

Caring for a Child with an Epileptic Encephalopathy: Caregiver Benefit

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INTRODUCTION

- Caring for a child with Epileptic Encephalopathy (EE) can be stressful and very challenging.
- Many caregivers also report that they experience rewards and benefits from caregiving.
- Caregiver benefit has not been well studied.

PURPOSE:

To examine caregiver benefit and associated factors in individuals caring for children or youth with EE.

METHODS

- Caregivers of children with an EE (N=143) responded to a self-reported online questionnaire.
- Pearson correlations, univariate linear regression analyses and Students T-tests examined relationships between perceived benefits and health, as well as benefit by income, education and gender.
- Benefit items most frequently endorsed were examined using summary statistics.

MEASURES

- UW Caregiver Benefit and Stress scales
- PROMIS-29 Profile (fatigue, anxiety, depression, sleep disturbance, physical function, social roles participation),
- PROMIS global health (physical, mental)
- UW Resilience scale

The mean of 50 for all scales represents the mean of a US community sample.



Table 1: Study sample characteristics

	N=143	Mean ± SD N (%)
Caregiver Age		40.5 ± 8.5
Caregiver Gender		
Male		11 (7.7%)
Female		132 (92.3%)
Caregiver Race/Ethnicity		
Non-Hispanic White		128 (89.5%)
Other		15 (10.5%)
Caregiver Marital Status		
Married/Live with Partner		124 (86.7%)
Single/Divorced/Widowed		19 (13.3%)
Caregiver Education		
High School		11 (7.7%)
Some College		38 (26.6%)
BA/BS		51 (35.7%)
Advanced Degree		43 (30.1%)
Caregiver Employment Status		
Full time		51 (36.2%)
Part time		30 (21.3%)
Unemployed/Retired		57 (40.4%)
Student		3 (2.1%)
Number of Children Caring For		2.0 ± 1.0
Household Income (n=134)		\$99,000 ± 89000

Table 2: Mean sample scores and univariate associations between UW Benefit scores and other health domains

	Mean Sample Score	Correlation with Benefit Score	Regression Coefficient	Regression p-value
Global Mental	39.1	0.24	0.34	0.01
Global Physical	45.5	0.16	0.20	0.06
Physical Function	49.9	0.09	0.12	0.26
Anxiety	59.6	0.01	0.01	0.93
Depression	56.3	-0.19	-0.21	0.03
Fatigue	59.5	-0.23	-0.26	0.01
Sleep Disturbance	57.1	-0.16	-0.20	0.06
Social Roles Participation	41.4	0.12	0.17	0.17
Resilience	47.3	0.26	0.28	0.00
Caregiver Stress	62.8	-0.14	0.17	0.17

Table 3: UW Caregiver Benefit items ranked from most to least likely to endorse

Item Number	Item Text	Mean Score
care10	Are you a better advocate for your child/children because of caregiving?	4.5
care02	How much does caregiving help you appreciate what is important in life?	4.4
care15	How much does caregiving make you a more accepting person?	4.3
care20	How much do you feel that caregiving has helped you put life in perspective?	4.3
care07	How much does caregiving help you find new strengths in yourself?	3.9
care30	How much do you feel that caregiving has made you a stronger person?	3.9
care23	How much does caregiving help you be more caring?	3.9
care13	How much does caregiving add meaning to your life?	3.8
care19	How much do you feel caregiving has made you a better person?	3.8
care24	How much does caregiving help you become a more patient person?	3.6
care08	Have you gained confidence in yourself because of caregiving?	3.4
care48	How often do you feel closer to your partner because of caregiving?	2.8
care26	How often does caregiving make you feel more connected with other people important to you?	2.8

NOTE: Items are on a scale from 1 ("Not at all" or "Never") to 5 ("Very Much" or "Always")

RESULTS

- Caregivers of children with EE reported significantly less benefit (M:46) than the caregivers in the community sample (M:50)
- Men (n=7) reported significantly less benefit (M:36) than women (M:47) (n=121)
- More benefit was associated with less fatigue and depression, and better mental health and resilience
- Caregivers with more education (advanced degree) reported less benefit (M:42) than those with less education (HS or AA degree) (M:48)
- Caregiver benefit had a non-linear relationship with the age of child or duration of EE. Caregivers with children 12 years or older or who had EE for 10 years or longer reported the most benefit



CONCLUSIONS

The significant associations between caregiver benefit and perceived fatigue, depression, mental health, and resilience suggest that positive psychology interventions that could help caregivers identify, focus on, and generally become more aware of the benefits derived from caregiving may result in improvements in these quality of life domains. More research to better understand caregiver benefit and to develop interventions is needed.

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