

Epilepsy Common Data Elements: Seizure Severity

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Purpose

To evaluate instruments that measure perception of seizure severity and make recommendations related to best instruments for the NINDS common data element repository.

Methods

MEDLINE and CINAHL databases were searched to identify instruments that measure perception of seizure severity. Search terms included the following: perception of seizure severity, epilepsy, measurement, and instruments. Articles were reviewed to identify the most commonly used instruments that measured perceptions of seizure severity, were available in English, and had information on psychometric properties. Other selection criteria were clinical relevance, breadth and depth of psychometric properties, respondent burden, and cost of the scale.

Results

A review of the literature indicated that there was not a consistent instrument used to measure perceptions of seizure severity in children. Therefore, the committee did not make any recommendations for pediatrics. There were two commonly used instruments to measure perception of seizure severity in adults: The **Liverpool Seizure Severity Scale (LSSS)** and the **Seizure Severity Questionnaire (SSQ)**. The committee recommends that both be added as common data elements for the measurement of perception of seizure severity in adults with epilepsy. Each is briefly described below.

Liverpool Seizure Severity Scale (LSSS)

Background: The original **Liverpool Seizure Severity Scale** was developed with 16 items that measured two domains: perception of control over seizures and ictal/post-ictal effects (Baker et al., 1991). Although psychometric properties were relatively strong, subsequent experience with the scale indicated that further development was needed. In the first revised version of the original scale, items were increased to 20 and response choices were increased for selected items. Although the revised version had some good psychometric properties, there were issues with the domain measuring perception of seizure control. The internal consistency reliabilities were not consistently strong, and an expert panel found the perception of seizure control subscale to measure impact on life and not seizure severity. In addition, there were issues related to handling missing data and handling patients with more than one seizure type. When adjustments were made to accommodate patients with multiple seizure types, the result was a more

cumbersome scale that was less user friendly for patient self-report (Baker, Smith, Jacoby, Hayes, & Chadwick, 1998). Therefore, the developers substantially revised the questionnaire and created a revised scoring system. This latter revised scale, which was labeled the **Liverpool Seizure Severity Scale 2.0 (LSSS 2.0)** (Scott-Lennox, Bryant-Comstock, Lennox, & Baker, 2001), is the version that is recommended for inclusion in the common data elements repository.

Description: The LSSS 2.0 version has 12 items and one dimension that includes items related to ictal/post-ictal effects. Patients are asked to complete the questionnaire with the *most severe seizure* that they have experienced in the past 4 weeks in mind. Before completing the 12 items, patients are asked to list how many seizures they have experienced during the past 4 weeks. If they have not had any seizures in the past 4 weeks, they do not complete the rest of the questionnaire. If they have had at least one seizure, they complete the 12 items. Of these, the first item asks the patient to rate the severity of his/her seizures on a 0 to 3 scale of “*very severe to very mild.*” The remaining 11 items are statements about the nature of their seizures (3 items) or statements about the after effects of their seizures (8 items). Of these 11 items, patients are asked to respond to 8 items using a 0 to 3 response scale, to 2 items using a 0 to 4 response scale, and to 1 item using a 0 to 5 response scale.

Scoring: The total score ranges from 0 (no seizures) to 100 (most severe possible). There are two steps to scoring:

- Step 1: Patients who have not had a seizure in the past 4 weeks are given a “0.” If the number of seizures during the past 4 weeks is greater than 0, then proceed to Step 2.
- Step 2: Reverse code responses to 9 items so that a lower value reflects less seizure severity. If responses to 4 or more questions are missing, assign a missing score for the scale. If responses to 1 to 3 questions are missing, replace the missing responses with the mean of the non-missing items. Sum the responses to questions 1 to 12, divide by 40, and multiply by 100.

Psychometric Properties: A factor analysis showed a single factor or dimension and supported the validity of the scale. The scale was also found to have adequate internal consistency reliability with a Cronbach’s alpha of >0.7 (Scott-Lennox et al., 2001). A known-groups validity analysis provided clinical evidence for validity (Scott-Lennox et al., 2001). Another study demonstrated that seizure severity was significantly related to quality of life, with individuals with lower (worse) seizure severity scores having worse quality of life scores. In this study, the association between seizure frequency and LSSS 2.0 total score was not statistically significant (Bautista & Glen, 2009).

Weaknesses: The scale is not valid for people who were seizure free in the prior 4 weeks (Bautista & Glen, 2009). There are also concerns about the validity of the scale for people with episodic seizures, which is especially a concern when a treatment is being evaluated over time. For example, if a patient becomes seizure free after treatment, it could reflect response to treatment or a pattern of severe but infrequent seizures (Scott-Lennox et al., 2001). Another concern with only describing the most severe seizure is that frequent minor seizures might be overlooked.

Sources and Primary Reference: The entire scale is provided in Appendix A and the scoring instructions are provided in Appendix B in the following reference:

Scott-Lennox J, Bryant-Comstock L, Lennox R, Baker GA. Reliability, validity and responsiveness of a revised scoring system for the Liverpool Seizure Severity Scale. *Epilepsy Res.* 2001;44(1):53-63.

Permission: All copyrights for the scale are in the public domain. The LSSS 2.0 can be used as printed and replicated and used without modification by anyone without express permission of the developers (Scott-Lennox et al., 2001).

References

- Baker GA, Smith DF, Dewey M, Morrow J, Crawford PM, Chadwick DW. The development of a seizure severity scale as an outcome measure in epilepsy. *Epilepsy Res.* 1991;8(3):245-251.
- Baker GA, Smith DF, Jacoby A, Hayes JA, Chadwick DW. Liverpool Seizure Severity Scale revisited. *Seizure.* 1998;7(3):201-205.
- Bautista RE, Glen ET. Seizure severity is associated with quality of life independent of seizure frequency. *Epilepsy Behav.* 2009;16(2):325-329.
doi:10.1016/j.yebeh.2009.07.037
- Scott-Lennox J, Bryant-Comstock L, Lennox R, Baker GA. Reliability, validity and responsiveness of a revised scoring system for the Liverpool Seizure Severity Scale. *Epilepsy Res.* 2001;44(1):53-63.

Seizure Severity Questionnaire (SSQ)

Background: The seizure severity questionnaire (SSQ) was first described by Cramer, Baker, and Jacoby in 2002 as a new scale to assess seizure severity as a treatment response. Aspects of the VA seizure frequency and severity rating, the National Hospital seizure severity scale, and the Liverpool Seizure Severity Scale were reviewed and the development of the SSQ ensued with item generation, determination of validity and reliability. Minimally important changes thresholds for the SSQ were more recently reported (Cramer, et al, 2014).

Description: This is a copyrighted instrument designed to capture the patient's, and an observer's, reported outcome (PRO) of the seizure experience including severity. The baseline version consists of ten "main" questions with zero to three "branch questions" for each main. The scale asks for a description of the person's most common type of seizure from the past four weeks; and subsequently asks questions pertaining to the time before, during, and after the seizures as well as severity. Specifically addressed areas are: frequency and helpfulness of auras; severity and bothersomeness of ictal phenomenon; and questions about cognitive, emotional, and physical recovery. The most bothersome aspect is also questioned.

The follow-up version is meant to be given after a particular treatment initiation or change to determine differences in outcomes. There are 11 main questions in the

follow-up version with zero to four “branching questions” and similar time frames as the baseline version.

Scoring: Baseline scoring is done on a “1” through “7” scale with “1” being very mild or no bother and “7” indicating very severe or very bothersome. When assessing change in outcome, items are scored 1 through 7 in a range from very much improved to very much worse.

Permission: V2.2 (Baseline and Follow-Up Versions) Copyright JA Cramer 2010

References

- Cramer JA, Baker GA, Jacoby A. Development of a new seizure severity questionnaire: initial reliability and validity testing. *Epilepsy Res.* 2002;48(3):187-197.
- Cramer JA, de la Loge C, Brabant Y, Borghs S. Determining minimally important change thresholds for the Seizure Severity Questionnaire (SSQ). *Epilepsy Behav.* 2014;31:286-290.
- Sancho J, Ivanez V, Molins A, et al. Changes in seizure severity and quality of life in patients with refractory partial epilepsy. *Epilepsy Behav.* 2010;19(3):409-413.