

University of Washington Caregiver Benefit Scale for caregivers of children with epileptic encephalopathy

Dagmar Amtmann,¹ Kendra S. Liljenquist,¹ Alyssa Bamer,¹ Arnold R. Gammaioni,² Carey R. Aron,² Bradley S. Galer,² Marita F. Johnson¹ & Mark P. Jensen¹

¹Department of Rehabilitation Medicine, University of Washington, Seattle, WA | ²Zogenix, Medical Affairs, 5858 Horton St., Suite 455, Emeryville, CA 94608

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

U | W | C | O | R | R
The University of Washington Center on Outcomes Research Rehabilitation



University of Washington Caregiver Benefit Scale (UW-CBS) Item Bank

Instructions: Below is a list of things that caregivers of children have said about how caregiving changed their lives. Please choose the response that best describes how you **usually** feel about caregiving. By caregiving we mean taking care of your child or children under 18 years -- that is providing help and support (typically unpaid) for their physical, psychological, or developmental needs.

	Not at All	A little bit	Some-what	Quite a bit	Very much	
1. How much does caregiving help you appreciate what is important in life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2. How much does caregiving help you find new strengths in yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3. Are you a better advocate for your child/children because of caregiving?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4. How much do you feel caregiving has made you a better person?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5. How much do you feel that caregiving has helped you put life in perspective?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6. How much does caregiving help you become a more patient person?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7. How much do you feel that caregiving has made you a stronger person?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
8. Have you gained confidence in yourself because of caregiving?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9. How much does caregiving add meaning to your life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
10. How much does caregiving make you a more accepting person?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
11. How much does caregiving help you be more caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	Never	Rarely	Some-times	Often	Always	
12. How often does caregiving make you feel more connected with other people important to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	N/A (I don't have a partner)	Never	Rarely	Some-times	Often	Always
13. How often do you feel closer to your partner because of caregiving?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

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% were 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

CONTACT

Mark Jensen at mjensen@uw.edu
Dagmar Amtman at dagmara@uw.edu
Arnold Gammaioni at agammaioni@zogenix.com

FUNDING

Research reported in this poster was funded by Zogenix, Inc and in part by a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number H133P120002). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this poster do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.