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Life impact of caregiving for severe childhood epilepsy: Results of expert panels and caregiver focus groups

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ABSTRACT

Severe epilepsy in children and young adults can significantly affect the lives of their caregivers. However, the lack of a reliable and valid measure of caregiver impact has limited our understanding of the scope and correlates of this impact, as well as our ability to measure the effects of treatments that could lessen it. The purpose of this study was to facilitate focus groups and interviews with an international group of clinician experts and caregivers to identify the most important domains that should be assessed in a measure of caregiver impact. Ten specific subdomains emerged from the panel discussions, which could be classified into the four overarching categories of physical health, mental health, social function, and financial resources. The caregivers highlighted the impact on the subdomains of sleep and fatigue as most critical. A review of existing caregiver impact measures confirmed that there is no measure currently available that assesses all of these relevant domains, indicating the need for the development of such a measure. The current findings highlight the significant life effects of caring for a child with severe epilepsy and can be used to inform the development of such a tool.

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1. Introduction

Severe childhood illness and disability present with many unique challenges that families must consider when caring for their child [1]. Caregivers of children with special needs must often provide substantially more care and coordination of healthcare and other services than caregivers of children who are otherwise healthy. The significant time, effort, and emotional demands associated with this caregiving can contribute to feelings of significant stress, anxiety, and depression [2,3]. Although caring for a child with any illness or disability can come with substantial demands, aspects of caregiver impact may differ as a function of diagnosis. Caregivers of children with severe epilepsy (i.e., epilepsy syndromes that are treatment refractory and associated with neurobehavioral developmental problems, such as epileptic encephalopathies [4]) must manage their children's often prolonged seizures while also dealing with the increasing impact of these seizures on the health and quality of life of their child. Severe epilepsy can lead to other significant comorbidities and problems, including cognitive impairments, motor limitations, and behavioral problems [5–9]. Concerns about these issues can contribute further to the impact of caregiving [10–13]. Measures of the impact of caregiving for children with severe health conditions, such as severe epilepsy, are needed in order to understand and mitigate the stress associated with this caregiving.

Although there is a significant body of research focusing on the impact of childhood epilepsy and ways to measure this impact on the person with epilepsy (e.g., [14–17]), there is much less research on the impact on caregivers. Preliminary studies that have examined impact on caregivers — virtually all of which focus primarily on the impact of caregiving on mothers — suggest that this impact can be severe [10–13,18]. The few studies that have explored the impact on fathers have found that while fathers can experience some depressive symptoms, the degree of negative impact on fathers may not be as much as on mothers, perhaps related to differences in gender roles [19–21]. Parental stress associated with caregiving could also have subsequent indirect negative effects on the health and well-being of the child with epilepsy, because of the potential reductions in the psychological, physical, and financial resources available to the caregiver and his or her ability to provide the most effective care. If research supports this hypothesis, then it would be important to study how to most effectively eliminate or reduce the negative effects while maximizing any positive effects of caregiving in this patient population to improve the quality of life of both the caregivers and their children or young adults, as well as possibly other family members.

Valid and reliable measures of the impact of caregiving are needed to further our understanding of the effects of caring for a child with severe

Abbreviations: DS, Dravet syndrome; PIP, Pediatric Inventory for Parents; CHIP, Coping Health Inventory for Parents.

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epilepsy on both the caregivers as well as the child with epilepsy and the entire family unit. A large number of measures which assess caregiving impact for a number of conditions exist (e.g., [22–24]). While none of these were developed to address the issues specifically relevant to caregivers of children and young adults with epilepsy, the domains they assess can provide some clues regarding the impact domains that might need to be assessed in a valid and reliable measure of caregiving impact. For example, the Pediatric Inventory for Parents (PIP) is a commonly used 42-item measure which assesses the frequency and difficulty associated with four key domains of caregiving impact: communication (sample item, "*Speaking with the child about his/her illness*"), emotional function (sample item, "Feeling numb inside"), medical care (sample item, "Helping my child with medical procedures"), and role function (sample item, "Being unable to go to work/job" [25]). Similarly, the Coping Health Inventory for Parents (CHIP) is a 45-item measure assessing three overarching domains of coping patterns which were labeled as follows: (1) Maintaining Family Integration, Cooperation, and an Optimistic Definition of the Situation; (2) Maintaining Social Support, Self-Esteem, and Psychological Stability; and (3) Understanding the Medical Situation Through Communication with Other Parents and Consultation with the Medical Staff [26]. Mu and colleagues found that all three of these coping patterns were associated significantly with maternal depression in a sample of 316 mothers caring for children with epilepsy [27]. Similarly, Hobdell and colleagues found that the second CHIP coping pattern (Maintaining Social Support, Self-Esteem, and Psychological Stability) was significantly positively associated with chronic sorrow in a sample of 67 parents of children with epilepsy [28].

However, although the existing measures can provide ideas for the caregiving impact domains that may be important to consider in a measure of caregiving impact for children with severe epilepsy, none of the measures that have been developed to date, including the PIP and CHIP, were developed specifically to assess impact on caregivers of children with severe epilepsy [18]. Therefore, a critical first step is to understand the key caregiving impact domains that need to be included to develop a validated measure that can accurately assess the impact of caregiving for a child or young adult with severe epilepsy.

The purpose of the current study was to fill this knowledge gap by identifying the most important domains that should be assessed in an efficient (i.e., both adequately thorough and adequately brief) measure of caregiver impact for caregivers of children and young adults with severe epilepsy. Because we anticipated that such a measure would have both clinical and research applications, we sought to obtain input from expert clinicians and researchers who work in this area, as well as from caregivers themselves. In addition, so that the measure is valid for use in both clinical and research settings and in different countries, we sought participation from experts and caregivers living and working in different parts of the world. Identifying domains that should be included when assessing caregiving impact for caregivers of children and young adults with severe epilepsy provides a necessary empirical foundation for the development of a new measure that is content valid and psychometrically sound for evaluation of caregiving impact in this population.

2. Methods

2.1. Study design overview

The study was conducted in two parts. Initially, an expert panel (EP) was convened, composed of clinicians who provide clinical care for, and researchers who, in their research programs, study children with severe epilepsy. The purpose of the EP was to develop definitions of key concepts (e.g., "caregiver" and "impact of caregiving") and to compile a list of the key domains of caregiver impact from the healthcare provider's perspective. Next, focus groups and interviews with caregivers of children and young adults with severe epilepsy were conducted to obtain feedback on the construct definitions proposed by the EP and the key domains of caregiver impact. Information was used to inform the development of a content-valid measure of caregiving impact for caregivers of children with severe epilepsy.

2.2. Participants

Primary caregivers (biological or other) of children aged 17 years or younger with Dravet syndrome or other severe epilepsy conditions (e.g., SCN8A epilepsy, Lennox–Gastaut syndrome, Doose syndrome) were invited to participate. In order to participate, the caregiver participants needed to be able to speak English. However, we sought to recruit caregiver participants from different countries to maximize the generalizability of the findings.

2.3. Measures

Participants completed demographic forms inclusive of information about their child's diagnosis (e.g., type of epilepsy, diagnosis date, number of seizures). Caregivers also completed many of the Patient Reported Outcomes Measurement Information System measures (http://www.nihpromis.com), including the PROMIS Global version 1.0 (physical and mental) health instrument, the PROMIS Profile version 2.0: physical function, anxiety, depression, fatigue, sleep disturbance, ability to participate in social roles and activities, and pain intensity; and the PROMIS pain interference short form 6b. As it is true with IRT-based item banks, the Cronbach's alpha is in the 99% range for all PROMIS domains (https://www.assessmentcenter.net/Manuals.aspx). Test–retest findings have only been published for the depression domain using PROMIS items and were found to be good (0.76–0.80) [29]. Participants also completed the Pediatric Renal Caregiver Burden Scale modified to make questions appropriate for parents of children with severe epilepsy [30]. No reliability information is available for this scale.

Development and calibration of PROMIS outcome measures utilized a large sample (>20,000) of the US general population [31]. Final PROMIS item banks and measures are centered on a subsample ($n = 5239$) that was representative of the 2000 US Census on age, gender, and race/ethnicity [32]. The Patient Reported Outcomes Measurement Information System instruments were developed using item response theory (IRT). For PROMIS scales used here, scores are reported on a T-score metric with a mean of 50 that represents the US general population and standard deviation (SD) of 10. Detailed information about all PROMIS measures, including look-up tables for the scoring utilized in this study, is provided on the PROMIS Assessment Center™ (www.assessmentcenter.net) website.

2.4. Procedures

2.4.1. Expert panel

Pediatric neurologists providing healthcare services to children and young adults with severe epilepsy and known to the study investigators or to colleagues of the study investigators were invited to participate in the EP. Members of the EP were asked to discuss what should be included in a definition of *caregiver* (i.e., Should it only include parents, or should it also include other family members [e.g., grandparents] who take on a caregiving role? Should it include paid caregivers?) and *impact of caregiving* (i.e., Should it include both the costs and burdens of caregiving, or might it also include potential benefits of caregiving?). The goal was to achieve consensus definitions of these key terms, which could then be used to generate ideas for a preliminary list of the domains that should be assessed in a measure of the impact of caregiving for a child with severe epilepsy. Members of the EP were also asked to identify the key impact domains relevant to caregivers of children with severe epilepsy. A preliminary list of potential domains was generated by the study investigators based on the review of existing measures of caregiver impact [22–24] and clinical experiences.

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