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Levels of epilepsy stigma in an incident population and associated factors

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ABSTRACT

We assess the psychometric properties of a revised stigma scale and report the levels of stigma in an incident population and the clinical, demographic, and quality-of-life factors associated with doing so. A total of 1566 people with new-onset epilepsy completed the revised stigma scale, as part of the Standard and New Antiepileptic Drugs (SANAD) trial. The revised scale had good internal consistency (0.85) and good concurrent validity. It also reduced the floor and ceiling effects associated with the original scale. Fifty-four percent of people reported feeling stigmatized (47.3% mild–moderate stigma, 6.1% high stigma). Reduced sense of mastery, younger age (<50), side effects of medication, poorer cognitive function, feeling socially restricted, poor global quality of life, and more than four seizures at baseline were significant factors determining scores on this revised scale. These should be the focus of interventions to try and reduce feelings of stigma in those with new-onset epilepsy.

1. Introduction

Epilepsy is felt to be a stigmatizing condition. This can have huge implications for an individual's quality of life (QOL). Although not all people with epilepsy experience stigma, feelings of stigma have been associated with learned helplessness, depression and anxiety, impaired physical health status, increased somatic symptoms and other health problems, reduced self-esteem, and reduced life satisfaction [1].

In many previous studies [2–7], perceived stigma has been measured using a three-item scale developed originally to assess patient perceptions of stigma in stroke [8], but reworded and adapted for epilepsy [9]. Individuals are asked to respond on a yes/no scale whether, because of their epilepsy, they feel that other people are (1) uncomfortable with them, (2) treat them as inferior, and (3) prefer to avoid them. Patients score one for each item they agree with and an individual's score is the sum of the positive responses. Therefore, scores range from 0 to 3, where a score of 0 indicates that the person does not feel stigmatized and a score from 1 to 3 indicates the person does feel stigmatized; the higher the score, the greater the person's perception of stigma. The stigma scale has been shown to be a reliable and valid measure (α coefficients = 0.82 [2] and 0.77 [10]).

In a recent revalidation study, however, the stigma scale was found to have noteworthy ceiling effects that likely reflect that the response continuum is dichotomous [10]. The authors suggested that the scale should be revised to include a graded response continuum, which may enhance its ability to detect more subtle differences in levels of felt stigma. The scale was revised to include a 4-point Likert-type scale (0 = not at all, 1 = yes, maybe, 2 = yes, probably, 3 = yes, definitely). Scores on this revised stigma scale range from 0 to 9, with a score of 0 indicating that the person does not feel stigmatized, scores of 1–6 indicating that the person feels mildly to moderately stigmatized, and scores of 7–9 indicating that the person feels highly stigmatized. This revised version was used, as part of the QOL assessment, in the Standard and New Antiepileptic Drugs (SANAD) trial [11,12]. SANAD was a pragmatic, randomized, unmasked, parallel-group clinical trial comparing the clinical and cost effectiveness of standard and new antiepileptic drugs (AEDs).

In this article, we first assess the psychometric properties (internal consistency, concurrent validity, floor and ceiling effects) of this revised stigma scale. Second, we report the levels of stigma in an incident population and the clinical, demographic, and QOL factors associated with doing so.

2. Methods

As discussed above, data were collected as part of the SANAD trial [11,12]. A full description of the study methods can be found in Marson et al. [11,12]. Briefly, SANAD recruited 2437 patients, aged 5 years and older with a history of two or more clinically definite unprovoked epileptic seizures in the previous year, from hospital-based outpatient clinics in the United Kingdom. Patients were randomized to either standard AEDs (carbamazepine or valproate) or newer AEDs (gabapentin, lamotrigine, oxcarbazepine, topiramate). Primary outcomes were time to treatment failure and time to 12 months of remission.

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Quality of life was also investigated, as part of the secondary outcomes, in those aged ≥5 years without any significant learning disability, as judged by the randomizing clinician from the history and examination. All eligible adults (aged ≥16 years) were asked to self-complete QOL questionnaires as early as possible following randomization and then at 3 months and yearly from the date of randomization up to a maximum of 4 years post-randomization. Questionnaires were sent by post, with a single, mailed reminder being sent to nonresponders 3 weeks after the initial mailing and telephone contact after a 3-week period to those failing to respond. All questionnaires were accompanied by a cover letter explaining the purpose of the QOL study and a reply-paid envelope. SANAD received appropriate multicenter and local ethics and research committee approvals. All patients gave informed written consent to inclusion and to long-term follow-up.

2.1. Quality-of-life outcomes

In addition to the revised stigma scale, QOL assessment for SANAD involved the use of a battery of previously validated generic and epilepsy-specific measures taken from the Newly Diagnosed Epilepsy Quality of Life (NEWQOL) battery, which examines physical, psychological, social, and cognitive functioning [10] (Table 1). All the measures have been extensively used and validated in previous studies by the Liverpool Epilepsy Research Group [10,13]. In addition, the battery included a revised 12-item version of the Impact of Epilepsy scale [14] and a single-item measure of global QOL [15]. For the purposes of this analysis, this global measure was transformed into a binary response (good QOL vs poor QOL). There were also single items relating to education, employment, driving, and marital status.

2.2. Statistical analysis

All analysis was conducted using SPSS Version 17.0. The internal consistency of the revised scale was estimated using Cronbach's α coefficient. Floor and ceiling effects were also studied. To evaluate the scale's concurrent validity, correlations between other QOL measures were measured using Spearman's correlation. To evaluate the factors associated with stigma in those with new-onset epilepsy, differences in clinical, demographic, and QOL factors between those who reported no stigma, mild–moderate stigma, or high stigma were assessed using analysis of variance, the Kruskal–Wallis test, and the χ^2 test. Any variables that were associated with significant differences between the three groups ($P<0.05$) were selected for entry into a multivariate regression, using the total revised stigma score as the outcome variable. A forward stepwise selection procedure was used to determine the final model (criteria for entry, $P<0.05$, and for removal, $P>0.01$).

3. Results

3.1. Response rate

Of the 1911 adults who were eligible to take part in the QOL study, 1611 completed questionnaires at baseline (response rate = 84.3%). Reasons for nonresponse included contacted but did not respond ($n=177$), not contacted ($n=62$), refused ($n=29$), withdrew from study ($n=20$), died or too ill ($n=11$), and not English speaking ($n=1$). For the purposes of this analysis, we are interested only in those who responded to all three items on the revised stigma scale. Thus the present analysis is based on 1566 respondents, which represents 81.9% of adults originally eligible and 97.2% of baseline respondents. The relative lack of missing items over the three items (item 1 $n=28$, item 2 $n=39$, item 3 $n=42$) suggests that respondents do not find it a burden to complete the scale. There were no differences in clinical and demographic factors between those who completed all items ($n=1566$) and those who did not respond to all items ($n=45$). However, there were significant differences on two of the QOL measures, with those who did not respond to all three stigma scale items reporting a reduced sense of mastery ($P=0.001$) and poorer general health perception ($P=0.002$).

3.2. Clinical and demographic characteristics

At entry into SANAD, the majority of respondents were men (55.2%), with a mean age of 40 years (SD = 16.48, range: 16–86). More than two-thirds (71.5%) had partial epilepsy, 13.2% generalized epilepsy, and 15.2% unclassified epilepsy. Only 4.5% reported experiencing one seizure at baseline. The majority (68.8%) had experienced more than four seizures before completing the baseline questionnaire. A total of 6.3% had a prior neurological deficit, and 17.8% had a previous or current neurological disorder recorded in their clinical notes. Approximately one-quarter (24.1%) had achieved postschool qualifications [e.g., higher school-leaving certificate (A level, degree level)], 38.9% had achieved school-level qualifications [including General Certificate of Education (CSE) and Ordinary (O level) qualifications], and 37% had not achieved any formal qualifications on leaving school (Table 2).

Table 1
Content of the NEWQOL battery.

Physical	Psychological	Cognitive	Social
General health perception [10] Single item Score: 0–4[a]	Seizure worry (2 items regarding past or future seizures, (transformed score of 0–60) [10][a]	Aldenkamp–Baker Neuropsychological Assessment Schedule [22] 24-item scale Score: 0–72	Social activities [10] 9-item scale Score: 0–27[a]
Health transition [10] Single item Score: 0–4[b]	Hospital Anxiety and Depression Scale [23] 14-item scale 7 items = anxiety 7 items = depression score: 0–21 for each domain		Social limitations [10] Single item Score: of 0–3[a]
Liverpool Adverse Events Profile [10] 19-item scale Score: 19–76	Sense of mastery [24] 7-item scale Score: 7–28 Felt stigma [10] 3-item scale Score: 0–9		Work limitations [10] 5-item scale Score: 0–20

[a] For purposes of this analysis, items were transformed to a binary response (general health perception = excellent, very good, good vs fair, poor; seizure worry = yes vs no; social activities = yes vs no; social limitations = restricted vs not restricted).
[b] For purposes of this analysis, items transformed to a better vs same vs worse response.