Development of the Caregiver Stress Scale for Caregivers of Children with Epilepsy

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INTRODUCTION

Caregiving for children with epileptic encephalopathies (EE) presents many benefits and challenges. To better understand how the challenges of taking care of a child with EE changes caregivers' lives, it is important to assess the areas of life that are most important to caregivers.

PURPOSE

To develop a brief, flexible, and psychometrically sound tool that can be used to assess stress of caregivers of children with EE.

PARTICIPANTS

Adult caregivers fluent in English, and caring for a child under 18 years of age with EE, Down syndrome, Muscular Dystrophy or a child with no special healthcare needs.

METHODS

An expert panel of pediatric neurologists 1 and caregivers of children with EE provided feedback on topics and items that should be included in the instrument.

- Importantly, the item stress was used to describe the challenges faced due to caregiving as caregivers reported they did not like the term burden.
- The candidate item bank was administered to caregivers via online 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.

RESULTS

- Caregivers of children with EE (n=128), Down syndrome (n=143), Muscular Dystrophy (n=129), and no special healthcare needs (n=322) responded to candidate items (n=35) either once (n=722), or twice (n=153), 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, 62% were white, 73% were married, 17% had high school education or less, and 41% were employed full time.
- Based on results of IRT analyses 16 items were removed due to problems with unidimensionality, LD, or model fit.
- The remaining 19 items were sufficiently unidimensional (CFI = 0.95) with no indication of LD or bias 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 total score from the first and second administration of 0.97.
- Correlation with the modified Paediatric Renal Caregiver Burden Scale, r(722) = 0.7, p<0.01 supported validity.
- Caregivers of children with EE reported significantly (p<0.001) higher stress (M=58.7, SD=8.8) than caregivers of children with Down syndrome (M=50.7, SD=8.8), Muscular Dystrophy (M=50.2, SD=6.8) and no special healthcare needs (M=46.1, SD=9.4).

CONCLUSION

- The 19 item UW Caregiver Stress Scale (UW-CSS) item bank/long form is a psychometrically sound, person-centered measure appropriate for caregivers of children with severe epilepsy.
- The UW-CSS can be used to evaluate the effects of EE treatments on caregiver stress.
- Short Form (3, 5 and 8 items) and Computerized Adaptive Testing administration can be used to reduce respondent burden.
- The UW-CSS is publicly available to researchers and clinicians.
- A companion measure of the caregiving benefits is also being developed.

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1. Drs. Boettcher, Cross, Knopp, Liu, Miller, Nabbout, Perry, Joseph Sullivan, and Samoz Zuberi

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