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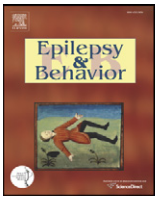

Quality of life in a cohort of men with epilepsy compared to a healthy population and those with common chronic diseases in the UK using a generic patient-reported outcome measure

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ABSTRACT

Patient-reported outcome measures (PROMs) are increasingly used in epilepsy. Epilepsy-specific instruments enable clinicians to gain insight into patients' health-related quality of life (HRQoL) but do not allow comparison between conditions and do not reflect subjective well-being (SWB). Using the World Health Organization Quality-of-Life Questionnaire — Brief (WHOQOL-Bref), a short generic PROM, we compared the HRQoL in a cohort of men with epilepsy (MWE) recruited from the epilepsy clinic and via the website of a large UK epilepsy charity, with seven other groups with chronic diseases. Multiple linear regression showed that mood was the most important independent predictor of the WHOQOL-Bref score. The sample, however, rated their global quality of life as highly as the UK control group, and 38% reported life 'very' or 'extremely' meaningful, and 4% enjoyed life 'very much' or 'extremely'. Because of its structure, the WHOQOL-Bref gives clinicians an indication not only of HRQoL but also of SWB, a broader construct. Our study suggests that the narrow focus of epilepsy-specific HRQoL questionnaires may give only a partial picture of a patient's quality of life. In addition, by concentrating on the negative aspects of life with epilepsy, these instruments may distract both the patient and the clinician from what is good about life, denying the patient the benefits of 'positive psychology' and the clinician the opportunity to build the patient's resilience.

1. Introduction

The term quality of life (QOL) is ubiquitous in everyday social and medical discourse. Where social scientists debate the relationship between the constructs of subjective well-being (SWB) and quality of life [1,2], clinicians and health economists have taken a pragmatic view, developing validated questionnaires to quantify the impact of illness and interventions in a systematic manner. Health-related quality-of-life (HRQoL) measures are incorporated into drug trials, and quality-adjusted life years (QALY) are required in submissions to the National Institutes for Health and Care Excellence (NICE).

In the past 20 years, HRQoL studies in epilepsy have burgeoned. A systematic review of 107 HRQoL in epilepsy studies showed that 66 of the 107 examined used epilepsy-specific patient-reported outcome measures and 32 generic instruments [3]. Validated questionnaires like the QOLIE-89, QOLIE-31, QOLIE-10, and Liverpool battery have the virtue of being epilepsy-specific, but they do not allow comparison with other groups with chronic diseases, neither do they enable comparison of QOL in people with epilepsy (PWE) with the background population or with PWE in different countries. Most epilepsy-specific HRQoL questionnaires were developed in English-speaking industrialized nations [4], raising the issue of how much may be lost in translation when these questionnaires are modified for use in non-Anglophone regions. Another potential criticism of epilepsy-specific questionnaires is that they may not give a holistic picture of QOL as defined by the World Health Organization (WHO) as an "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" [5].

In the mid-1990s, the WHO commissioned the development of an instrument to assess QOL which would have cross-cultural validity and be developed simultaneously in a large variety of languages and cultures (WHOQOL Group, 1998). This led to the development of the WHOQOL-Bref, a 26-item instrument with four clear dimensions [5], which has the advantage in most cases of not needing translation, unlike the SF-36. There are now bands of normative data from field trials and studies in Australia [6], France [7], Brazil [8], Denmark [9], and the UK [10].

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2. Aims of study

The aims of the study were as follows: first, to compare the WHOQOL-Bref scores of our cohort of men with epilepsy (MWE) with the data from healthy UK subjects and the data collected worldwide; second, to compare our cohort's scores with the WHOQOL-Bref results from 7 common chronic conditions in the UK; and third, to test our hypothesis that as the WHOQOL-Bref incorporates nondisease questions but inquires about the overall quality of life and enjoyment of life, the major determinant of WHOQOL-Bref score would be mood.

3. Methods

The study was approved by the Lothian Research Ethics Committee. A total of 149 consecutive men with epilepsy (MWE), aged between 20 and 60 years, were approached in the epilepsy clinic. After giving informed consent, they were asked to complete a number of self-administered questionnaires at home. These were the World Health Organization Quality-of-Life Questionnaire — Brief (WHOQOL-Bref-UK) and the Hospital Anxiety and Depression Scale (HADS). A demographic questionnaire containing questions about past medical history, coexisting medical complaints and medications for conditions other than epilepsy, and marital and employment status was completed in the clinic by the participants, with epilepsy syndrome and current drug therapy completed by LG or SD. The men were provided with stamped envelopes addressed to SD to whom they were asked to return the completed questionnaires.

In addition, the questionnaires were transformed using SNAP survey software and put onto the website Epilepsy Action (British Epilepsy Society). The website on its front page invites people who wish to take part in research to navigate to a dedicated page where research projects looking for recruits can be found.

3.1. Questionnaires

The WHOQOL-Bref is a 26-item brief version of the WHOQOL 100 (World Health Organization Quality of Life). The methodology behind the development of the questionnaires and their field trials is described elsewhere [5]. The instrument consists of 4 domains, and each question is answered on a Likert scale of 1 to 5. Two questions are analyzed separately — “How would you rate your quality of life?” and “How satisfied are you with your health?” There is a bank of data for the UK from 4628 people, 1328 of whom were in good health at the time of completing the questionnaire [10]. Worldwide, there are data available from 11,000 people sampled across 23 countries [5].

The mean age of the UK sample we used for comparison was 45.5 years (STD = 14.4), and the mean age of our sample was 37.5 years (95% CI: 35.4–39.6). Because of this disparity and because the UK sample was not analyzed by gender, we examined two other banks of normative data available, from Australia and Denmark. Scrutiny of these data showed that in the 30 to 50 age bracket, scores were stable for both sexes with age making little difference. In addition, comparison using unpaired t-tests showed that there were no significant differences between the sexes in scores. Thus, we felt confident in using the combined data available for the UK.

The Hospital Anxiety and Depression Scale (HADS) is a 14-item questionnaire, seven about the symptoms of anxiety and seven about those of depression [11]. There are UK normative values available for both sexes [12]. There is a consensus that “caseness” for the HADS is a score of 8 or above in either of the subscales [13].

The raw scores from the WHOQOL-Bref were converted according to the scoring manual into both the 1–100 scale, bringing it into line with the WHOQOL 100, and the 1–20 scale developed for the WHOQOL-Bref.

Table 1
Demographic characteristics of MWE from the epilepsy clinic, Epilepsy Action website, and non-responders.

	Men recruited in outpatients	Men recruited via EA website	Nonresponders	P
Mean age in years (STD)	40.1 (11.9)	38.5 (10.6)	35.7 (11.4)	N/S
Mean duration of epilepsy (years)	18.2 (11.9)	20.3 (12.6)	16.8 (12.5)	N/S
Marital status	Married/living as married: 45 Single: 32 Divorced: 4 (11 did not answer)	Married/living as married: 63 Single: 44 Divorced: 5	Married/living as married: 24 Single: 33 Divorced: 1	N/S
Number of drugs	No AED: 2 1 AED: 35 2 AEDs: 32 3 AEDs: 16 4 AEDs: 5 (2 did not reply)	No AED: 2 1 AED: 47 2 AEDs: 33 3 AEDs: 25 4 AEDs: 4 5 AEDs: 1	No AED: 1 1 AED: 28 2 AEDs: 21 3 AEDs: 6 4 AEDs: 2	N/S
Number taking enzyme-inducing antiepileptic drugs (EIAEDs)	Not on EIAED: 47 1 EIAED: 38 2 EIAEDs: 4 3 EIAEDs: 1 (2 did not reply)	Not on EIAED: 62 1 EIAED: 35 2 EIAEDs: 8 3 EIAEDs: 2 (5 did not reply)	Not on EIAED: 35 1 EIAED: 20 2 EIAEDs: 3	N/S
Smoking status	Smoker: 22 Nonsmoker: 66 (4 did not answer)	Smoker: 20 Nonsmoker: 92	Smoker: 12 Nonsmoker: 40 (6 did not answer)	N/S
Diabetes	With diabetes: 3 Without diabetes: 87 (2 unrecorded in notes)	With diabetes: 3 Without diabetes: 109	With diabetes: 1 Without diabetes: 52 (5 unknown)	N/S
Hypertension	Yes: 11 No: 80 (1 not recorded)	Yes: 8 No: 104	Yes: 4 No: 50 (4 not recorded)	N/S
Epilepsy syndrome	85% focal	75% focal	79% focal	N/S
Focal/generalized in percentages	15% generalized	25% generalized (13 could not be assigned a syndrome)	21% generalized	
Employment	52% employed	52% employed	47% employed	N/S
Seizure status	26% at least one seizure in the previous 12 months 31.5% one seizure a month 18% one seizure a week 8% one seizure a day 10% seizure-free	26% at least one seizure in the previous 12 months 25% one seizure a months 19% one seizure a week 8% one seizure a day 22% seizure-free		N/S