

## Brief Communication

## Caregiving in pediatric epilepsy: Results of focus groups and implications for research and practice



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## ABSTRACT

The process of caring for youth with epilepsy (YWEs) has been understudied. Previous research has identified that caregivers of YWEs report increased parenting stress, unanticipated caregiving responsibilities, and negative effects on family life. Using the adapted Caregiving Process Model, perceptions of the caregiving process were explored in four focus groups of caregivers of youth with epilepsy diagnosed at <1 year, between 1 and 5 years, and >5 years. Thematic analysis guided the data analysis. The prevalent theme that emerged during the data analysis was *navigating the noncontingencies* (lack of a perceived relationship between action and outcome, unpredictability). This was supported by the subthemes, namely, *blessings and sacrifices*, *uncertainty today and tomorrow*, *constant vigilance*, and *caregiving is more than parenting*. The focus groups displayed similarities and differences in caregiving perceptions across the three postdiagnosis time periods, providing support for conceptualization of the caregiving as multifactorial, multidirectional, and fluid process. With this knowledge, epilepsy health-care professionals are encouraged to promote patient and family centeredness, provide information on how to access community resources, and work with caregivers to enhance epilepsy self-management skills.

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### 1. Introduction

Epilepsy is diagnosed in at least 1% of youth before 20 years of age and is the most common neurological disorder in childhood [1]. New-onset epilepsy is stressful for families [2–4], and both youth and parents have unmet psychosocial care needs up to 24 months after diagnosis [5]. The impact of a chronic illness diagnosis such as epilepsy is associated with increased parenting stress [3], unanticipated caregiving responsibilities, and negative effects on family life [6–8]. Epilepsy comorbid effects (i.e., challenges in social, cognitive, emotional, and physical functioning [9]) can also negatively impact family functions [10,11] and reduce quality of life in caregivers and youth with epilepsy (YWEs) [12,13]. Despite evidence-based treatment, more than 30% of youth still experience seizures [14], and this creates challenges for families related to the unpredictability (noncontingency) of seizures [15]. Caregivers' coping and illness management behaviors

have a strong influence not only on their mental health and quality of life outcomes but also on outcomes in their children [16–18].

Investigators have focused on the psychosocial and learning needs of youth and families with new-onset epilepsy, including comorbid conditions occurring before and after the onset of epilepsy [5,17,19,20]. Although findings from a few longitudinal studies have identified challenges beyond the first year postdiagnosis [5,17,20], there is still a lack of evidence regarding management [21] of the psychosocial, learning, and support needs of caregivers beyond this first year and over time. Similar to other investigators' findings [19], studying distinct time periods postdiagnosis may add knowledge needed to develop successful interventions for caregivers' coping and management interventions, as youth and family trajectories are not static.

Not surprisingly, behavioral health interventions targeting caregivers' coping and management behaviors are few in number. To address this need, Wagner et al. [22] developed and pilot tested a group-based epilepsy self-management intervention for YWEs and their caregivers. Although the intervention was targeted at enhancing youths' skills, it was anticipated that caregivers would adopt and incorporate these skills into their own lives. Caregivers reported significant improvements in their children's coping skills, and youth reported

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improved epilepsy knowledge and epilepsy self-efficacy postintervention. However, the caregivers, who were taught the same coping skills as the YWEs, reported difficulty incorporating the skills into their daily lives and did not report improvements in their own epilepsy self-efficacy [22,23]. These recent study findings and national research priorities [24] led to the current study to explore caregiving processes and outcomes in caregivers of YWEs.

Specifically, using the Caregiving Process Model [7] adapted for caregivers of youth with epilepsy (Fig. 1), process variables such as caregivers' coping resources (i.e., self-efficacy and social support), self-management/family management behaviors (i.e., treatment plan management, lifestyle behaviors, and interactions with health providers), and the impact of these variables on caregiving outcomes (i.e. health-related quality of life (HRQoL), physical status, and psychological status) require further exploration. Moreover, understanding how caregiving processes and outcomes change over time postdiagnosis, particularly in light of the developmental vulnerability of YWEs, can provide information unique to the experience of the caregivers and inform the development of future interventions aimed at improving quality of life and health outcomes for caregivers and YWEs. Therefore, the purpose of this pilot study was to explore caregivers' perceptions of the caregiving process at different time periods postepilepsy diagnosis. These data were part of a larger cross-sectional mixed method pilot study.

## 2. Methods

### 2.1. Participants

A purposive sample of caregivers was recruited from the only level 4 comprehensive epilepsy center at an urban academic medical center in an economically disadvantaged state. The institutional database consolidates data from various computer systems across the academic medical center and was used to identify potential participants. The electronic medical chart review confirmed diagnosis, demographics, and specific epilepsy variables (Table 1). Caregivers were divided into groups by time since epilepsy diagnosis in the youth. Nineteen caregivers of YWEs participated in one of the four focus groups: 1) <1-year epilepsy diagnosis ( $n = 6$ ) (new onset), 2) between 1 and 5 years postepilepsy diagnosis ( $n = 3$ ) (recent onset), and 3) >5 years postepilepsy diagnosis (2 groups,  $n = 10$ ) (enduring). Time points were chosen based on previous investigations of developmental brain changes in YWEs and

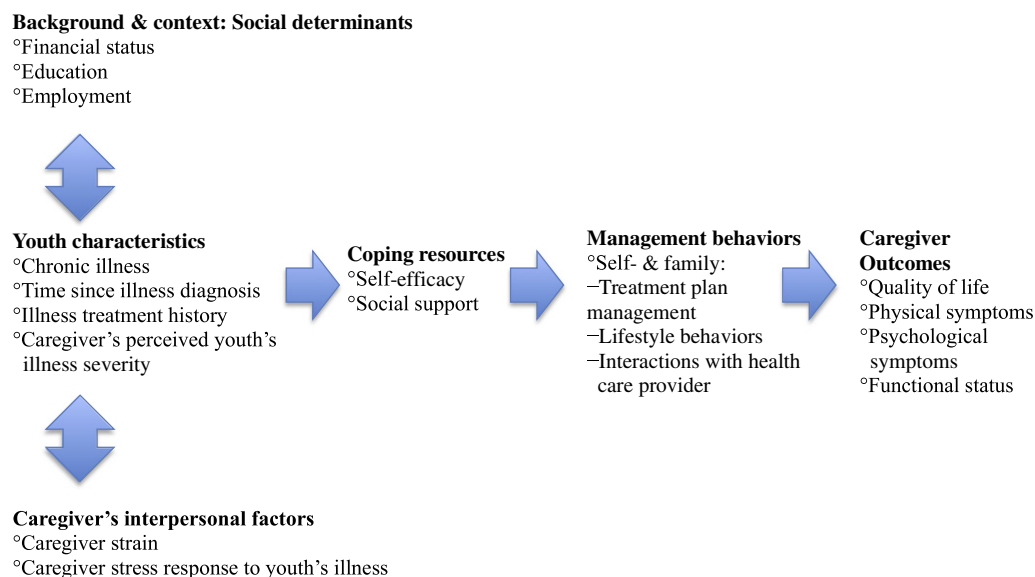
of psychosocial care needs in caregivers of YWEs [4,5,19]. The demographics and composition of the groups are detailed in Table 1.

Caregivers were included if they were legally authorized adult caregivers of youth (<18 years of age) who had a confirmed diagnosis of epilepsy (e.g., ICD-9 345 codes), resided within an 80-mile radius of the medical center, read and spoke English, and were willing to participate. Caregivers were excluded if the YWEs had a diagnosis of a comorbid serious or life-threatening medical condition as determined by the medical chart review. If the information was not available in the chart, the principal investigator (PI) reviewed the criteria with the clinic health-care provider caring for the YWEs. All study activities were approved by and conducted in accordance with the institution's review board.

### 2.2. Procedures

Participants were recruited through clinic flyers or a letter regarding their eligibility to participate in the study after electronic chart screening by the PI. Eighty-five YWEs were identified to meet eligibility criteria. Within 1–2 weeks of the letters being mailed, the PI contacted eligible participants to provide study information. Potential participants were informed that the purpose of the study was to explore the caregivers' perceptions of the caregiving process regarding their YWEs. Out of the 85 potential participants contacted, 29 agreed to participate in the focus groups. A total of 19 participants attended the focus group meetings, with the other 11 participants citing nonattendance due to a death in the family ( $n = 1$ ), due to having difficult seizures ( $n = 1$ ), due to inclement weather ( $n = 7$ ), or due to lack of transportation ( $n = 2$ ). Prior to the scheduled focus group meeting, the PI obtained informed consent from the caregiver. Caregivers received a copy of the consent forms and received a \$25 gift card for their participation in the study.

A trained focus group leader (clinic pediatric nurse practitioner) and an assistant (neurology resident) led the focus groups. The questions (Table 2) were developed in consultation with an epilepsy nurse expert, psychiatric nurse expert, linguistics and content expert, and a pediatric psychologist. Focus group questions began with broad topics related to the caregivers' perceptions of the caregiving process regarding their YWEs followed by questions focused on the constructs of the Caregiving Process Model by Raina et al. [7]. The trained focus group assistant took field notes, and the sessions were digitally recorded and transcribed verbatim. These standardized methods were previously used in a focus group of caregivers of YWEs [25].



**Fig. 1.** Caregiver process for caregivers of youth with epilepsy. Adapted from [7].

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