INTRODUCTION
• Taking care of children with epileptic encephalopathy (EE) is challenging, but can also bring perceived benefits, which are often overlooked in research and clinical practice
• Benefits of caregiving may be protective against caregiver stress
• To study caregiver benefits a psychometrically sound measure is essential

PARTICIPANTS
• Adult caregivers in the USA, fluent in English, and caring for a child under 18 years of age with EE, Down syndrome, Muscular Dystrophy or, in the community sample, any child younger than 18

METHODS
• An expert panel of pediatric neurologists and caregivers of children with EE provided feedback on topics and items that should be included in the instrument
• The candidate item bank was administered to caregivers in the USA via on-line survey
• Test-retest data were collected 40 to 80 hours from initial assessment and test-retest reliability was evaluated using the Intraclass correlation (ICC)
• Items were examined for unidimensionality, local dependence (LD) and differential item functioning (DIF)
• A 2-parameter graded response IRT model was used to develop the item bank

PURPOSE
To develop a brief, flexible, person-centered, clinically meaningful and psychometrically sound measure to assess benefits of caregiving for children with EE

RESULTS
• Caregivers of children with EE (n=128), Down syndrome (n=143), Muscular Dystrophy (n=129), and no special health care needs (n=322) responded to candidate items (n=15) either once (n=722) or twice (n=133), and also provided information about demographic and clinical characteristics of the children and themselves
• Average age of caregivers was 42 years (SD=9), 83% were female, 82% white, 73% were married, 17% had high school education or less, and 41% were employed full time
• Based on results of IRT analyses 2 items were removed due to problems with LD or model fit
• The remaining 13 items were sufficiently unidimensional (CFI = 0.95) with no indication of LD or DIF due to gender, education, or child diagnosis.
• Five response options functioned well for all items
• Test-retest reliability was excellent with an ICC between the first and second administration of 0.92 on the 13 item score
• Caregivers of children with EE reported significantly (p<0.01) lower benefit (M=46.6, SD=8.5) than the community sample (M=49.1, SD=9.4), but the benefit was similar to caregivers of children with Down syndrome (M=47.2, SD=9.0) and Muscular Dystrophy (M=46.1, SD=9.5).
• As expected, caregiver benefit scores are negatively correlated (-0.21) with scores on a companion caregiver stress scale.

CONCLUSIONS
• The 13 item UW Caregiver Benefit Scale (UW-CBS) is a psychometrically sound, person-centered measure, clinically appropriate for caregivers of children with epilepsy
• Results indicate caregivers of children with EE report lower benefits than caregivers from a community sample
• A short form will be available and the current scale can be administered by Computerized Adaptive Testing to minimize respondent burden
• The UW-CBS is publicly available to researchers and clinicians
• A companion measure of caregiving stress has also been developed
• The UW-CBS can be used by researchers to examine the role the perceived benefits of caregiving play in carers of children with health conditions, including epilepsy

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