The Chalfont Seizure Severity Scale

John S Duncan, J W A S Sander

Abstract
Seizure severity has been largely neglected in studies of patients with epilepsy and the evaluations of treatment. A seizure severity scale, that measures the components of seizures that cause patients the most disturbance, is presented with an assessment of the scale's validity and reliability.

The evaluation of medical and surgical treatments of epilepsy has traditionally used seizure numbers as the principle index of efficacy. It has been recognised that it is not adequate to rely solely on numbers of seizures, either as a measure of the effect of treatment, or when the severity of a seizure disorder is being quantified. It is, for example, inappropriate to equate a brief simple partial seizure and a prolonged secondary generalised convulsion, as would occur if no account was taken of seizure severity. Further, antiepileptic drug (AED) treatment may result in seizures becoming briefer and less severe, resulting in a marked improvement for the patient, with no change in overall numbers of seizures, a benefit that would be missed if no account was taken of seizure severity.

A few attempts have been made to take seizure severity into account in AED evaluation studies. We have developed a seizure severity scale that may be readily utilised for these purposes, and in a routine clinical setting.

Method
First, open interviews of 50 patients with epilepsy, attending an epilepsy clinic, and their close relatives were held, and they were asked what features of their seizures caused disruption and disturbance, and whether these were mild, moderate or severe. This enquiry led to a list of 11 factors that were most commonly perceived to be important.

Second, these factors were combined into a scale, and each factor was assigned a weighted score, the initial weightings being guided by the results of the open interviews.

Third, the next step was to adjust the weightings of the individual factors and to assess the content and face validity of the scale. This was done by several methods:
1) A battery of eight different examples of seizures were drawn up and seizure severity scores obtained for each. The relative severity scores of the different seizure types were then compared with the opinion of a panel comprising the investigators and six other medical and nursing professionals with particular expertise in the management of epilepsy.
2) The scale was piloted on 24 patients with epilepsy, in an inpatient epilepsy assessment unit, and the relative seizure severity scores compared with the opinions of trained nursing and care staff who had witnessed all the seizures considered. This population encompassed a broad range of patients, ranging from those with no neurological or psychological deficit who were admitted for review of diagnosis or a simple change of medication, to individuals who had associated mental and physical handicap.
3) The scale was applied to inpatients and outpatients who had two or more different types of seizure, and they and their relatives were asked to compare the perceived relative severity of their seizures, with the severity scores obtained by the scale.

As a result of these processes, the factor weightings were adjusted and the above steps repeated. The final (seventh) version of the scale was then validated using the above steps, and tested in 37 patients (clinic attenders and inpatients in assessment unit) who each had more than one seizure type, including patients with simple partial, complex partial, generalised tonic-clonic, tonic, atomic, absence and myoclonic seizures. It was useful to allow fractionation of scores for factors such as dropping of a held object, falling to the ground, injury and incontinence, according to how commonly these features occurred in seizures.

Fourth, inter-rater and test-retest reliability of the final version of the scale were assessed. For inter-rater reliability assessments, patients and a reliable witness were interviewed by the two observers, independently, at the same clinic attendance. Retest reliability was assessed after an interval of two to three weeks and each patient was interviewed with the same witness as previously. Patients were excluded from the test-retest assessment if it was thought, subjectively, by the patient or witness that there had been a material change in seizure severity in the intervening period. Data from both observers were pooled for analysis of test-retest reliability. Statistical analysis of validity and reliability was by the method of Bland and Altman.

Results
The face and content validity of the scale was assessed by patients, their relatives and a panel of medical and nursing professionals who were experienced in the management of epilepsy. The hierarchy of scores obtained from different seizure types showed good agreement with their perceived relative severity, by patients, relatives and professional carers. When applied...
Table 1 Chalfont Seizure Severity Scale Inter-rater and Test-retest reliability

<table>
<thead>
<tr>
<th></th>
<th>Mean (SD)</th>
<th>Range of scores</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Inter-rater reliability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Observer 1</td>
<td>48.9 (34.9)</td>
<td>1-147</td>
</tr>
<tr>
<td>Observer 2</td>
<td>47.8 (34.3)</td>
<td>1-146</td>
</tr>
<tr>
<td>Difference between observers</td>
<td>1.1 (6.7)</td>
<td>1-146</td>
</tr>
<tr>
<td>Coefficient of reliability = 13.4</td>
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<td></td>
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<tr>
<td>n = 93</td>
<td></td>
<td></td>
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<tr>
<td><strong>Test-retest reliability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>First test</td>
<td>44.1 (30.3)</td>
<td>1-101</td>
</tr>
<tr>
<td>Second test</td>
<td>44.6 (30.6)</td>
<td>1-100</td>
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<tr>
<td>Difference between tests</td>
<td>-0.05 (7.9)</td>
<td>1-100</td>
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<tr>
<td>Coefficient of reliability = 15.9</td>
<td></td>
<td></td>
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<tr>
<td>n = 101</td>
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</table>

To the 37 patients with two types of seizure, the mean relative severity score of each patient's seizures, obtained by the scale was 8.9, compared with the mean patients' perceived relative severity of 8.5. The mean (SD) difference between the ratios was 0.6 (144.4). The scale, notes on its completion, and the scores obtained by the eight examples of typical seizures that were used in its development, are summarised in the Appendix (see page 876).

Inter-rater reliability data were available for 93 different seizure types, in 57 patients (table). There was no relationship between the mean of the two observers' scores and the difference between the scores. The mean (SD) difference between the two observers was 1.1 (6.7), the difference between the scores was normally distributed. The limits of agreement were -12.3 and +14.5, and the coefficient of reliability was 13.4. The 95% confidence limits for the mean difference were -0.3 to +2.5, for the lower limit of agreement -14.7 to -9.9, and for the upper limit of agreement +12.1 to +16.9.

Test-retest reliability data were available for 101 different seizure types, 51 by observer one and 50 by observer two, in a total of 34 patients (table). There was no relationship between the mean of the two scores and the difference between them. The mean (SD) difference between the two sessions was -0.05 (7.9), the difference scores were normally distributed. The limits of agreement were -15.8 and +15.9, and the coefficient of reliability 15.9. The 95% confidence limits for the mean difference was -1.6 to +1.5, for the lower limit of agreement -18.5 to -13.1, and for the upper limit of agreement +13.2 to +18.6.

Discussion

Previously, seizures have been classified as mild and severe, and generalised seizures have been arbitrarily assigned a severity twice that of partial seizures. More recently, seizure severity has been taken into account by assigning scores to generalised tonic-clonic, simple and complex partial seizures, with account taken of whether there was a warning, loss of awareness or precipitating factors. Others have also recently addressed the question of seizure severity. Seizure severity needs to be quantified for the purposes of evaluating the efficacy of medical and surgical treatments, and to form part of quality of life measures.

A scale such as this has to compromise between the conflicting aims of being comprehensive and being workable in clinical practice. The Chalfont Seizure Severity Scale is more appropriate than assigning arbitrary severity scores for different types of seizures, for example, two for a generalised convulsion and one for a partial seizure, for example, a prolonged complex partial seizure may be more disruptive than a brief generalised seizure.

The Chalfont Seizure Severity Scale was deliberately not bound by the current classification of seizure types, but was designed to measure, and to be responsive to, the components of seizures that concern patients and their carers.

The assessment of the validity of the scale had to be subjective, but we believe that it was the best achievable. It is open to the criticism that the factor weightings were unduly influenced by professional opinion, but the factors to be included in the scale were generated by open inter-view of a cohort of patients and their relatives and carers, and particular notice was taken of the views of patients who had two or more types of seizures, as to their relative severity. The resultant factor weightings represented a consensus view; there were occasional idiosyncratic opinions. For example, a patient with simple partial seizures comprising aphasia for 30 seconds (Scale score 1) felt that this was 25% as troublesome as a secondarily generalised convulsion in which he would fall to the ground, and take two hours to return to normal (Scale score 86), his rationale being that he was aware of the episode of aphasia, but unaware of the convulsion.

The inter-rater and test-retest reliability of the scale was reasonable for a profile of this type. There was no significant difference between the mean scores on either assessment. The coefficient of reliability was slightly higher in the test-retest situation than for the inter-rater reliability. This would be expected as seizures may have altered in the interval between the two assessments, even though we excluded those patients who had had an obvious change in seizure severity between the two assessments. In the absence of a gold standard it is difficult to judge the clinical importance of a coefficient of reliability of 13 points, we would judge that a change of 10 or more points would be of clinical importance in most patients.

The reliability of a scale such as this depends critically on the quality of information obtained. It is essential to have a clear and reliable witness, to have the same witness on subsequent assessments and to be consistent with questions, such as the definition of return to normal.

The scale scores were heavily influenced by the time to return to normal. This factor was, almost invariably, regarded as the most important by patients. We attempted fractionating this factor into 30 minute epochs, but found this to decrease the reliability of the data. The fractionation of scores for the factors: dropping of an held object, falling to the ground, injury,
incontinence and automatisms, according to the frequency of their occurrence in a patient’s seizures, was found to be a useful sophistication. Otherwise, patients would end up with an unworkable multitude of different seizure types.

We emphasise that the Chalfont Seizure Severity Scale is of seizure severity and is not a measure of the overall impact of epilepsy on a patient’s life. The latter is a separate, difficult issue and needs to encompass the unpredictability of seizure occurrence and the fact that an identical seizure may have a greatly different impact on two different patients; for example, a complex partial seizure lasting five minutes with speech automatisms would be likely to be more disruptive to the life of a lawyer than to a gardener.

The Chalfont Seizure Severity Scale has features of both a patient-based and an observer-based scale. The factors to be included were obtained by open interview of patients and carers and factor weightings were affected by the views of patients, carers and professionals. The scale is completed by an observer, but responses are patient-determined. The scale was developed at a specialised epilepsy clinic and inpatient assessment unit, but will be readily employed in non-specialised outpatient clinics, and may be completed in a few minutes by a doctor or nurse practitioner.

We believe that the Chalfont Seizure Severity Scale will be particularly useful in longitudinal studies, in which each patient acts as their own control, of the efficacy of medical and surgical treatments; and will also find a role in an epilepsy quality of life schedule, and in correlations with measures of psychiatric, psychological and social morbidity. In common with other data, however, the scale is less likely to be useful for cross-sectional studies. The next stage in the evaluation of the scale, that is in progress, is its inclusion in a prospective, double-blind, placebo-controlled, parallel group AED study, and determination of its reliability when used by non-specialised personnel. A possible further development, that would require careful assessment, may be an evaluation of the combination of the numbers and severity of seizures of different types in a patient, in a unit time, to yield an overall “Epilepsy Activity Index”.

We are grateful to Dr AL Johnson, MRC Biostatistics Unit, Cambridge for statistical advice and to our colleagues at the Chalfont Centre for Epilepsy and National Hospitals for Neurology and Neurosurgery for their assistance with developing this scale.

2 Gruber CM, Moizer JM, Grant P. Objective comparison of primidone and phenobarbital in epileptics. J Pharmacol Exp Ther 1957;120:184-7.
### Appendix

#### Classification of seizure type:

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#### Duration of seizure.

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<th>&gt; 10 min</th>
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<tbody>
<tr>
<td>no</td>
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<td>no</td>
<td>yes</td>
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</table>

#### Time to return to normal from onset.

<table>
<thead>
<tr>
<th>&lt; 1 min</th>
<th>1-10 min</th>
<th>10-30 min</th>
<th>&gt; 30 min</th>
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</thead>
<tbody>
<tr>
<td>no</td>
<td>yes</td>
<td>no</td>
<td>yes</td>
</tr>
</tbody>
</table>

#### Calculation of Chalfont Seizure Severity Scale

1. **Classification of seizure type**, according to International League against Epilepsy Classification.
   - Simple partial, for example, deja vu, < 10 seconds, no sequelae. Seizure Severity Score = 1.
   - Complex partial, aura warning, drops a held object, no fall or injury, no incontinence, mild automatisms (lip smack, chew), lasts 5 minutes, return to normal within a total of 10 minutes. Seizure Severity Score = 18.
   - Generalised tonic-clonic. No warning, drops a held object and falls, with injury 25-50% of the time, nearly always incontinent, severe automatisms (stamp, shout), lasts 13 minutes, and returns to normal in 40 minutes. Seizure Severity Score = 86.
   - Generalised tonic/atonic. No warning, drops a held object and falls with injury and incontinence, no automatisms. Convulsion lasts 4 minutes, returns to normal in two hours. Seizure Severity Score = 154.

2. **Examples of Chalfont Seizure Severity Scale Scores**

   - **Type 1**: Absence. No warning, no motor accompaniment or incontinence, duration < 10 seconds, immediate recovery. Seizure Severity Score = 2.
   - **Type 2**: Simple partial, for example, deja vu, < 10 seconds, no sequelae. Seizure Severity Score = 1.
   - **Type 3**: Complex partial, aura warning, drops a held object, no fall or injury, no incontinence, mild automatisms (lip smack, chew), lasts 5 minutes, return to normal within a total of 10 minutes. Seizure Severity Score = 18.

3. **Appendix Notes on completion of Chalfont Seizure Severity Scale**

   - 1) Classification of seizure type, according to International League against Epilepsy Classification.
   - 2) In each section, score what usually occurs in that seizure type with fractionation as follows:
     - No score if that factor does not occur;
     - Quarter score if occurs in up to 25% of occurrences;
     - Half score if occurs in 25%-50% of occurrences;
     - Full score if occurs in > 50% of occurrences;
   - 3) Drop/spill a held object includes spilling a held drink, even if the vessel is not dropped.
   - 4) Injury includes tongue-biting, bruising and lacerations.
   - 5) Incontinence includes urine and/or faeces.
   - 6) Automatism. Mild implies features that are not socially disabling, for example, chewing, repeated swallowing, fiddling with objects. Severe implies features that are socially disabling, such as, swearing, running, undressing, hitting out. This score may also be fractionated (see note 2, above).
   - 7) Seizure is taken to mean clonic jerking of limbs.
   - 8) Duration of seizure. Time from onset, until judged to have terminated, by patient and/or a reliable witness.
   - 9) Time to return to normal from onset is taken as the duration of time until the patient is able to resume the activity that they were pursuing when the seizure occurred.
   - 10) A score of 0 is added, if the total score otherwise = 0. For example a simple partial seizure consisting of an epigastric rising sensation that lasts less than 10 seconds.
   - 11) If a given seizure type occurs only in sleep, the total score, for that seizure type, is divided by 2.
   - 12) The total of the scores obtained for a given seizure type is its severity score.

#### TOTAL