Caregiver Stress and Benefit: Brief scales for Caregivers of Children with Epilepsy

Mark P. Jensen1, Alyssa Bamer1, Kendra S. Liljenquist1, Arnold R. Gammaitoni2, Carey R. Aron2, Bradley S. Galer2, Dagmar Amtmann1
1Department of Rehabilitation Medicine, University of Washington, Seattle, WA  |  2Zogenix, Medical Affairs, 5858 Horton St., Suite 455, Emeryville, CA 94608

INTRODUCTION

• Caregivers of children with medical conditions experience both challenges and benefits related to caregiving.
• Sometimes caregivers become overwhelmed by demands of caregiving.
• It is important to screen for caregivers who need additional support; it is also important to examine the benefits of caregiving as they are associated with better coping, lower levels of depression and may be protective against stress.
• The University of Washington Caregiver Stress Scale (UWCSS) and Benefit Scale (UWCBS) were developed to improve clinical care and to facilitate research.

RESULTS

• The final SFs include 10 (UWCSS) and 8 (UWCBS) items.
• Both SFs have excellent reliability (ICC [2,1]>.95) and are suitable for use in clinical trials.
• Test-retest reliability was high for both SFs (ICC [2,1]> .95).
• SFs are scored by summing item level scores and converting to T-scores using conversion tables.
• UWCSS and UWCBS scores are on the T-score metric (M=50, SD=10); the mean of 50 represents the mean stress and benefits reported by a community sample of US caregivers.
• Higher scores indicate more stress and more benefit.
• Scoring with missing data is also available.

CONCLUSIONS

• The UW Caregiver Stress Scale Short Form (UWCSS SF) and UW Caregiver Benefit Scale Short Form (UWCBS SF) 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 administered by Computerized Adaptive Testing.
• User guides and SFs are available at: http://uwcorr.washington.edu/self-reported-instruments.

METHODS

• A set of items calibrated to Item Response Theory (IRT) was developed with feedback from pediatric neurologists and caregivers of children with epilepsy in the US & EU.
• A development sample included caregivers of children (N=722) (age <18) with Epileptic Encephalopathies, Down syndrome, Muscular Dystrophy and a community sample of caregivers.
• Retest data were collected <80 hours later and analyzed using the Intraclass correlation (ICC).
• The items for the SFs were selected from a larger pool of items by balancing item content, item difficulty, and score reliability.

UW Caregiver Stress Scale Short Form

- 10 items
- Reliable (ICC [2,1]>.95)
- Suitable for use in clinical trials
- Scoring: sum of item-level scores, converted to T-scores

UW Caregiver Benefit Scale Short Form

- 8 items
- Reliable (ICC [2,1]>.95)
- Suitable for use in clinical trials
- Scoring: sum of item-level scores, converted to T-scores

PURPOSE:

Develop short forms (SFs) for UWCSS and UWCBS for use in clinical trials and clinical practice

CONTACT

Mark Jensen – mjensen@uw.edu
Arnold Gammaitoni - agammaitoni@zogenix.com

FUNDING

Research reported in this abstract was supported by a grant awarded to the University of Washington by Zogenix, Inc., under contract #ZXIIIS2015-005