



What areas of lives of caregivers of children with severe, refractory epilepsy are affected by caregiving? An expert panel report

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Background

- Caregiving for children with severe disabilities can have a dramatic impact on caregivers' lives.^{1,2}
- Caregiving for children with Dravet syndrome and other epileptic encephalopathies (EE) has particularly unique challenges as children can have many seizures per day and typically develop cognitive and physical disabilities.^{3,4}
- Existing measures of the impact of caregiving are inadequate in terms of psychometric properties as well as content.

Purpose

To obtain information from an international expert panel of pediatric neurologists as a first step toward the development of a psychometrically sound and clinically relevant measure of the impact of caregiving on parents of children with EE and other medical conditions.

Methods

Eight pediatric neurologists (5 men and 3 women) from the USA and Europe who work with children with epilepsy participated in expert panel discussions by phone to develop a definition of caregiving and a list of life domains important to measure in order to assess caregiving burden.

Results

- The expert panel recommended that both challenges and benefits of caregiving be assessed.
- The expert panel agreed on the following definition of impact of caregiving: The caregiver's perception of the physical, social, and emotional effects of caregiving on the caregiver's life. It also includes the caregiver's perception of the effects of caregiving on the financial resources, time resources, and other resources available to the caregiver.
- Nine subdomains of caregiving impact were identified by the expert panel.

Subdomains of Caregiving

1. Impact on *work hours/employment* of the caregiver.
2. Impact on *household work* of the caregiver.
3. Impact on *family finances*.
4. Impact on *emotional health* of the caregiver (e.g., happiness, sadness, anxiety).
5. Impact on *physical health* of the caregiver, including impact on sleep and fatigue.
6. Impact on the caregiver's *relationship with spouse/significant other* (if there is a spouse or significant other).
7. Impact on the caregiver's *relationships with other children* (if there are other children)
8. Impact on the caregiver's *relationships with friends*.
9. Impact on the caregiver's *sense of confidence in/self-efficacy for caregiving*.

Conclusions

- It is important to consider both challenges and benefits of caregiving; any measure of caregiving impact should include items that assess both.
- Definitions and identified domains will inform the development of items for a new measure of caregiving impact.

Moving Forward

Next steps for the development of the scale include:

- Focus groups with caregivers to determine if the domains identified are appropriate;
- Item generation and cognitive interviewing; and
- Field testing of the items in a large sample of caregivers including caregivers of healthy children and children with medical conditions other than epilepsy.

Expert Panel Members

- Berten Ceulemans, M.D., PhD., Antwerp, Belgium
- Helen Cross, M.D., PhD., London, United Kingdom
- Kelly Knupp, M.D., Aurora, CO, United States
- Ian Miller, M.D., Miami, FL, United States
- Rima Nabbout, M.D., Paris, France
- Scott Perry, M.D., Fort Worth, TX, United States
- Joseph Sullivan, M.D., San Francisco, CA, United States
- Sameer Zuberi, M.D., Glasgow, United Kingdom

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