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**Caregiver stress and benefit: Brief scales for caregivers of children with epilepsy**

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**Rationale:** Caregivers of a child with health care needs often experience both challenges and benefits related to this caregiving. It is important to identify caregivers who are overwhelmed by caregiving and may need additional support. It is also important to study the benefits in caregiving as they are associated with better coping and lower levels of depression. The University of Washington Caregiver Stress Scale (UWCSS) and Benefit Scale (UWCBS) were developed using patient-centered and modern psychometric methodology including item response theory (IRT). Short forms (SF) were developed to provide scores sufficiently reliable to be used in clinical trials.

**Methods:** The items for the SFs were selected by a panel of experts from a larger pool of IRT calibrated items. Scores are on the T-score metric ( $M=50$ ,  $SD=10$ ) and the mean of 50 represents stress and benefits reported by the community sample of caregivers. Higher score indicates more stress and more benefit, respectively. The pool of items was developed with feedback by pediatric neurologists and caregivers of children with epileptic encephalopathy in the US and EU. Items were administered to caregivers of children ( $N=722$ ) (age <18) with Epileptic Encephalopathies, Down syndrome, Muscular Dystrophy and a community sample through an online survey. Test-retest data were collected 40 to 80 hours after the initial administration ( $n=133$ ) and test-retest reliability was evaluated using the Intraclass correlation (ICC).

**Results:** The panel of experts selected 8 and 10 items for the SFs assessing caregiving benefit and stress, respectively, which both maximize reliability and ensure inclusion of topics most important to caregivers. Both SFs evidenced good reliability ( $>.80$ ) across a wide range of scores (i.e., 2SD below to 1.5SD above the mean for UWCSS and 3SD below to 1SD above the mean for UWCBS). Test-retest reliability was high for both SFs ( $ICC(2,1)>.95$ ). SFs can be scored by summing items and converting to T-scores using conversion tables, and recommendations for scoring with missing data are available.

**Conclusions:** The UWCSS and UWCBS SFs are brief and reliable measures of caregiver stress and benefits suitable for use in clinical trials, research and clinical practice. SFs can be administered by a computer or on paper. Scores based on the SFs are directly comparable to the scores based on the full item bank that can also be administered by Computerized Adaptive Testing.

**Biography**

Dagmar Amtmann is a psychologist and UW research associate professor with the Department of Rehabilitation Medicine. Dr. Amtmann's research interests include improving measures of patient reported outcomes such as pain, fatigue, and participation using modern measurement theories; statistical analytic approaches using multilevel and latent variable modeling; and instructional, information, and assistive technology for individuals with cognitive disabilities (with a particular focus on reading and writing technology for both children and adults).

**Notes:**