" to all three items, and this shows that they were highly stigmatized. Respondents were more likely to feel stigmatized if they had frequent seizures (χ^2 = 23.57; df = 6; p < 0.0001) or mixed seizure types (χ^2 = 20.65; df = 6; p < 0.009; Table 3). At the same time, only 37.4% considered their seizures very severe or severe. Those who had experienced seizures during the last year (χ^2 = 18.63; df = 1; p < 0.0001) and those who had tonic–clonic type of seizures only or together with other seizure types (χ^2 = 7.02; df = 1; p < 0.008) were more likely to score highly (to give two or three "yes" answers) on the stigma scale. Stigmatization was more common among those having university or high school education (χ^2 = 12.89; df = 6; p < 0.05). No differences were found in scores on the stigma scale by sex, marital status, or employment status.

Employment

A third of all respondents were working full-time. Employment status (working either full-time or being underemployed; those retired or receiving disability pension were excluded) was significantly related to age (χ^2 = 12.02; df = 4; p = 0.03), seizure frequency (χ^2 = 10.81; df = 2; p = 0.004), age at the onset of seizures (χ^2 = 15.13; df = 5; p = 0.01) and education (χ^2 = 11.38; df = 3; p = 0.01). Sixty-two percent of those

who were un- or underemployed named epilepsy as the significant reason for it. Respondents with frequent seizures were more likely to believe it (χ^2 = 11.03; df = 2; p = 0.001). During the last 2 years, 29% of respondents had changed jobs (meaning a change of workplace, not change of speciality or loss of job). Men (χ^2 = 7.07; df = 1; p < 0.003) and those with frequent seizures (χ^2 = 11.79; df = 2; p<0.006) were more likely to do this. Forty-four percent said that they had been treated unfairly at work or when getting a job. There were significant interactions between this opinion and seizure frequency, type, and education: respondents with frequent seizures (χ^2 = 16.26; df = 2; p = 0.0001), respondents having tonic–clonic or multiple seizure types (χ^2 = 8.94; df = 1; p = 0.002) and respondents who had lower than high school education (χ^2 = 7.32; df = 1; p = 0.007) were more likely to report this. We cannot leave unmentioned here that, although it was not asked, several respondents commented on the fact that they had hidden their diagnosis of epilepsy from employers and colleagues because of the fear of discrimination and shame. There also was a significant interaction between full-time work and educational level (those retired or receiving a disablement pension were excluded): the higher the person's education, the more likely he or she was to be working full-time (χ^2 = 12.12; df = 6; p = 0.04).

TABLE 4. *Descriptive statistics and features of score distributions for the RAND-36 Health Survey by seizure type*

Domain	Tonic–clonic only (n = 84)				Tonic–clonic and others (n = 61)				Others only (n = 58)				p Value[a]
	Mean	Median	CI	SEM	Mean	Median	CI	SEM	Mean	Median	CI	SEM	
Physical functioning	74.5	87.5	68.7–80.4	2.9	74.2	75	67.4–79.0	2.9	83.0	90	77.7–88.4	2.7	0.06
Role–physical	48.5	25	39.1–57.9	4.7	43.9	25	32.5–55.2	5.7	60.8	62.5	51.2–70.3	4.8	0.05
Role–emotional	51.6	33.3	42.5–60.7	4.6	39.9	33.33	29.5–50.3	5.2	53.5	66.66	42.6–64.3	5.4	0.03
Energy/fatigue	46.0	45	40.9–51.2	2.6	45.2	50	39.7–50.6	2.7	52.6	55	47.2–57.9	2.7	0.1
Emotional well-being	60.8	64	56.4–65.1	2.2	55.2	56	49.5–60.9	2.8	63.2	64	58.3–68.2	2.5	0.02
Social functioning	67.7	75	61.6–73.9	3.1	62.5	62.5	55.4–69.6	3.6	79.1	87.5	72.8–85.4	3.1	0.006
Bodily pain	68.4	68.75	62.2–74.6	3.1	60.1	67.5	52.2–67.9	3.9	74.6	77.5	68.1–81.1	3.3	0.04
General health	42.1	40	37.4–46.9	2.4	43.9	40	37.6–50.1	3.1	46.5	45	40.9–52.0	2.8	0.4

CI, 95% confidence interval; SEM, standard error of the mean.

[a] Variance between seizure types. Test of significance was Kruskal–Wallis one-way analysis of variance.

TABLE 5. *Descriptive statistics and features of score distributions for the RAND-36 Health Survey by seizure frequency status in the last year*

Domain	≥1 seizure/mo (n = 53)				<1 seizure/mo (n = 81)				Seizure free (n = 69)				p Value[a]
	Mean	Median	CI	SEM	Mean	Median	CI	SEM	Mean	Median	CI	SEM	
Physical functioning	73.0	75	67.3–78.7	2.8	74.3	85	68.5–80.2	2.9	81.9	90	76.3–87.5	2.8	0.07
Role–physical	33.5	25	23.4–43.6	5.0	49.4	50	40.3–58.5	4.6	65.2	100	55.1–75.4	5.1	0.0001
Role–emotional	27.0	30	17.7–36.4	4.7	49.0	33.33	39.9–58.1	4.6	64.7	100	55.0–74.4	4.9	0.0001
Energy/fatigue	45.1	50	39.7–50.5	2.7	43.2	40	38.2–48.2	2.5	54.8	60	49.5–60.1	2.6	0.004
Emotional well-being	55.1	56	49.6–60.6	2.7	58.4	60	53.8–63.0	2.3	65.0	72	60.3–69.8	2.4	0.02
Social functioning	59.2	62.5	51.6–66.8	3.8	69.1	75	63.0–75.3	3.1	77.5	87.5	71.5–83.5	3.0	0.001
Bodily pain	56.2	57.5	48.1–64.3	4.0	68.1	77.5	61.8–74.4	3.1	76.1	80	69.9–82.2	3.1	0.0006
General health	39.3	40	33.6–44.9	2.8	41.0	40	36.0–45.9	2.5	50.9	50	45.4–56.3	2.7	0.005

CI, 95% confidence interval; SEM, standard error of the mean.
[a] Variance between seizure frequencies. Test of significance was Kruskal–Wallis one-way analysis of variance.

RAND-36

The correlations between the RAND-36 scales and seizure status together with descriptive statistics for the questionnaire are given in Tables 4 and 5. Variance between seizure types was statistically significant in five RAND-36 domains. The comparisons between groups were investigated for each domain using the Tukey HSD test at the 0.05 level. Patients who did not have generalized tonic–clonic seizures or multiple seizure types had significantly higher scores in the Role–physical and Social functioning domains. Those who had multiple seizure types had lower scores than did those with only tonic–clonic seizure types or those with other types of seizures only in the Role–emotional domain. Those who experienced multiple seizure types scored significantly lower in the Emotional well-being and Bodily pain domains compared with those who did not have generalized tonic–clonic seizures (Fig. 1).

Variance between seizure frequency statuses was statistically significant in seven domains. The differences were significant between all three groups in the Role–emotional domain. Between those who had not had seizures in the past year and those who had had seizures at least once a month or less often than once a month, the differences were significant in the Role–physical, Energy/fatigue, and General health domains. Those experiencing seizures at least once a month scored significantly

lower in Emotional well-being and Social functioning compared with those who had been seizure free in the past year. In the Bodily pain domain, the differences were significant between those having seizures once or more in a month compared with those who had had seizures less often than once a month or had not had them in the past year (Fig. 2).

Study respondents scored lower in all domains on the RAND-36 than did persons from the control group, meaning that they were more dysfunctional (Fig. 3). The greatest differences were found in five domains: Social functioning, Role limitations–physical, Role limitations–emotional, General health, and Energy/fatigue (Table 6).

The results of the final models fitted to each RAND-36 domain score, including the factors that remain significant after controlling for the others, are shown in Table 7. Each multifactor model is a main-effect model (no significant interactions were found between the factors). Pairs of groups of significantly different factors were compared using Tukey HSD or Bonferroni's procedures. Scores of the RAND-36 domains were first compared in terms of the clinical variables. Significant differences were found for seizure frequency in all domains, except the Physical functioning domain. Seizure-free patients scored significantly higher than did patients who had experienced seizures during the last year in the Role limitations–physical, Energy/fatigue, Bodily pain,
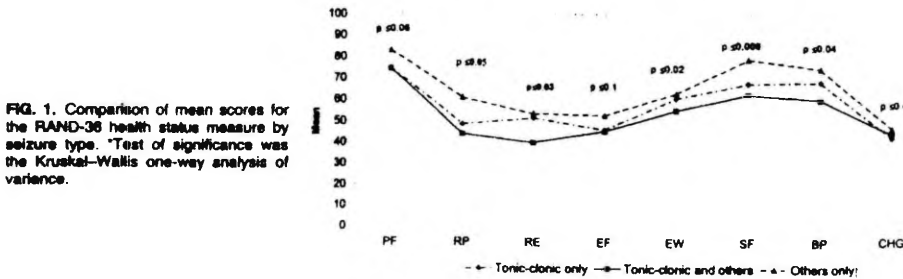

FIG. 1. Comparison of mean scores for the RAND-36 health status measure by seizure type. *Test of significance was the Kruskal–Wallis one-way analysis of variance.
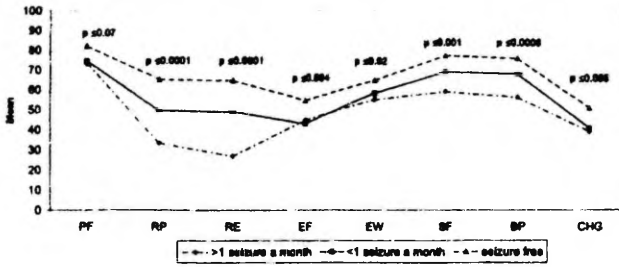
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FIG. 2. Comparison of mean scores for the RAND-36 health status measure by seizure frequency status. *Test of significance was the Kruskal–Wallis one-way analysis of variance.

and General health domains. The difference between those who had had seizures once or more in a month compared with those having seizures less often than once a month or not having seizures during the last year was significant in the Role limitations–emotional, Emotional well-being, and Social functioning domains.

In the Role limitations–physical domain, age, stigmatization, stigma severity, and age at onset of epilepsy became significant after controlling for seizure frequency. Younger people were less likely to score low in this domain, and there were significant differences were between the 20–29 and 30–39 age groups compared with people who belonged to the 60 years and older age group. Mean scores for this domain were significantly lower for those who were stigmatized, and for those who expressed very strong feelings of stigma (gave three "yes" answers on the stigma scale) compared with those who expressed less (one "yes" answer). Later age at onset was associated with lower scores; differences were significant between those for whom epilepsy had been diagnosed at the age of 41–50 or older than 50 compared with those for whom it had been diagnosed at younger than 20 years.

In the Role limitations–emotional domain, mean scores were significantly lower for those who were stigmatized and for those who expressed very strong feelings of stigma (gave three "yes" answers on the stigma scale) compared with those who expressed themselves less strongly (one "yes" answer).

In the Energy/fatigue domain employment status, du-

ration of epilepsy, and age at onset of epilepsy were significant. In this domain, mean scores were significantly lower for those currently unemployed, in comparison to those who were in full-time or underemployed work, for those who had had epilepsy for 2 to 5, and 6 to 10 years compared with those who had epilepsy longer and for those whose epilepsy had been diagnosed at the age of 41–50 or older than 50 compared with those for whom it had been diagnosed at younger than 20 years.

In the Emotional well-being domain, those who were stigmatized had significantly lower scores than did those who were not and of those who had had epilepsy 2 to 5 years compared with those who had had epilepsy >20 years.

In the Social functioning domain, stigmatization, stigma severity, employment status, seizure type, and age at onset of seizures became significant. Significantly lower scores were obtained by those who were stigmatized; those who expressed very strong feelings of stigma (gave three "yes" answers) compared with those who did not feel this so strongly (one "yes" answer), those who were currently unemployed compared with those who were in full-time employment or underemployed, those who experienced either tonic–clonic or multiple seizure types compared with those who had only other types of seizures, and those for whom epilepsy had been diagnosed at the age of 41–50 or older than 50 compared with those for whom it had been diagnosed at younger than 20 years.
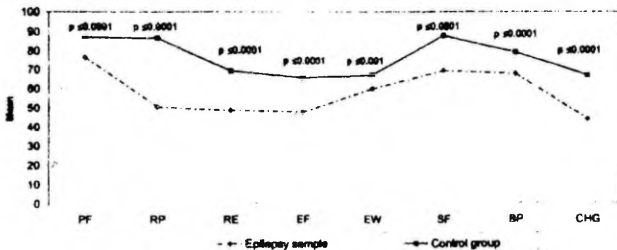
In the Bodily pain domain, lower scores were related

FIG. 3. Discriminative power of RAND-36. Comparison of mean scores for the RAND-36 health status measure: people with epilepsy and the control group. *Test of significance was the Kruskal–Wallis one-way analysis of variance

TABLE 6. *Mean scores of dimensions of RAND-36 questionnaire*

Dimension	Epilepsy group	Control group	p Value[a]
Physical functioning	76.56	87.20	0.0001
Role limitations (physical problems)	50.62	86.71	0.0001
Role limitations (emotional problems)	48.60	69.13	0.0001
Energy/fatigue	47.64	65.54	0.0001
Emotional well-being	59.80	67.12	0.001
Social functioning	69.40	87.82	0.0001
Bodily pain	67.69	78.97	0.0001
General health	43.89	66.85	0.0001

[a] Variance between groups. Test of significance was Kruskal-Wallis one-way analysis of variance.

to a shorter (2–5 years) rather than longer (11–20 and >20 years) duration of epilepsy.

In the General health domain, mean scores were significantly lower for those whose epilepsy had been diagnosed at the age of 41–50 or at older than 50 years compared with those for whom it had been diagnosed at younger than 20 years. Those who were stigmatized also scored significantly lower than those who were not, and those who expressed very strong feelings of stigma (gave three "yes" answers) in comparison to those who did not (one "yes" answer).

In the Physical functioning domain, stigmatization, age at onset, and current age were found to be significant.

Mean scores in this domain were significantly lower for those who were stigmatized compared with those who were not and for those aged 60 years or older compared with those aged 20–29 years. The overall pattern of variation in terms of age at onset was similar to that in the General health domain.

DISCUSSION

The importance of measuring quality of life in epilepsy patients has been emphasized (8,13,26,43,44,51–54). In dealing with epilepsy, several authors have drawn attention to the special importance of considering the social aspects. At the same time, recent investigations based on community populations suggest that although significant social difficulties may be experienced, many people with epilepsy cope well in society. However, patients with poor seizure control, multiple seizure types, or associated handicaps have significant social problems (55). Our study focused on adults living in the community. To give a more extensive and accurate survey, the sample for the study was drawn from two Estonian towns differing from each other in several respects. One of them represented the country's urban society, and the other, a mainly provincial and rural population. On January 1, 1996, the estimated crude prevalence ratio of ac-

TABLE 7. *Results of analysis-of-variance models*

Domains	Factors	Mean square ratio	p Value
Physical functioning	Stigmatization	4.78	0.03
	Age at onset	3.65	0.001
	Current age	4.39	0.001
Role limitations (physical problems)	Seizure frequency	9.27	0.0001
	Current age	3.54	0.02
	Stigmatization	8.93	0.003
	Stigma severity	4.16	0.02
	Age at onset	3.15	0.01
Role limitations (emotional problems)	Seizure frequency	13.89	0.0001
	Stigmatization	7.91	0.005
	Stigma severity	3.47	0.03
Energy/fatigue	Seizure frequency	24.20	0.0001
	Employment	3.26	0.02
	Duration of disease	3.27	0.02
	Age at onset	2.66	0.03
Emotional well-being	Seizure frequency	3.96	0.03
	Stigmatization	4.27	0.04
	Duration of disease	3.27	0.02
Social functioning	Seizure frequency	11.88	0.0001
	Stigmatization	6.98	0.01
	Stigma severity	8.83	0.0007
	Employment	23.85	0.0001
	Seizure type	5.88	0.003
	Age at onset	3.34	0.007
Bodily pain	Seizure frequency	7.76	0.0006
	Duration of disease	2.44	0.05
General health	Seizure frequency	5.36	0.005
	Age at onset	3.25	0.009
	Stigmatization	4.69	0.03
	Stigma severity	3.82	0.03

TABLE 8. *Comparison of sex and age structure of Tartu people with epilepsy and those included in the present study*

Parameter	Among people with epilepsy in Tartu		Among people with epilepsy in Tartu in the present study		p
	n	%	n	%	
Sex					
Male	172	55.7	56	45.9	0.07
Female	137	44.3	66	54.1	
Age groups					
20–29 yr	53	17.2	26	21.3	0.3
30–39 yr	74	23.9	27	22.1	0.7
40–49 yr	70	22.6	24	19.7	0.5
50–59 yr	54	17.5	20	16.4	0.8
≥60 yr	58	18.8	25	20.5	0.7
Total	309	100.0	122	100.0	

tive epilepsy in Tartu was 4.1 per 1,000 (56). When comparing the percentages of sex and age structure of the people with epilepsy in the present study with the same data available about the people with epilepsy of Tartu, there were no significant differences, and thus we consider our study consecutive (Table 8). The clinical characteristics of the present study were similar to most other series of prevalence cases of epilepsy (57–59). Most of the study respondents had generalized seizures with or without other seizure types, the average duration of the disease was 11 years, and patients were predominantly receiving CBZ monotherapy. More than half of those who had experienced seizures during the last year reported having injuries related to them. Findings regarding the rate and severity of seizure-related injuries were slightly higher compared with the results of studies conducted in other countries (43,60). Beran (61) pointed out that the purpose of treating epilepsy may not necessarily be that of seizure eradication but rather the maximal improvement of quality of life for the patient. In comprehensive management, the treating physician must very seriously consider the influence of the therapy on the patients' quality of life (53). Eighty-four percent of our study respondents were receiving monotherapy. This was higher compared with the other studies (26,43,62). The explanation is that all of the patients from Tartu were participating in an epidemiologic survey with consultation by an epileptologist, which often resulted in the correction of medication. The number of untreated cases (11%) was not high and probably reflects insufficient compliance. However, AED prescription patterns had some distinctive features. CBZ was a much more frequently reported drug than in other studies, whereas the percentage of those using valproate (VPA) or phenytoin (PHT) was lower. To our surprise, two patients reported taking bensobarbital, a drug that is no longer officially used in Estonia. The results indicate that treatment strategies in Estonia probably should be modified. Significant numbers of study respondents (67%) reported side effects from the AEDs; the most commonly experienced side effects were nonspecific. In the past year, 41% of respondents had changed their medication; at present, 78% stated that the level of seizure control was satisfactory.

The problem of stigmatization has been projected as one of the most common social problems faced by persons with epilepsy in a number of studies (23,37,63–66). Stigmatization seems to vary from region to region, and it tends to be more severe outside the developed world (67–72). However, despite its changed manner, it is still a difficult problem in Western countries. As stigmatization is difficult to compare, we collated our results only with the results from the European study (43) in which the same scale was used for measuring stigma. According to this, the highest proportions of stigmatized persons (>60%) were found among the respondents from two highly developed countries (i.e., France and Germany). The study also included respondents from Poland, the Czech Republic, and Hungary, where the percentages of stigma were 32, 55, and 52, respectively. In Estonia, the levels of stigma among people with epilepsy were also high (52%), although 40% of our study's respondents had less than one seizure a month, and 34% had been seizure free in the last year. The majority of patients stated that they were nevertheless satisfied with the current treatment, and the percentage of stigmatization in general and the percentage of severely stigmatized persons was high. The factors influencing the development and maintenance of stigma in different countries are diverse, but we speculate that in general, the higher percentage of stigmatization could be a characteristic of Eastern European countries and could be the result of a general lack of knowledge and of indifference, because the individual's health and well-being was not valued, for a long period, because of the complicated political status. Furthermore, more precise studies from other Eastern European countries could perhaps clarify this topic. Respondents were more likely to feel stigmatized by epilepsy if they had frequent seizures or a combination of seizure types, findings that were in agreement

with the results of other studies (26,43,63,65). Stigmatization was more common among educated persons.

Unemployment and part-time employment, being much more frequent in the epilepsy population than in general, have been identified as being among the most serious problems facing people with epilepsy (73,74). The percentage of people working full-time and part-time was 65 in the present study; 11% were unemployed. We do not consider this high because, according to the data of the labor force surveys of the Statistical Office of Estonia, the percentage of employees (both employed and underemployed) residing in Tartu and aged 20 years and older on January 1, 1998, was 63%, the unemployment rate was 9.5%, and 25.5% were pensioners receiving the state pension (75). At the same time, more than half of the study's respondents believed that their employment problems were caused by their disease. A little fewer than half stated that they were being treated unfairly at work. Perceived discrimination may not always correspond to real discrimination (1). Although the findings of this study do not provide evidence of active discrimination against people with epilepsy, this topic must be investigated in greater depth. Of respondents, 55.7% had at least high school education, and problems connected with unemployment or part-time employment were not much expressed among this group. Not surprisingly, seizure frequency was positively related to the unemployed and underemployed workers, but we could not find a relationship with the type of seizure. The finding supports the data of previous research in which lower seizure frequency had been related to the greater likelihood of being employed (1,42,76). The results of our study showed very clearly that there are a variety of reasons for the existence of the stigma. Although it has been found that unemployment and employment problems are on the whole the main source of the stigma (17,42,65), the most educated respondents in our study who had jobs were even more stigmatized.

To assess general health status, a multidimensional instrument, the RAND 36-Item Health Survey 1.0, was used. Although they have proven useful in their countries of origin, such instruments are not directly applicable across nations because of cultural diversity (77). Before using it in our study, we performed a thorough translation and validation process. The construct validity of the scale was supported by the findings that those with frequent seizures did poorly compared with those who experienced infrequent seizures or were currently seizure free. This expected finding was in accordance with other studies (26,41,62,78,79). Although the differences between seizure types were not significant in all the RAND-36 domains, there was a clear tendency toward a greater likelihood of lower scores in the case of patients with generalized tonic–clonic seizures. Patients who experienced both generalized tonic–clonic and other types

of seizures did poorly compared with the others, as was to be expected (26,43,78). Discriminant validity was highly acceptable. People with epilepsy had significantly lower scores than did the controls in all domains. Although the mental health of the study respondents was not much worse than that of the control group, their social functioning was significantly lower, and limitations due to emotional problems were more expressed. The results of the European study had previously drawn attention to the fact that it was unclear why respondents with epilepsy scored relatively poorly on the domain concerned with physical function (43). Although current seizure activity remained the most important predictor, there was a concomitant importance of sociodemographic variables (current age and employment status) in quality of life. Older people and people who were currently unemployed were more likely to score lower. The other substantial disease characteristics in explaining the variation in the scores of several domains after controlling for seizure status were age at onset of epilepsy, duration of disease, and seizure type. Age at onset became significant in the case of Physical functioning, Role limitations–physical, Energy/fatigue, Social functioning, and General health. In all those domains, later age at onset was associated with lower scores. Dominian et al. (80) reported an association between depression and older age at onset. Jacoby et al. (26) considered older age at onset to be implicated in feelings of depression and stigma. Duration of disease was significant in the case of Energy/fatigue, Emotional well-being, and Bodily pain. Here, a shorter duration of epilepsy was related to lower scores. Seizure type became significant in relation to Social functioning; those who experienced either tonic–clonic or multiple seizure types scored significantly lower than did those who had only other types of seizures.

To increase the clinical significance of these tests, it is essential to perform repetitive trials. This will be one of the subjects of further investigation. As the RAND-36 was not designed to measure limitations or restrictions specifically associated with epilepsy, a disease-specific instrument may be more sensitive in evaluating variations in patient perception (81,82).

We consider the strength of our study to be that epilepsy diagnosis was based on a clinical assessment. A profound translation and psychometrical testing phase preceded the inclusion of the RAND-36 questionnaire in the research. Although we are aware of the limitations to the generalizability of the study in the interpretation of the results because of a relatively small and somewhat biased sample size, the findings of the study reveal quite clearly that one of the main problems of people with epilepsy in Estonia is their perception of stigmatization. The characteristics describing their disease, its medication, and complications were generally in accordance

with the data from other countries, and also marital and educational status (except when assessing the stigmatization) were not statistically significant. Achieving better control of seizures and reducing side effects are essential in improving the quality of life of people with epilepsy, because this reduces the stigma associated with the condition. We emphasize to doctors the importance of psychological support in the care of patients with epilepsy. Unfortunately, the results of our study suggest that, at least in our country, many physicians ignore or do not recognize this actuality, considering it irrelevant.

In conclusion, the findings of this study confirm that psychosocial problems accompany the diagnosis of epilepsy. Although the study demonstrated quality of life decreases in subjects with epilepsy, we consider the results encouraging. No remarkable differences were found in terms of medical problems. A further study is required in this field within our community to help people with epilepsy to better understand their condition, to analyze the reasons for stigma, and if it is not possible to eliminate them completely, then to promote adjustment.

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The impact of epilepsy on people in Estonia: evaluation of the RAND-36 questionnaire and quality-of-life measurement

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Abstract

The purpose of this investigation was to test the acceptability, validity, and reliability of the RAND-36 and to describe, by it, how quality of life (QOL) is affected by patients' and epilepsy characteristics in an Estonian sample of adults with epilepsy. The form was translated with accompanying translation quality ratings and pilot tested. It was administered to 203 epileptic patients and to a control group of 200 healthy subjects. The RAND-36's ability to distinguish between high and low symptom load was determined assessing by seizure type and frequency. All sub-scales passed tests for item-internal consistency and item-discriminant validity. Reliability coefficients exceeded 0.40 in all instances. QOL was poor for patients with frequent seizures and tonic-clonic or multiple seizures. The patients with epilepsy were more dysfunctional in all RAND-36 domains than were persons from control group. Though the emotional well-being of the study respondents was not much worse than that of the control group, their social functioning was significantly lower and limitations due to emotional problems more expressed. Although current seizure activity remained the most important predictor, there was a concomitant importance of socio-demographic variables (current age and employment status) and disease characteristics (age at onset, duration of epilepsy, and seizure type).

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Introduction

Quality-of-life issues are most relevant to disorders that are chronic and associated with problems beyond the experience of the obvious disease symptoms. Epileptic seizures are usually infrequent but antiepileptic drug (AED) therapy, side effects, and attendant psychosocial problems are usually chronic [10]. The extent to which an individual with a chronic illness feels the impact of his or her condition may vary with its course and depend on different factors at different stages in its history. Health-related quality of life can be assessed through various objective indicators and much empirical data gained through this approach are now available regarding various epilepsy populations. However, it has been realised for a long time that people act or feel in accordance with their perceptions of reality, which may or may not relate directly to their actual circumstances or to objective indicators of their medical condition [7]. At the same time, it is useful to have a focus on objectivity in research and clinical practice. Today many researches agree on the importance of a comprehensive view within epilepsy-care [5, 18, 43].

A variety of instruments are available for evaluating health-related quality of life in the general population. One among the most widely used questionnaires is the RAND 36-Item Health Survey 1.0. It is a brief and intensively tested instrument that was derived from longer instruments developed by RAND researchers (Santa Monica, California) for the Medical Outcome Study (MOS) and the Health Insurance Experiment [8]. The purposes and methods of the RAND study have been fully summarised [20]. The RAND 36-Item Health Survey 1.0 items are identical to the MOS 36-item short-form health survey (MOS SF-36) described by Ware and Sherbourne [42]. They were adapted from longer instruments completed by patients participating in the Medical Outcomes Study [19]. The conceptual framework is based on the multidimensional World Health Organisation definition of health [44]. Although the RAND version has a slightly different scoring method, it allows users of the MOS SF-36 and RAND-36 to relate their findings [20]. The RAND 36-Item Health Survey also forms the core component of two quality of life measures in epilepsy, the Epilepsy Surgery Inventory (ESI-55) [43] and the Quality of Life in Epilepsy Inventory (QOLIE-89) [12]. The RAND-36 has a high validity and reliability as compared with the Nottingham Health Profile and can discriminate between healthy controls and subjects who have mild health problems [16, 39]. It has been carefully tested, validated, and extensively used among patients with chronic disease [36]. Due to its long developmental history and use in research as well as in clinical practice, it provides a rich database enabling researches to compare their results. In the international context, thus it is possible research on the cultural universality vs. differences in quality-of-life assessment [6]. Standard scales are needed to meet the demands of international studies. Although proven useful in their country of origin these measures are not directly applicable across nations due to cultural diversity. In order to use such instru-

ments in a new national context, a thorough translation and testing phase preceding the inclusion of an instrument in a study is necessary. Measures need also to be psychometrically tested in a specific cultural context to assure their psychometric soundness [6, 21, 29].

The purpose of the present paper was to test the acceptability, validity, and reliability of the RAND 36-Item Health Survey 1.0 questionnaire and to analyse by means of it how QOL is affected by socio-demographic and epilepsy characteristics.

Methods

The RAND-36 is a short questionnaire with 36 items which measure eight multi-item variables: physical functioning (PF) — ten items, role limitations due to physical health problems (RP) — four items, role limitations due to personal or emotional problems (RE) — three items, energy/fatigue (EF) — four items, emotional well-being (EW) — five items, social functioning (SF) — two items, bodily pain (BP) — two items, and general perception of health (GH) — five items. It also includes a single item that provides an indication of perceived change in health over the past year (CHG). For each variable item scores are coded, summed, and transformed on to a scale from 0 (worst possible health state measured by the questionnaire) to 100 (best possible health state) [31]. The RAND-36 questionnaire takes about five minutes to complete.

Translation

The translation procedure was carried through taking into account the recommendations of the developers of the Nottingham Health Profile, the Sickness Impact Profile, The Quality of Well-Being Scale, etc. [2] and the International Quality of Life Assessment (IQOLA) — translation group [1]. The items and responses of the original American RAND-36 questionnaire were translated into Estonian independently by two native Estonian speakers with excellent knowledge of English. The translators then met to discuss and agree upon the common version of the questionnaire. Subsequently the common version was evaluated by another native Estonian speaker in terms of conceptual equivalence, linguistic performance and clarity. The agreed upon Estonian form was then translated back into English and rated. If modifications were necessary, the reformulation in the Estonian version was performed.

Piloting

The Estonian questionnaire was given for self-assessment to 15 epilepsy patients who visited their neurologist at the University's Outpatients' Clinic. During individual interviews, each item and response choice was carefully discussed as to its meaning and connotations with the responders. As a result the wording of five questions was altered slightly. Then the questionnaire was mailed by post to 15 epilepsy patients. The goal of this administration was to detect problems with the forms in terms of missing data, inconsistent answers and ease of administration.

No respondent found the questionnaire either difficult or too personal.

Subjects

Our results are based on data gained from a sample of 203 patients, in the 20–70 age group. The research took place in 1997–98. The QOL data was collected from respondents with epilepsy living in two towns of Estonia — Tartu and Viljandi. Tartu, with a population of 100 977 [35] is the country's second largest city. Southern Estonia revolves around Tartu which is the intellectual and educational centre of Estonia. Viljandi County, with a population of 62 782 [35], is located in south-central Estonia. The administrative centre of the county is the town of Viljandi, the country's sixth largest town by its population, which is situated 81 kilometres from Tartu. In Tartu, the study followed an an epidemiological survey of epilepsy in the town of Tartu. The patients for the present study were selected at random from the preliminary lists of the epidemiological study. The epidemiological survey included persons who were residents of Tartu and were aged 20 and over, and had before or within the course of 01.01.1991–01.01.1996 had at least two unprovoked epileptic seizures, at least one of them within the previous five years. Data collection for the epidemiological study consisted of two parts: data registration from a multi-source medical register review and data registration from a personal case re-examination. Case records of patients treated in the University Hospital, Outpatients' Clinics, physicians' offices, emergency rooms, the electroencephalographic laboratory with a diagnosis of epilepsy, convulsions, syncope, amnestic attacks, abnormal involuntary movements were reviewed and invitations for re-examination were sent to the suitable persons. During the last 2 years, all the patients were re-examined at least once by a neurologist to specify the type of their seizures. In Viljandi, primary information about people with epilepsy was gathered through the local epilepsy support group, and clinical information was abstracted from medical notes held in the County Hospital and Outpatients' Clinic register. To evaluate the accuracy of diagnoses, the problematic cases were investigated by one of the authors and re-examined if necessary. The present study excluded the Russian-speaking people because there were not any

sufficiently well translated questionnaires available for them. All patients gave their consent to participate in the research and the project was approved by the Ethics Committee of the University of Tartu. All of the respondents had a basic education level with sufficient ability to read and write, and were capable of understanding and completing the questionnaires. Clinical information, if needed, was abstracted once again from medical notes and during the personal re-examination of subjects. Abstracted information used in the study related to the aetiology of epilepsy, classification of seizure type and current AED therapy. All the patients were sent a questionnaire by mail that employed a combination of open questions together with two previously translated and validated scales (the Stigma of Epilepsy Scale and the RAND 36-Item Health Survey). Information was obtained about subjects` sex, age, marital and employment status, and educational level. To evaluate seizure frequency, patients were asked whether they had had seizures once or more in a month, less often than once a month, or not at all in the past year. Also patients were asked about age at first attack. Perceived stigma was measured with a three-item scale (Cronbach's alpha = 0.71), which Estonian translation and validation has been described [33]. Respondents with epilepsy had to state whether they (a) felt that other people were uncomfortable with them, (b) treated them as inferior, or (c) preferred to avoid them. Each of the three items required a yes/no response. An individual's score was the sum of the "yes" responses and the higher the score, the greater was the perception of stigma.

In addition, a control group of 200 healthy subjects corresponding in age, sex, and educational level was randomly selected among the patients visiting the dentist at University's Dental Clinic.

Response to the study

Questionnaires were sent to the identified individuals by post, with a covering letter from the study conductors, explaining the purpose of the study. To those who did not respond to the initial questionnaire a reminder was sent about three to six weeks later. Questionnaires, to be completed individually, were mailed to 290 patients, of whom 225 replied — a response rate of 78%. From all the questionnaires returned, 22 appeared to be unusable and the rest of 203 questionnaires were included in the study.

Statistical analysis

The data were analysed using statistical analysis package SPSS Professional Statistics™ 7.5 [34]. Test of significance was one-way analysis of variance (ANOVA). Attention is drawn to results which differences were significant at the 5% level or less ($p \leq 0.05$). The RAND-36 was evaluated using the data

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completeness at an individual item and scale level, correlations between items and hypothesised scales, correlations between items and other scales, average inter-item correlation, internal-consistency reliability (Cronbach's alpha [9]) and score distributions (floor and ceiling effects, skewness and kurtosis). 95% confidence intervals (CI) were computed to define the range of variation around the mean.

Construct validity, showing the extent to which the questionnaire supports predefined hypotheses [24] and the main requirement of any measuring tool [4], was assessed in connection with seizure frequency and seizure type. This followed the hypothesis that patients with frequent seizures and patients with tonic-clonic or multiple seizure types would have poorer health status. To test for such comparisons between groups, Tukey's studentized range test was used for each variable. To assess the influence of patient characteristics on quality of life (RAND-36) domains, the effects of the clinical variables (seizure frequency, type of seizures, age at onset, duration of disease), stigmatisation and its severity, and socio-demographic variables (age, sex, educational level, employment status, marital status) on each domain total score were studied, using multifactor analysis of variance models. Preliminary analyses were first carried out to investigate which of the clinical variables predominated. At each stage, factors found to be no longer significant after adjusting for the remainder were excluded. The final model includes only the factors, which contributed significantly in predicting the domain score. To determine significant differences between pairs of groups, Tukey HSD procedure or Bonferroni's methods were used [38].

Results

Characteristics of respondents

The main characteristics of respondents are given in table 1. The median age of the study epilepsy sample was 41 (25th and 75th percentiles 29 and 57) years. The respondents of the study were divided into five age groups: 20–29 years — 26.6%, 30–39 years — 20.7%, 40–49 years — 17.2%, 50–59 years — 13.8%, and 60 years and older — 21.7%. Median age of the onset of epilepsy was 26.9 years, and the median duration of epilepsy was 11.3 years (25th and 75th percentiles 5.8 and 22.4). Patients were divided into five groups by duration of the disease and into six groups by age at onset of their epilepsy. 88.7% were receiving AED treatment. From those, 83.9% were receiving monotherapy. From those on monotherapy, the majority (74.8%) were receiving carbamazepine. 52.4% felt stigmatised by their epilepsy. From those, 24.7% answered "yes" to all three items, 27.8% to two and 47.5% to one item showing their stigmatisation.

Table 1. Characteristics of respondents.

Parameter	Study respondents	%
Age (median)	41 years	
Sex (M/F)	99/104	48.8/51.2
Marital status		
married/cohabiting	83	40.9
single	84	41.4
divorced	21	10.3
widowed	15	7.4
Employment status		
full-time	67	33.0
underemployed	65	31.9
unemployed	22	11.0
retired or receiving disablement pension	49	24.1
Education		
less than primary (lower than 8th level)	22	10.8
primary (8th or 9th level)	68	33.5
high school (11th or 12th level)	93	45.8
university	20	9.9
Duration of epilepsy (median)	11.3 years	
until 1 year	11	5.4
2-5 years	45	22.2
6-10 years	46	22.7
11-20 years	44	21.7
over 20 years	57	28.1
Age at onset		
under 10 years	20	9.9
11-20 years old	68	33.5
21-30 years old	38	18.7
31-40 years old	36	17.7
41-50 years old	15	7.4
over 50 years old	26	12.8
Seizure type		
tonic-clonic only	84	41.4
tonic-clonic and others	61	30.0
others only	58	28.6
Seizure frequency status in the last year		
seizure free	69	34.0
<1 seizure a month	81	39.9
≥1 seizure a month	53	26.1
Medication		
free from medication	23	11.3
on AED treatment	180	88.7

The median age of the control group was 40 (25th and 75th percentiles 27 and 56) years. 49% were men. 8% had less than primary education (lower than 8th

grade), 32% had primary education (8th or 9th grade), 49% had high school education and 11% had graduated from university.

Data completeness

The distribution of responses of the respondents from epilepsy group to the 36 items, as well as the number and percentage of patients missing each of the 36 items is given in Table 2. Missing value rates for the items were low and did not exceed 1.5% for any item. The total number of omitted items per questionnaire was 8.3%. 92% completed all 36 items.

Table 2. Item frequency distributions — the epilepsy sample.

Item	Nr	Item						Missing nr	%
		1	2	3	4	5	6		
PF1	202	40.1% (81)	33.7% (68)	26.2% (53)				1	0.5
PF2	202	6.9% (14)	26.7% (54)	66.3% (134)				1	0.5
PF3	202	10.9% (22)	24.3% (49)	64.9% (131)				1	0.5
PF4	202	16.3% (33)	34.7% (70)	49.0% (99)				1	0.5
PF5	202	2.5% (5)	18.8% (38)	78.7% (159)				1	0.5
PF6	202	17.3% (35)	31.2% (63)	51.5% (104)				1	0.5
PF7	202	16.3% (33)	20.3% (41)	63.4% (128)				1	0.5
PF8	202	5.9% (12)	15.4% (31)	78.7% (159)				1	0.5
PF9	202	3.5% (7)	9.0% (18)	87.5% (176)				2	1.0
PF10	202	2.5% (5)	9.4% (19)	88.1% (178)				1	0.5
RP1	202	43.1% (87)	56.9% (115)					1	0.5
RP2	202	54.5% (110)	45.5% (92)					1	0.5
RP3	202	49.5% (100)	50.5% (102)					1	0.5
RP4	202	50.0% (101)	50.0% (101)					1	0.5

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Item	Nr	Item						Missing nr	%
		1	2	3	4	5	6		
RE1	202	45.1% (91)	55.0% (111)					1	0.5
RE2	202	61.4% (124)	38.6% (78)					1	0.5
RE3	202	47.0% (95)	53.0% (107)					1	0.5
EF1	201	16.9% (34)	29.9% (60)	22.4% (45)	18.9% (38)	10.5% (21)	1.5% (3)	2	1.0
EF2	202	21.8% (44)	20.3% (41)	27.2% (55)	19.3% (39)	7.9% (16)	3.5% (7)	1	0.5
EF3	202	2.5% (5)	9.4% (19)	15.8% (32)	20.8% (42)	25.3% (51)	26.2% (53)	1	0.5
EF4	202	9.9% (20)	10.9% (22)	24.8% (50)	28.7% (58)	21.3% (43)	4.5% (9)	1	0.5
EW1	201	0.5% (1)	9.0% (18)	16.9% (34)	25.9% (52)	31.8% (64)	15.9% (32)	2	1.0
EW2	202	2.0% (4)	5.0% (10)	12.9% (26)	17.8% (36)	20.8% (42)	41.6% (84)	1	0.5
EW3	202	4.5% (9)	19.3% (39)	35.2% (71)	15.4% (31)	20.3% (41)	5.5% (11)	1	0.5
EW4	202	1.5% (3)	10.9% (22)	14.9% (30)	21.8% (44)	31.7% (64)	19.3% (39)	1	0.5
EW5	202	7.4% (15)	26.7% (54)	25.7% (52)	21.8% (44)	15.8% (32)	2.5% (5)	1	0.5
SF1	202	3.5% (7)	16.5% (33)	15.5% (31)	28.5% (57)	36% (72)		3	1.5
SF2	202	5.0% (10)	12.9% (26)	22.8% (46)	17.8% (36)	41.6% (84)		1	0.5
BP1	202	2.5% (5)	11.4% (23)	19.8% (40)	17.3% (35)	20.8% (42)	28.2% (57)	1	0.5
BP2	202	5.5% (11)	10.9% (22)	21.3% (43)	23.3% (47)	39.1% (79)		1	0.5
GH1	202	16.8% (34)	55.9% (113)	22.8% (46)	3.5% (75)	1.0% (2)		1	0.5
GH2	202	11.9% (24)	15.4% (31)	32.2% (65)	24.3% (49)	16.3% (33)		1	0.5
GH3	202	23.8% (48)	22.3% (45)	22.3% (45)	24.8% (50)	6.9% (14)		1	0.5
GH4	202	6.4% (13)	13.9% (28)	44.1% (89)	15.8% (32)	19.8% (40)		1	0.5
GH5	202	31.7% (64)	20.3% (41)	20.3% (41)	23.8% (48)	4.0% (8)		1	0.5
CHG	202	4.5% (9)	22.3% (45)	51.5% (104)	16.8% (34)	5.0% (10)		1	0.5

Psychometric analyses

The data about the psychometric characteristics is given in Tables 3 and 4.

As Table 3 shows, means and standard deviations of the scales were in the range of 44–77 (SD 21–42) for epilepsy group and in the range of 66-88 (SD 9–33) in the control group. In the epilepsy group mean and median scores were higher for physical function and lower for general health. Skewness, measuring the asymmetry of response distributions, was most marked for physical function in the epilepsy group and for role — physical in the control group. Most of the scales were negatively skewed, meaning that subjects more often gave responses representing positive health states. There were substantial ceiling effects for four domains — Physical functioning, Role – physical, Role — emotional, Social functioning in both groups, in the epilepsy group in addition to these — for Bodily pain. Floor effects were significant in two domains in the epilepsy group: 31% and 32.5% of subjects had the minimum possible score in the Role — physical and Role — emotional domains respectively. The internal consistency coefficients, being above 0.70 for all dimensions, met the level acceptable for group comparisons. The internal consistency coefficients ranged from 0.75 to 0.92. Scaling assumptions were tested in two ways. Corrections between items and hypothesised scales were substantial within each scale and reached the level of >0.40 in all instances, supporting the reliability of the RAND-36 scales in both groups. In epilepsy group the lowest median item-total correlation was 0.53 for general health, the highest 0.84 for bodily pain. Discriminant validity was considered acceptable when these correlations exceeded all correlations between items and other scales. All the eight scales in both groups passed this level.

Table 3. RAND-36 subscale psychometric results.

RAND-36 subscales	Mean (0-100)	Median	Std	Range	Skewness	Kur-tosis	Floor (%)	Ceiling (%)
The epilepsy group								
Physical functioning	76.56	85.00	24.26	100.00	-1.14	0.55	1.0	18.2
Role-physical	50.62	50.00	42.10	100.00	-0.01	-1.69	31.0	33.5
Role-emotional	48.60	33.33	41.59	100.00	0.10	-1.62	32.5	32.5
Energy/fatigue	47.64	50.00	22.14	100.00	0.01	-0.73	1.0	0.5
Emotional well-being	59.80	60.00	20.49	96.00	-0.27	-0.73	0	0.5
Social functioning	69.40	75.00	27.68	100.00	-0.54	-0.78	1.5	28.1
Pain	67.69	70.00	28.67	100.00	-0.55	-0.73	2.5	26.1
General health	43.89	45.00	22.46	95.00	0.12	-0.92	2.0	0

RAND-36 subscales	Mean (0-100)	Median	Std	Range	Skewness	Kur-tosis	Floor (%)	Ceiling (%)
The control group								
Physical functioning	87.20	87.00	9.42	30.00	-0.15	-0.83	0	25.0
Role-physical	86.71	100.00	20.76	100.00	-2.36	6.70	3.0	59.0
Role-emotional	69.13	66.00	33.11	100.00	-0.66	-0.75	8.5	45.0
Energy/ fatigue	65.54	64.00	12.36	76.00	-0.19	0.90	0	0.5
Emotional well-being	67.12	64.00	16.92	72.00	-0.05	-0.27	0	3.0
Social functioning	87.82	88.00	11.50	62.00	-1.11	1.83	0	32.5
Pain	78.97	80.00	12.44	78.00	-1.94	5.72	0	3.5
General health	66.85	64.00	14.09	60.00	0.54	0.25	0	3.0

Table 4. Results of scaling success tests and reliability estimates.

Dimension	Internal consis-tency[a]	Homo-genity[b]	Item dis-criminant validity[c]	Cron-bach`s α	Relia-bility coefficients
The epilepsy group					
Physical functioning	0.55-0.80	0.55	0.21-0.70	0.92	0.91
Role limitations (physical problems)	0.67-0.76	0.61	0.34-0.63	0.86	0.86
Role limitations (emotional problems)	0.58-0.67	0.56	0.31-0.60	0.79	0.78
Energy/fatigue	0.59-0.73	0.57	0.35-0.69	0.84	0.83
Emotional well-being	0.52-0.75	0.55	0.22-0.74	0.86	0.85
Social functioning	0.62	0.63	0.49-0.61	0.77	0.77
Pain	0.84	0.84	0.52-0.67	0.91	0.90
General health	0.54-0.79	0.53	0.31-0.64	0.85	0.83
The control group					
Physical functioning	0.57-0.72	0.55	0.44-0.70	0.77	0.75
Role limitations (physical problems)	0.42-0.69	0.41	0.35-0.61	0.76	0.78
Role limitations (emotional problems)	0.58-0.76	0.52	0.55-0.72	0.80	0.80
Energy/fatigue	0.56-0.68	0.55	0.40-0.65	0.76	0.75
Emotional well-being	0.68-0.73	0.60	0.57-0.70	0.88	0.88
Social functioning	0.61	0.59	0.42-0.60	0.79	0.78
Pain	0.53-0.76	0.48	0.48-0.69	0.82	0.81
General health	0.47-0.69	0.50	0.43-0.63	0.74	0.75

[a] Correlations, corrected for overlap, between items and hypothesised scales.

[b] Average inter-item correlation

[c] Correlations between items and other scales

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Validity

Validity of the RAND-36 was assessed using discriminant techniques. The RAND-36`s ability to distinguish between high and a low symptom load was determined assessing by seizure type and frequency. The descriptive statistics and features of score distribution for the RAND-36 scales are detailed in Tables 5 and 6. Variance between seizure types was statistically significant in five RAND-36 domains. The comparisons between groups were investigated for each domain using Tukey's studentized range test at the 0.05 level. Patients who did not have generalised tonic-clonic seizures or multiple seizure types had significantly higher scores in the Role — physical and Social functioning. Those who had multiple seizure types had lower scores than those with only tonic-clonic seizure types or those with other types of seizures only in the Role — emotional. Those who experienced multiple seizure types scored significantly lower in the Emotional well-being and Bodily pain domains compared to those who did not have generalised tonic-clonic seizures.

Variance between seizure frequency statuses was statistically significant in seven domains. The differences were significant between all the three groups in the Role — emotional domain. Between those who had not had seizures in the past year and those who had had seizures at least once a month or less often than once a month the differences were significant in the Role — physical, Energy/fatigue, and General health domains. Those experiencing seizures once or more in a month scored significantly worse in the Emotional well-being and Social functioning compared to those who had been seizure-free in the last year. In the Bodily pain domain the differences were significant between those having seizures once or more in a month compared to those who had had seizures less often than once a month or had not had them in the last year.

Discriminative power was examined by comparing RAND-36 score profiles of the healthy respondents and respondents with epilepsy. As shown in Fig. 1, the respondents with epilepsy scored significantly lower in all RAND-36 domains than the controls ($p \leq 0.001$), indicating that their perceived health status was poorer. The differences were most remarkable in Role – physical, Role – emotional, Social functioning and General health domains.

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Table 5. Descriptive statistics and features of score distributions for the RAND-36 Health Survey by seizure type.

Domain	Tonic-clonic only (n=84)				Tonic-clonic and others (n=61)				Others only (n=58)				p-value*
	Mean	Median	CI	SEM	Mean	Median	CI	SEM	Mean	Median	CI	SEM	
Physical functioning	74.5	87.5	68.7-80.4	2.9	74.2	75	67.4-79.0	2.9	83.0	90	77.7-88.4	2.7	0.06
Role-physical	48.5	25	39.1-57.9	4.7	43.9	25	32.5-55.2	5.7	60.8	62.5	51.2-70.3	4.8	0.05
Role-emotional	51.6	33.3	42.5-60.7	4.6	39.9	33.33	29.5-50.3	5.2	53.5	66.66	42.6-64.3	5.4	0.03
Energy/fatigue	46.0	45	40.9-51.2	2.6	45.2	50	39.7-50.6	2.7	52.6	55	47.2-57.9	2.7	0.1
Emotional well-being	60.8	64	56.4-65.1	2.2	55.2	56	49.5-60.9	2.8	63.2	64	58.3-68.2	2.5	0.02
Social functioning	67.7	75	61.6-73.9	3.1	62.5	62.5	55.4-69.6	3.6	79.1	87.5	72.8-85.4	3.1	0.006
Bodily pain	68.4	68.75	62.2-74.6	3.1	60.1	67.5	52.2-67.9	3.9	74.6	77.5	68.1-81.1	3.3	0.04
General health	42.1	40	37.4-46.9	2.4	43.9	40	37.6-50.1	3.1	46.5	45	40.9-52.0	2.8	0.4

CI, 95% confidence interval; SEM, standard error of the mean.

* Variance between seizure types. Test of significance was Kruskal-Wallis one-way analysis of variance.

Table 6. Descriptive statistics and features of score distributions for the RAND-36 Health Survey by seizure frequency status in the last year.

Domain	≥1 seizure a month (n=53)				<1 seizure a month (n=81)				seizure free (n=69)				p-value*
	Mean	Median	CI	SEM	Mean	Median	CI	SEM	Mean	Median	CI	SEM	
Physical functioning	73.0	75	67.3-78.7	2.8	74.3	85	68.5-80.2	2.9	81.9	90	76.3-87.5	2.8	0.07
Role-physical	33.5	25	23.4-43.6	5.0	49.4	50	40.3-58.5	4.6	65.2	100	55.1-75.4	5.1	0.0001
Role-emotional	27.0	30	17.7-36.4	4.7	49.0	33.33	39.9-58.1	4.6	64.7	100	55.0-74.4	4.9	0.0001
Energy/fatigue	45.1	50	39.7-50.5	2.7	43.2	40	38.2-48.2	2.5	54.8	60	49.5-60.1	2.6	0.004
Emotional well-being	55.1	56	49.6-60.6	2.7	58.4	60	53.8-63.0	2.3	65.0	72	60.3-69.8	2.4	0.02
Social functioning	59.2	62.5	51.6-66.8	3.8	69.1	75	63.0-75.3	3.1	77.5	87.5	71.5-83.5	3.0	0.001
Bodily pain	56.2	57.5	48.1-64.3	4.0	68.1	77.5	61.8-74.4	3.1	76.1	80	69.9-82.2	3.1	0.0006
General health	39.3	40	33.6-44.9	2.8	41.0	40	36.0-45.9	2.5	50.9	50	45.4-56.3	2.7	0.005

CI, 95% confidence interval; SEM, standard error of the mean.

* Variance between seizure frequencies. Test of significance was Kruskal-Wallis one-way analysis of variance.
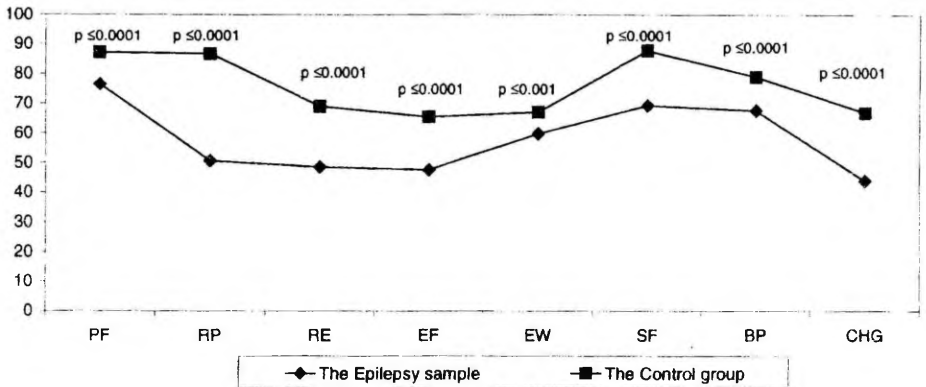
Fig.1. Discriminative power of the RAND-36.
Comparison of mean scores for the RAND-36 health status measure: people with epilepsy and the control group.
* Test of significance was Kruskal-Wallis one-way analysis of variance.

Impact of epilepsy on quality of life

The results of the final models fitted to each RAND-36 domain scores, inclu-ding the factors that remain significant after controlling for the others, are shown in Table 7. Each multifactor model is a main effect model (no significant interactions were found between the factors). Pairs of groups of factors significantly different were compared using Tukey HSD or Bonferroni's procedures. Scores of the RAND-36 domains were first compared in terms of the clinical variables. Significant differences were found for seizure frequency in all domains, except the Physical functioning domain. Seizure free patients scored significantly higher than patients who had experienced seizures during the last year in the Role limitations — physical, Energy/fatigue, Bodily pain, and General health domains. The difference between those who had had sei-zures once or more in a month compared to those having seizures less often than once a month or not having seizures during the last year was significant in Role limitations – emotional, Emotional well-being, and Social functioning domains.

In the Role limitations — physical domain, after controlling for seizure frequency, age, stigmatisation, stigma severity, and age at onset of epilepsy, became significant. Younger people were less likely to score low in this do-main, significant differences were between the 20–29 and 30–39 age groups compared to people who belonged to the age group of 60 years and over. Mean scores of this domain were significantly lower for those who were stigmatised, and for those who expressed very strong feelings of stigma (gave three "yes"

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answers on the stigma scale) compared to those who expressed less (one "yes" answer). Later age at onset was associated with lower scores, differences were significant between those for whom epilepsy had been diagnosed at the age of 41–50 or more than 50 years compared to those for whom it had been diagnosed at an age under 20 years.

In the Role limitations — emotional domain, mean scores were significantly lower for those who were stigmatised, and for those who expressed very strong feelings of stigma (gave three "yes" answers on the stigma scale) compared to those who expressed themselves less strongly (one "yes" answer).

Table 7. Results of analysis of variance models.

Domains	Factors	Mean square ratio	p-value
Physical functioning	Stigmatization	4.78	0.03
	Age at onset	3.65	0.001
	Current age	4.39	0.001
Role limitations	Seizure frequency	9.27	0.0001
(physical problems)	Current age	3.54	0.02
	Stigmatization	8.93	0.003
	Stigma severity	4.16	0.02
	Age at onset	3.15	0.01
Role limitations	Seizure frequency	13.89	0.0001
(emotional problems)	Stigmatization	7.91	0.005
	Stigma severity	3.47	0.03
Energy/fatigue	Seizure frequency	24.20	0.0001
	Employment	3.26	0.02
	Duration of disease	3.27	0.02
	Age at onset	2.66	0.03
Emotional well-being	Seizure frequency	3.96	0.03
	Stigmatization	4.27	0.04
	Duration of disease	3.27	0.02
Social functioning	Seizure frequency	11.88	0.0001
	Stigmatization	6.98	0.01
	Stigma severity	8.83	0.0007
	Employment	23.85	0.0001
	Seizure type	5.88	0.003
	Age at onset	3.34	0.007
Bodily pain	Seizure frequency	7.76	0.0006
	Duration of disease	2.44	0.05
General health	Seizure frequency	5.36	0.005
	Age at onset	3.25	0.009
	Stigmatization	4.69	0.03
	Stigma severity	3.82	0.03

In the Energy/fatigue domain, employment status, duration of epilepsy, and age at onset of epilepsy were significant. In this domain, mean scores were significantly lower for those currently unemployed compared to those who were in full-time or underemployed work, for those who had suffered from epilepsy two to five, or six to ten years compared to those who had suffered longer and for those whom epilepsy had been diagnosed at the age of 41-50 or more than 50 years compared to those for whom it had been diagnosed at an age under 20 years.

In the Emotional well-being domain, significantly lower were the scores of those who were stigmatised compared to those who were not and of those who had suffered from epilepsy two to five years compared to those who had suffered more than twenty years.

In the Social functioning domain, stigmatisation, stigma severity, employment status, seizure type, and age at onset of seizures became significant. Significantly lower scores by those who were stigmatised, those who expressed very strong feelings of stigma (gave three "yes" answers) compared to those who felt it not so strongly (one "yes" answer), those who were currently unemployed compared to those who were in full-time employment or underemployed, those who experienced either tonic-clonic or multiple seizure types compared to those who had only other types of seizures, and those for whom epilepsy had been diagnosed at the age of 41–50 or more than 50 years compared to those for whom it had been diagnosed at an age under 20 years.

In the Bodily pain domain, lower scores were related to shorter time of duration of epilepsy (2–5 years) compared to longer periods (11–20 and more than 20 years).

In the General health domain, mean scores were significantly lower for those whose epilepsy had been diagnosed at the age of 41–50 or more than 50 years compared to those for whom it had been diagnosed at an age under 20 years. Those who were stigmatised also scored significantly lower compared to those who were not, and those who expressed very strong feelings of stigma (gave three "yes" answers) compared to those who did not (one "yes" answer).

In the Physical functioning domain, stigmatisation, age at onset, and current age were found to be significant. Mean scores of this domain were significantly lower for those who were stigmatised compared to those who were not and for those who were aged 60 years or more compared to those 20–29 years old. The overall pattern of variation in terms of age at onset was similar to that in the General health domain.

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Discussion

The RAND 36-Item Health Survey 1.0 is a generic self-completed multidimensional questionnaire measuring health-related quality of life in larger populations and different subgroups e.g. patients. It is developed as a measure of health status or health outcome for use in cross-sectional and longitudinal studies [27]. Although the questionnaire has been quite widely used, it has been suggested that different ethnic or cultural groups may interpret same items of the questionnaire differently [13, 17]. Also different disease groups can score too close to the bottom or top of the score range, thus limiting the usefulness of a scale for comparing disease-burden profiles [30].

The preliminary study reported here concerned the translation, pilot-testing and psychometric evaluation of the Estonian RAND 36-Item Health Survey 1.0 for evaluating the people with epilepsy. It was preliminary in that results presented were first of a series of applications of the questionnaire in Estonian studies. In general, the translation and pilot testing of the Estonian version demonstrated a satisfactory feasibility of the form and suggested that the response choices in the Estonian version were ordinal and comparable to the response choices in the U.S. version. We achieved a response rate of 78%. The results of the item descriptive statistics showed a high completeness of data (over 98.5% on the item level) and a good distribution across response choices on the scale levels. The application of the RAND-36 showed up very well regarding satisfactory psychometric results in terms of scale characteristics with reliability coefficients above 0.70. For the epilepsy group both floor and ceiling effects were low for mental health, vitality and general health. Floor effects in the epilepsy sample were negligible for six scales, ceiling effects for three – mental health, vitality and general health. The construct validity was supported by the findings that those with frequent seizures did poorly compared to those with infrequent seizures or currently seizure-free. A finding, which was expected and in accordance with other studies [3, 11, 23, 28, 32]. Although the differences between seizure types were not significant in all the RAND-36 domains, there was a clear tendency to higher significance of scoring lower when having generalised tonic-clonic seizures. Patients who experienced both generalised tonic-clonic and other types of seizures did poorly when compared to those who did not experience them. That was also expectable [3, 11, 23]. Discriminant validity was highly acceptable. People with epilepsy had significantly lower scores than the controls in all domains. The RAND-36 is currently being applied in further validation studies along with other instruments. In Estonia, it is, together with additional condition-specific measures, included in trials evaluating the health status of people with stroke, Parkinson's disease, migraine, and after head trauma. Results from our study are encouraging and the following research will show the sensitivity of the instrument to change among patients with other particular illnesses. We hope that our work of validating

questionnaire with clinical assessment will contribute to the growing capacity of Estonian as well as general research into the RAND-36 health profile.

Our study focused on adults living in the community. The clinical characteristics of the present study were similar to most other series of prevalence cases of epilepsy [15, 25, 26]. Most of the study respondents had generalised seizures with or without other seizure types, the average duration of the disease was 11 years and patients were predominantly on carbamazepine monotherapy. According to this study, the levels of stigma among people with epilepsy were also high (52%) in spite of the fact that 40% of the study's respondents had less than one seizure a month and 34% had been seizure-free in the last year.

Though the mental health of the study respondents was not much worse than that of the control group, their social functioning was significantly lower and limitations due to emotional problems more expressed. Previously, the results of the European study had brought attention to the fact that it was unclear why respondents with epilepsy scored relatively badly on the domain concerned with physical function [3]. Although current seizure activity remained the most important predictor, there was a concomitant importance of socio-demographic variables (current age and employment status) to the quality of life. Older people and people who were currently unemployed were more likely to score lower. The other substantial disease characteristics in explaining the variation in the scores of several domains after controlling for seizure status were age at onset of epilepsy, duration of disease, and seizure type. Age at onset became significant in the case of Physical functioning, Role limitations – physical, Energy/fatigue, Social functioning, and General health. In all those domains, later age at onset was associated with lower scores. Dominian et al. [14] have reported an association between depression and older age at onset, Jacoby et al. [23] considered older age at onset to be implicated in feelings of depression and stigma. Duration of disease was significant in case of Energy/fatigue, Emotional well-being and Bodily pain. Here, a shorter time of duration of epilepsy was related to lower scores. Seizure type became significant in relation to Social functioning — those who experienced either tonic-clonic or multiple seizure types scored significantly lower compared to those who had only other types of seizures.

To increase the clinical significance of these tests, it is essential to perform repetitive trials. This will be one of the subjects of further investigation. As the RAND-36 was not designed to measure limitations or restrictions specifically associated with epilepsy, a disease-specific instrument may be more sensitive in evaluating variations in patient perception [22, 37].

We consider the strong sides of our study to be that epilepsy diagnosis was based on a clinical assessment and that a profound translation and psychometrical testing phase preceded the inclusion of the RAND-36 questionnaire in the research. Although we are aware of the limitations to the generalisability of the study in interpreting the results due to it being a relatively small and somewhat biased sample size.

The RAND-36 is a reliable and valid descriptive health status measure for epilepsy population that enables to get valuable additional information concerning the quality of the everyday-life of the people with epilepsy. The questionnaire has been criticised for its ceiling and floor effect [22, 41]. In our study, we found high ceiling effects associated with most of the domains. Jenkinson et al. have mentioned that the instrument has its limitations - for instance contains no variable on sleep [24]. However, we would conclude that it gives a good survey of the general health status of the people and enables an adequate health assessment comparison between the groups of patients with disease of varying severity.

Acknowledgements

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VI

M. Herodes, A. Õun, S. Haldre, A.-E. Kaasik.
The Estonian version of the Quality-of-Life
in Epilepsy Inventory (QOLIE-31):
a psychometric assessment and quality-of-life measurement.
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The Estonian version of the Quality-of-Life in Epilepsy Inventory (QOLIE-31): a psychometric assessment and quality-of-life measurement

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Abstract

Background: The Quality-of-Life in Epilepsy Inventory (QOLIE-31) was developed in effort to assess health-related quality of life (QOL) in patients with epilepsy.

Objectives: To test the acceptability, validity, and reliability of the Estonian version of the QOLIE-31 and to describe, by it, how QOL is affected by patients' and epilepsy characteristics.

Research Design: Postal survey by using a booklet containing the QOLIE-31 and several other items concerned with lifestyles and illness.

Subjects: 203 patients with epilepsy aged 20–70.

Measures: The 7 domains within the QOLIE-31 questionnaire.

Results: The form was translated with accompanying translation quality ratings and pilot tested. All sub-scales passed tests for item-internal consistency and item-discriminant validity. Correlations between items and hypothesised scales exceeded 0.40 in all instances, except one. The QOLIE-31's ability to distinguish between high and low symptom load was determined assessing by seizure type and frequency.

Conclusions: QOL was the poorest for patients with frequent seizures and for those with multiple seizures types. Although current seizure activity

remained the most important predictor, there was a concomitant importance of socio-demographic variables (education, marital status and employment) and characteristics connected with the disease (seizure type, type of AED therapy, AED side effects, age at onset, and duration of epilepsy). Also, stigmatisation and stigma severity turned out to be very important. The results of the QOLIE-31 were compared with the same data obtained in other countries. The values of the domains were generally lower than in developed countries and similar to those given in another Easten European country.

Introduction

Epilepsy is a diagnosis that enfolds a group of disorders in which seizures recur. Because different seizures manifest themselves differently, they also vary in the degree to which they present a risk to physical safety, their predictability, their responsiveness to treatment and their potential to interfere peoples' everyday-life [1]. At the same time, epilepsy is one of the most common neurological conditions, with an age-adjusted incidence of between 20 and 70 per 100,000 and an estimated prevalence of 0.4 to 1% [1–5]. According to the present available data, originating from Tartu, the estimated prevalence ratio of active epilepsy is 5.3 per 1,000. This means, in Estonia, with a population of approximately 1.4 million people, epilepsy roughly affects 7950 adults with approximately 530 new cases yearly [6, 7].

As there is often a poor correlation between the patient's and the physician's assessments [8], many researchers agree on the importance of a comprehensive view within epilepsy-care [9-11] and quality-of-life measures are assuming greater importance in medical practice [12]. A diverse consortium of epilepsy and health services researchers (The QOLIE Development Group) initiated development of a broader, but epilepsy-specific instrument by expanding on the RAND 36-Item Health Survey [13] and ESI-55 [14] concept of a self-report measure of health-related quality of life (HRQOL). The QOLIE-31 has been validated extensively to assure that the identified domains relate to different issues. It is a 31-item questionnaire that addresses 7 domains of HRQOL in subscales that can be compiled into a summary score reflecting experiences in the previous month [15-17]. To be effective, an instrument must be practical for the specific setting, measure what it purports to measure (valid), and be consistent from one administration to the next (reliable) [12]. But, measures need also to be psychometrically tested in a specific cultural context to assure their psychometric soundness [18-20].

The purpose of the present paper was to test the acceptability, validity, and reliability of the Estonian version of the QOLIE-31 questionnaire and to describe the QOL of the Estonian people with epilepsy by using it.

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Methods

Clinical information, if needed, was abstracted from medical notes and during the personal re-examination of subjects. Abstracted information used in the study related to the etiology of epilepsy, classification of seizure type and current antiepileptic drug (AED) therapy. To evaluate the impact of epilepsy on employment status and perceived stigma, the patients were sent a questionnaire by mail. The questionnaire employed a combination of open questions together with a previously translated and validated stigma scale (The Stigma of Epilepsy Scale) (Cronbach's alpha = 0.71) [21]. The questionnaire covered the following issues: (1) Demographic characteristics — information was obtained about subjects' sex, age, marital and employment status, and educational level. (2) Seizure frequency — patients were asked whether they had had seizures once or more in a month, less often than once a month, or not at all in the past year. (3) History of the epilepsy — patients were asked about age at first attack. (4) AED treatment and side effects — patients were asked about the AED they were taking and about the experienced side effects during the past month. (5) Perceived stigma was measured with a three-item scale developed originally for stroke [22], adapted for epilepsy and already used in other QOL studies [23, 24]. Respondents with epilepsy had to state whether they (a) felt that other people were uncomfortable with them, (b) treated them as inferior, or (c) preferred to avoid them. Each of the three items required a yes/no response. An individual's score was the sum of the "yes" responses. (6) Epilepsy-specific data about QOL that was collected using the QOLIE-31 questionnaire — respondents were asked to complete an epilepsy-specific measure, the QOLIE-31 [25], which contained 7 multi-item scales: Seizure worry (SW) — 5 items, Overall quality of life (OQL) — 2 items, Emotional well-being (EWB) — items, Energy/fatigue (E/F) — 4 items, Cognitive functioning (COG) — 6 items, Medication effects (ME) — 3 items, Social functioning (SF) — 5 items. A QOLIE-31 overall score was obtained using a weighted average of the multi-item scale scores. The QOLIE-31 also included a single item that assessed overall health. During the scoring procedure, first, the raw precoded numeric values of items were converted to 0–100 point scores, with higher converted scores always reflecting better QOL. Next, the subtotal scores for each scale were summed and divided by the number of items that the respondent answered within each scale. The QOLIE-31 overall score was calculated by summing the product of each scale score times its weight and summing over all scales.

Patients were divided into 3 groups by seizure type (as having only tonic-clonic, only other types, or both tonic-clonic and other types) and frequency.

For the use of the QOLIE-31 questionnaire, written permission was asked and received from the RAND Office of Contract and Grant Services in Santa Monica, California, USA, in October 1997.

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Translation

As recommended [26], the translation procedure included translation into Estonian, assessment of item comprehension, back-translation into English, and development of a consensual version. The items and responses of the original American QOLIE-31 questionnaire were first translated into Estonian by 2 independent native Estonian speakers with excellent knowledge of English. The translators then met to discuss until agreement was reached on item wording according to content correspondence. Subsequently the common version was evaluated by an other native Estonian speaker in terms of conceptual equivalence, linguistic performance and clarity. The agreed upon Estonian form was then backtranslated into English and rated. If modifications were necessary, the reformulation in Estonian version was performed. The final version was tested in a pilot study.

Piloting

The translated Estonian versions of the QOLIE-31 questionnaire was given for self-assessment to 15 epilepsy patients who visited their neurologist at the University's Outpatients' Clinic. During individual interviews, each item and response choice was carefully discussed as to its meaning and connotation with the responders. As a result the wording of 4 questions of the QOLIE-31 was altered slightly. Then the questionnaires were mailed by post to 15 epilepsy patients. The goal of this administration was to detect problems with the forms in terms of missing data, inconsistent answers and ease of administration. No respondent found the questionnaires either difficult or too personal.

A question, concerning problems with driving for patients on AED treatment, was excluded during the scoring procedure from the QOLIE-31 questionnaire for those who did not have a driving-license because it did not directly assess the Social function domain in these people. The reason was, as in our society, it is quite common for older people, especially for women, not to have a driving licence or use a car. From 30 patients in the pilot-study, 22 had never had a driving licence. From 15 questionnaires mailed to patients, 9 of those who had reported not having a driving-license had left the question unfilled, 4 reported having had no trouble with it and 2 marked they had had some trouble.

Subjects

Our results are based on data gained from a sample of 203 patients, in the 20–70 age group. The research took place in 1997–98. The QOL data was collected from respondents with epilepsy living in 2 towns of Estonia — Tartu and Viljandi. Tartu, with a population of 100 977 [27] is the country's second

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largest city. Southern Estonia revolves around Tartu which is the intellectual and educational centre of Estonia. Viljandi County, with a population of 62 782 [27], is located in south-central Estonia. The administrative centre of the county is the town of Viljandi, which is situated 81 kilometres from Tartu. In Tartu, the study followed an epidemiological survey of epilepsy. The patients for the present study were selected at random from the preliminary lists of the epidemiological study. The epidemiological survey included persons who were residents of Tartu and were aged 20 and over, and had before or within the course of 01.01.1991-01.01.1996 had at least 2 unprovoked epileptic seizures, at least 1 of them within the previous 5 years. Data collection for the epidemiological study consisted of data registration from a multi-source medical register review and data registration from a personal case re-examination. Case records of patients treated in the University Hospital, Outpatients' Clinics, physicians offices, emergency rooms, the electroencephalograpic laboratory with a diagnosis of epilepsy, convulsions, syncope, amnestic attacks, abnormal involuntary movements were reviewed and invitations for re-examination were sent to the suitable persons. During the last 2 years, all the patients were re-examined at least once by a neurologist to specify the type of their seizures. In Viljandi, primary information about people with epilepsy was gathered through the local epilepsy support group, and clinical information was abstracted from medical notes held in the County Hospital and Outpatients' Clinic register. To evaluate the accuracy of diagnoses, the problematic cases were investigated by one of the authors and re-examined if necessary. The present study excluded the Russian-speaking people because there were not any sufficiently well translated questionnaires available for them. All patients gave their consent to participate in the research and the project was approved by the Ethics Committee of the University of Tartu.

Response to the study

Questionnaires were sent to identified individuals by post, with a covering letter from the study conducters, explaining the purpose of the study. To those who did not respond to the initial questionnaire a reminder was sent about 3 to 6 weeks later. Questionnaires to be completed individually were mailed to 290 patients, of whom 225 replied — a response rate of 78%. From all the questionnaires returned, 22 appeared to be unusable, the rest were included in the study.

Statistical analysis

The data were analysed using statistical analysis package SPSS Professional Statistics[TM] 7.5 [28]. Test of significance was one-way analysis of variance

(ANOVA). Attention is drawn to results which differences were significant at the 5% level or less (p≤0.05). The questionnaire was evaluated using the data completeness at an individual item and scale level, correlations between items and hypothesised scales, correlations between items and other scales, average inter-item correlation, internal-consistency reliability (Cronbach's alpha [29]) and score distributions (floor and ceiling effects, skewness and kurtosis). 95% confidence intervals (CI) were computed to define the range of variation around the mean.

Construct validity was assessed in connection with seizure frequency and seizure type following hypotheses that patients with frequent seizures and patients with tonic-clonic or multiple seizure types would have poorer health status. To test for such comparisons between groups, Tukey's studentized range test was used for each variable.

Results

Characteristics of respondents

The main characteristics of respondents are given in **Table 1**. The median age of the study epilepsy sample was 41 (25th and 75th percentiles 29 and 57) years. Median age of the onset of epilepsy was 26.9 years, and the median duration of epilepsy was 11.3 years (25th and 75th percentiles 5.8 and 22.4). Patients were divided into five groups by duration of the disease and into six groups by age at onset of their epilepsy. Eighty-eight point seven percentage were receiving AED treatment. From those, 83.9% were receiving monotherapy. From those on monotherapy, the majority (74.8%) were receiving carbamazepine. The most commonly experienced side effects were non-specific: memory problems (31%), tiredness (25%), sleepiness (20%), headache (20%) and nervousness (20%). From those experiencing any of the symptoms associated with the AED treatment, the majority (73.9%) reported having three or more. A third of subjects (33%) reported no side effects. Fifty-two point four percentage felt stigmatised by their epilepsy. From those, 24.7% answered "yes" to all three items, 27.8% to two and 47.5% to one item showing the severity of the stigmatisation.

Table 1. Characteristics of respondents.

Parameter	Study respondents	%
Age (median)	41 years	
Sex (M/F)	99/104	48.8/51.2
Marital status		
married/cohabiting	83	40.9
single	84	41.4
divorced	21	10.3
widowed	15	7.4
Employment status		
full-time	67	33.0
underemployed	65	31.9
unemployed	22	11.0
retired or receiving disablement pension	49	24.1
Education		
less than primary (lower than 8th level)	22	10.8
primary (8th or 9th level)	68	33.5
high school (11th or 12th level)	93	45.8
university	20	9.9
Duration of epilepsy (median)	11.3 years	
until 1 year	11	5.4
2-5 years	45	22.2
6-10 years	46	22.7
11-20 years	44	21.7
over 20 years	57	28.1
Age at onset		
under 10 years	20	9.9
11-20 years old	68	33.5
21-30 years old	38	18.7
31-40 years old	36	17.7
41-50 years old	15	7.4
over 50 years old	26	12.8
Seizure type		
tonic-clonic only	84	41.4
tonic-clonic and others	61	30.0
others only	58	28.6
Seizure frequency status in the last year		
seizure free	69	34.0
<1 seizure a month	81	39.9
≥1 seizure a month	53	26.1
Medication		
free from medication	23	11.3
on AED treatment	180	88.7

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Data completeness
Missing value rates for the items of the QOLIE-31 were low and did not exceed 2% for any item. The total number of omitted items per questionnaire was 6.5%. Ninety-four percentage completed all 31 items.

Psychometric analyses
As **Table 2** shows, means and standard deviations of the scales were in the range of 48–64 (SD 18–26). The mean and median scores were higher for Medication effects and lower for Energy/fatigue. Skewness that measures the asymmetry of response distributions was most marked for Seizure worry. There were substantial ceiling effects for 2 domains — Energy/fatigue and Social functioning. Floor effects were significant in 2 domains: 3.45% and 1.97% of subjects had the minimum possible score in the Seizure worry and Medication effects' domains, respectively. Reliability was assessed through internal consistency. The internal consistency coefficients, being above 0.70 for all dimensions, met the level acceptable for group comparisons. The internal consistency coefficients ranged from 0.71 to 0.88. Scaling assumptions were tested in two ways. Correlations between items and hypothesized scales, which assess the extent to which an item is related to the remainder of its scale, were substantial within each scale and reached the level of >0.40 in all instances, except within one — the Medication effects domain (0.38–0.50), supporting the reliability of the QOLIE-31 scales. The lowest median item-total correlation was 0.42 for Medication effects, the highest 0.62 for Overall quality of life. Discriminant validity was considered acceptable when these correlations exeeded all correlations between items and other scales. All the 7 scales passed this level. The data about the psychometric characteristics is given in **Tables 2 and 3**.

Table 2. QOLIE-31 subscale psychometric results.

QOLIE-31 subscales	Mean (0–100)	Median	SD	Range	Skewness	Kurtosis	Floor (%)	Ceiling (%)
Seizure worry	54.67	60	26.26	95	–0.43	–0.97	3.45	0.49
Overall quality of life	49.18	50	17.59	95	0.31	0.12	0.49	0.49
Emotional well-being	60.14	60	19.95	100	–0.30	–0.75	0.49	0.49
Energy/ fatigue	48.40	50	20.17	85	–0.11	–0.70	0.49	4.43
Cognitive functioning	59.41	61.95	23.75	92.50	–0.32	–0.85	0.49	0.99
Medication effects	63.64	63.90	27.70	188.90	0.11	1.05	1.97	0.49
Social functioning	63.54	65	25.08	95	–0.29	–0.83	0.49	11.33

Table 3. Results of scaling success tests and reliability estimates.

Dimension	Internal consistency[a]	Homo-geneity[b]	Item discri-minant validity[c]	Cron-bach`s α	Reliability coefficients
Seizure worry	0.59-0.81	0.56	0.21-0.57	0.86	0.86
Overall quality of life	0.62	0.62	0.28-0.67	0.77	0.77
Emotional well-being	0.59-0.75	0.55	0.23-0.73	0.85	0.86
Energy/fatigue	0.53-0.67	0.50	0.19-0.69	0.79	0.80
Cognitive functioning	0.62-0.75	0.55	0.28-0.59	0.88	0.88
Medication effects	0.38-0.50	0.43	0.20-0.48	0.72	0.71
Social functioning	0.51-0.65	0.47	0.30-0.64	0.77	0.78

[a]Correlations, corrected for overlap, between items and hypothesised scales.
[b]Average inter-item correlation
[c]Correlations between items and other scales

Validity

Validity of both scales was assessed using discriminant techniques. The QOLIE-31's ability to distinguish between high and a low symptom load was determined assessing by seizure type and frequency.

The descriptive statistics and features of score distribution for the QOLIE-31 scales are detailed in **Tables 4 and 5**. Variance between seizure types was statistically significant in 4 QOLIE-31 domains. The comparisons between groups were investigated for each domain using Tukey's studentized range test at the 0.05 level.

Patients who did not have generalised tonic-clonic seizures or multiple seizure types had significantly higher scores in the Overall quality of life and Social functioning domains. Those who had multiple seizure types had lower scores than those with only tonic-clonic seizure types or those with other types of seizures only in the Seizure worry and Medication effects. Those who experienced multiple seizure types scored significantly lower in the Seizure worry, Medication effects and Social functioning domains compared to those who did not have generalised tonic-clonic seizures. (**Fig. 1**) The overall score of the QOLIE-31 was significantly different between all the 3 groups of seizure types.

Variance between seizure frequency statuses was statistically significant in all 7 domains. The differences were significant between all the 3 groups in the Seizure worry, Medication effects and Social functioning domain. Between those who had not had seizures in the past year and those who had had seizures at least once a month or less often than once a month, there were significant differences in the Overall quality of life, Emotional well-being, Energy/fatigue, Cognitive function domains and between the values of the overall score of the questionnaire. (**Fig. 2**)

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Table 4. Descriptive statistics and features of score distributions for the QOLIE-31 by seizure type.

Domain	Tonic-clonic only (n=84)				Tonic-clonic and others (n=61)				Others only (n=58)				p-value*
	Mean	Median	CI	SEM	Mean	Median	CI	SEM	Mean	Median	CI	SEM	
Seizure worry	56.27	60.8	50.8-61.7	2.8	47.83	48.3	40.9-54.8	3.5	59.52	65.7	52.8-66.3	3.4	0.04
Overall quality of life	47.89	50.0	44.2-51.6	1.8	46.27	45.0	41.4-51.2	2.5	54.09	50.0	49.9-58.3	2.1	0.03
Emotional well-being	60.91	62.0	56.7-65.1	2.1	56.85	52.0	51.2-62.5	2.8	62.48	68.0	57.6-67.3	2.4	0.27
Energy/fatigue	46.19	45.0	41.5-50.8	2.3	47.54	45.0	42.4-52.7	2.6	52.50	55.0	47.7-57.3	2.4	0.17
Cognitive functions	60.54	66.1	54.9-66.1	2.8	55.43	56.1	49.5-61.3	2.9	61.96	62.6	56.4-67.5	2.8	0.28
Medication effects	65.04	66.7	59.3-70.8	2.9	58.43	61.1	52.8-66.2	3.4	67.10	62.5	57.6-71.4	3.5	0.05
Social functioning	63.51	65.6	57.9-69.1	2.8	57.68	57.5	51.0-64.4	3.4	69.75	68.8	64.2-75.3	2.8	0.03
Overall	57.50	58.0	53.4-61.6	2.1	53.40	51.3	48.4-58.4	2.5	61.40	59.6	57.1-65.7	2.1	0.05

CI, 95% confidence interval; SEM, standard error of the mean.
* Variance between seizure types. Test of significance was Kruskal-Wallis one-way analysis of variance.

Table 5. Descriptive statistics and features of score distributions for the QOLIE-31 by seizure frequency status in the last year.

Domain	≥1 seizure a month (n=53)				<1 seizure a month (n=81)				seizure free (n=69)				p-value*
	Mean	Median	CI	SEM	Mean	Median	CI	SEM	Mean	Median	CI	SEM	
Seizure worry	44.76	48.0	37.2-52.3	3.7	53.95	62.7	48.5-59.4	2.8	63.12	70.0	57.2-69.0	3.0	0.0005
Overall quality of life	46.79	50.0	43.4-50.1	1.7	45.15	45.0	41.2-49.1	2.0	55.73	55.0	51.2-60.3	2.3	0.0005
Emotional well-being	57.28	56.0	51.9-62.7	2.7	57.09	60.0	52.6-61.6	2.3	65.91	72.0	61.4-70.4	2.3	0.01
Energy/fatigue	46.51	45.0	41.2-51.8	2.7	44.51	45.0	40.1-48.9	2.2	54.42	55.0	49.6-59.3	2.4	0.008
Cognitive functions	53.10	57.0	47.5-58.7	2.8	56.85	61.1	51.7-62.0	2.6	67.27	73.6	61.3-73.3	3.0	0.002
Medication effects	54.98	55.6	47.4-62.5	3.8	59.57	58.3	54.0-65.2	2.8	75.08	77.8	69.6-82.5	3.2	0.0001
Social functioning	53.36	56.3	47.1-59.6	3.1	61.24	62.5	56.1-66.4	2.6	74.07	82.5	68.1-80.1	3.0	0.0001
Overall	51.50	50.9	47.0-56.0	2.3	54.50	54.4	50.7-58.4	1.9	65.20	69.3	60.7-69.8	2.3	0.0001

CI, 95% confidence interval; SEM, standard error of the mean.
* Variance between seizure frequencies. Test of significance was Kruskal-Wallis one-way analysis of variance.
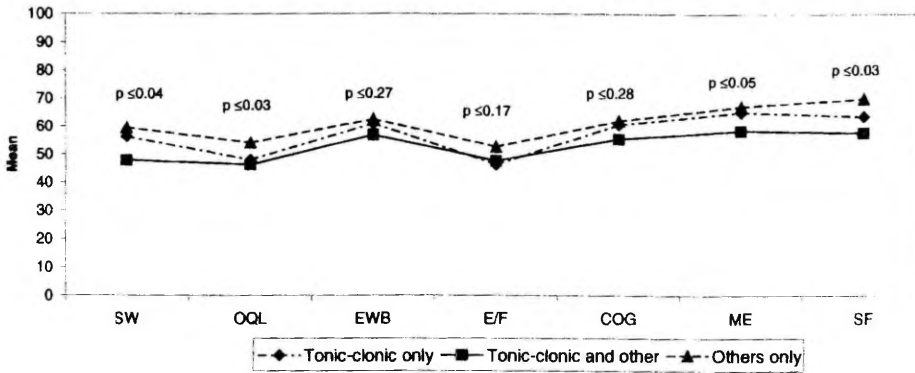
Fig. 1. Comparison of mean scores for the QOLIE-31 by seizure type.
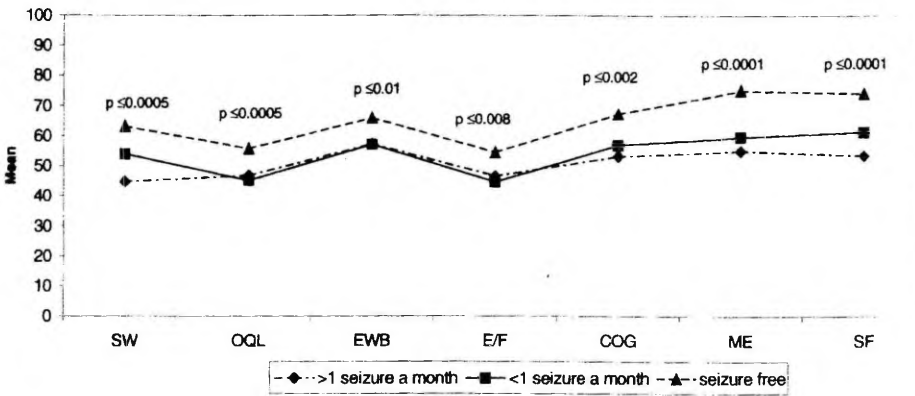* Test of significance was Kruskal-Wallis one-way analysis of variance.

Fig. 2. Comparison of mean scores for the QOLIE-31 by seizure frequency.
* Test of significance was Kruskal-Wallis one-way analysis of variance.

Impact of epilepsy on QOL

Scores of the QOLIE-31 domains were first compared in terms of the clinical variables. Significant differences were found for seizure frequency in all domains. The results of the final models after controlling for seizure status are shown in **Table 6**. Each multifactor model is a main effect model (no significant interactions were found between the factors). Pairs of groups of factors significantly different were compared using Tukey HSD or Bonferroni's procedures.

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In the Seizure worry domain, seizure type, education, type of AED therapy, stigmatisation and stigma severity remained significant. Significantly lower scores were obtained by those who experienced either tonic-clonic or multiple seizure types compared to those who had only other types of seizures, those who had high school or university education compared to those who had primary or less than primary education, those who were on polytherapy compared to those on monotherapy, those who were stigmatised, and those who expressed very strong feelings of stigma (gave three "yes" answers) compared to those who did not (one "yes" answer).

In the Overall quality of life domain, seizure type, stigmatisation, age at onset, marital status, employment, type of AED therapy and AED side effects remained significant. Significantly lower scores were obtained by those who experienced either tonic-clonic or multiple seizure types compared to those who had only other types of seizures, those who expressed very strong feelings of stigma (gave three "yes" answers) compared to those who did not (one "yes" answer), those for whom epilepsy had been diagnosed at the age of 41-50 or above 50 compared to those for whom it had been diagnosed at an age under 20, those who were married or cohabiting compared to those who were single, those who were currently unemployed compared to those who were in full-time employment or underemployed, those who were on polytherapy compared to those on monotherapy, and those who stated having experienced side effects of the AEDs.

In the Emotional well-being domain, duration of epilepsy, employment, and AED side effects remained significant. Significantly lower scores were obtained by those who had suffered from epilepsy for 2 to 5 years compared to those who had suffered more than 20 years, those who were currently unemployed compared to those who were in full-time employment or underemployed, and those who stated having experienced side effects of the AEDs.

In the Energy/fatigue domain, age at onset, employment, and AED side effects remained significant. In this domain, scores were significantly lower for those whose epilepsy had been diagnosed at the age of 41–50 or over 50 compared to those for whom it had been diagnosed at an age under 20 years, for those who were currently unemployed compared to those who were in full-time employment or underemployed, and for those who stated having experienced side effects of the AEDs.

In the Cognitive functions domain, age at onset, education, type of AED therapy, AED side effects, and stigmatisation remained significant. Significantly lower scores were obtained by those for whom epilepsy had been diagnosed at the age of 41–50 or over 50 compared to those for whom it had been diagnosed at an age under 20 years, those who had had primary or less than primary education compared to those who had high school or university education, those who were on polytherapy compared to those on monotherapy, those who stated having experienced side effects of the AEDs and those who were stigmatised.

In the Medication effects domain, AED side effects, stigmatisation, and stigma severity remained significant. Significantly lower scores were obtained by those who stated having experienced side effects of the AEDs, those who were stigmatised, and those who expressed very strong feelings of stigma (gave three "yes" answers) compared to those who did not (one "yes" answer).

In the Social functioning domain, marital status, employment, AED side effects, stigmatisation, and stigma severity remained significant. Significantly lower scores were obtained by those who were single, divorced or widowed compared to those who were married, for those who were currently unemployed or retired compared to those who were in full-time employment or underemployed, those who stated having experienced side effects of the AEDs, those who were stigmatised, and those who expressed very strong feelings of stigma (gave three "yes" answers) compared to those who did not (one "yes" answer).

In the Overall score, stigmatisation, stigma severity, age at onset, AED side effects, and type of AED therapy remained significant. Significantly lower scores were obtained by those who were stigmatised, those who expressed very strong feelings of stigma (gave three "yes" answers) compared to those who did not (one "yes" answer), those for whom epilepsy had been diagnosed at the age of 41–50 or over 50 compared to those for whom it had been diagnosed at an age under 20 years, those who stated having experienced side effects of the AEDs, and those who were on polytherapy compared to those on monotherapy.

Table 6. Results of the QOLIE-31 using analysis of variance models.

Domains	Factors	Mean square ratio	p-value
Seizure worry	Seizure frequency	25.46	0.0001
	Seizure type	4.26	0.03
	Education	2.45	0.04
	Type of AED therapy	3.89	0.005
	Stigmatisation	5.73	0.001
	Stigma severity	5.68	0.02
Overall quality of life	Seizure frequency	15.47	0.0001
	Seizure type	12.86	0.004
	Stigmatisation	8.35	0.007
	Age at onset	7.32	0.008
	Marital status	4.12	0.01
	Employment	3.68	0.03
	Type of AED therapy	3.53	0.03
	AED side effects	2.75	0.04
Emotional well-being	Seizure frequency	6.36	0.001
	Duration of epilepsy	4.25	0.003
	Employment	3.78	0.04
	AED side effects	2.74	0.05
Energy/fatigue	Seizure frequency	7.36	0.0007
	Age at onset	4.71	0.004
	Employment	4.24	0.02
	AED side effects	2.52	0.05
Cognitive function	Seizure frequency	9.36	0.0003
	Age at onset	4.71	0.006
	Education	4.42	0.009
	Type of AED therapy	3.59	0.01
	AED side effects	2.82	0.04
	Stigmatisation	2.63	0.04
Medication effects	Seizure frequency	6.47	0.003
	AED side effects	3.92	0.007
	Stigmatisation	3.54	0.03
	Stigma severity	2.94	0.05
Social functioning	Seizure frequency	15.63	0.0001
	Marital status	4.27	0.006
	Employment	5.76	0.005
	AED side effects	3.38	0.03
	Stigmatisation	3.41	0.03
	Stigma severity	3.35	0.05
Overall	Seizure frequency	11.24	0.0001
	Stigmatisation	4.67	0.03
	Stigma severity	4.83	0.01
	Age at onset	3.74	0.01
	AED side effects	3.95	0.05
	Type of AED therapy	3.48	0.05

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Conclusions

The Estonian version of the QOLIE-31 showed psychometric properties comparable to those of the American version. The construct validity of the questionnaire was supported by the findings based on the values of the overall score that those with frequent seizures did poorly compared with those who experienced infrequent seizures or were currently seizure free and that those who had multiple seizure types had the lowest value, followed by those who experienced generalised tonic-clonic seizures and those with other types only. These expected findings were in accordance with other studies [23, 24, 30–32].

The most important predictor in assessing the QOL was seizure frequency. The other substantial disease characteristics after controlling for seizure status were seizure type, type of AED therapy, AED side effects, age at onset, and duration of epilepsy. Seizure type became significant in the case of Seizure worry and Overall quality of life. In both cases, people having generalised tonic-clonic seizures, either only or together with some other type of seizure, scored lower. Type of AED therapy became significant in relation to Seizure worry, Overall quality of life, Cognitive functions and the overall score. In all these cases, people receiving polytherapy had lower scores compared to these on monotherapy. People who stated experiencing AED side effects got lower values of the domains in Overall quality of life, Emotional well-being, Energy/fatigue, Cognitive function, Medication effects and in the overall score compared to those who reported no side-effects. Age at onset became significant in the case of Overall quality of life, Energy/fatigue, Cognitive function and in the case of overall score. In all those cases differences were significant between 2 groups of patients: lower scores were obtained by those for whom epilepsy had been diagnosed at the age of 41-50 or over 50 compared to those for whom it had been diagnosed at an age under 20 years. Duration of epilepsy remained significant only in the case of Emotional well-being where significantly lower scores were obtained by those who had suffered from epilepsy 2 to 5 years compared to those who had suffered more than 20 years. The other substantial socio-demographic variables included education, stigmatisation, stigma severity, marital status and employment. As the QOLIE-31 questionnaire is a relatively new measure, there is not much data about its use in the QOL studies. The averages for the Estonian patients of all domains were compared to the available data from USA [15], Spain [33] and Hungary [34]. (**Table 7**) The SDs did not show a significant difference between the groups. The overall scores of the scale were highest for the USA and Spain, followed by Estonia and Hungary. The values of the domains of the Estonian QOLIE-31 were significantly lower compared to 3 other countries in the Overall quality of life domain. In the Energy/fatigue domain, the average differed significantly only from the data from the USA and Spain. To surprise, in the Medication effects domain the average value of the Estonian epilepsy group was significantly higher compared to the same data from the USA and

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Hungary. That can be explained, at least partly, by the fact that the people with epilepsy from Tartu were during the epidemiological study consulted by a neurologist in terms of their treatment problems. The authors of the Hungarian study [34] have explained their higher value in this domain compared to the USA by the different mental health expectations, the difference in the expected efficacy of treatment, the confidence in doctors and by the different circumstances and opportunities open to people from developed countries and from Eastern European countries. As well could it be the result of a general lack of knowledge and indifference, as due to the complicated political status, an individual's health and well-being was not valued for a long period. The averages of the domains of the Estonian QOLIE-31 were most similar to those of the Hungarian epilepsy group. Also, there was no statistically significant difference in the value of the overall score. The averages were generally lower (the negative judgement) compared to the American and Spanish data but they changed in parallel with it.

Table 7. Comparison of the mean scores of the QOLIE-31 domains of the respondents from USA, Spain, Hungary and Estonia.

Domains	Averages (SD) of the QOLIE-31 domains			
	USA (n=304)	Spain (n=252)	Hungary (n=170)	Estonia (n=203)
Seizure worry	58.29 (25.76)	51.47 (29.73)	53.95 (28.53)	54.67 (26.26)
Overall quality of life	67.17 (18.38)*	63.80 (16.95)*	55.45 (19.32)*	49.18 (17.59)
Emotional well-being	67.20 (19.28)*	61.78 (19.13)	58.28 (18.48)	60.14 (19.95)
Energy/fatigue	55.30 (21.10)*	60.89 (20.27)*	49.68 (17.68)	48.40 (20.17)
Cognitive function	59.96 (22.76)	60.32 (23.80)	59.26 (20.23)	59.41 (23.75)
Medication effects	55.34 (30.52)*	60.30 (29.10)	57.39 (31.13)*	63.64 (27.70)
Social functioning	67.25 (26.88)	66.44 (27.96)	56.88 (23.60)*	63.54 (25.08)
Overall score	62.87 (16.31)*	61.77 (17.33)*	56.45 (16.50)	57.38 (18.50)

* The means different from the corresponding results of the Estonian epilepsy group at 0.05 significance level (t-test).

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Education

1978–1989	Tartu M. Härma Secondary School No. 2 *(cum laude)*
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2001–	residency in neurology, Department of Neurology and Neurosurgery, University of Tartu

Special courses

2001	2nd EFNS European Cooperation Neurology Workshop in Třešť, Czech Republic.

Topics of scientific research

Research fields:	quality of life research of people with epilepsy, investigation of autonomic nervous system in different neurological diseases (Parkinson's disease, polyneuropathies, stroke)
Total:	14 scientific publications, 6 presentations in international scientific conferences
Membership:	Estonian Junior Doctors' Association, Estonian League against Epilepsy

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1978–1989	M. Härma nim. Tartu 2. Keskkool *(cum laude)*
1989–1995	Tartu Ülikooli arstiteaduskond, ravi eriala
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2001–	residentuur neuroloogias

Erialane täiendus

2001	EFNS 2. Euroopa neuroloogide seminar, Třešť, Tšehhi Vabariik.

Teadustegevus

Peamiseks uurimisvaldkonnaks on epilepsiahaigete elukvaliteet. Osalemine käimasolevates uuringuprojektides: autonoomne närvisüsteem neuroloogiliste haiguste (insult, Parkinsoni tõbi, polüneuropaatiad) korral, epilepsiahaigete sotsiaalse rehabilitatsiooni programmi kontseptsiooni väljatöötamine. Ilmunud 14 publikatsiooni, 6 ettekannet rahvusvahelistel konverentsidel.
Eesti Nooremarstide Ühenduse liige, Eesti Epilepsiavastase Liiga liige.

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