



Changes in daily activity patterns of caregivers of children with newly diagnosed epilepsy: A case-controlled design



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ABSTRACT

Having a child diagnosed with a chronic pediatric illness is a major stressor for families that can alter their daily lives. The primary study aim was to use Daily Phone Diaries (DPDs), a cued-recall procedure to track parents through their activities over a 24-hour period, to assess the activity patterns of a group of caregivers with a child diagnosed with new-onset epilepsy (group with NOE; $n = 30$) and a group of matched comparisons (comparison group; $n = 29$). The time caregivers spent in sleep and recreation was evaluated over the first 5.5 months after diagnosis. Caregivers of children with NOE spent significantly more time in recreation inside the home, while the comparison group spent significantly more time in recreation outside the home. These data suggest that families with children with NOE reallocate their time post-diagnosis from recreation outside to inside the home, which raises concerns about the overall adaptation of the family to the diagnosis and presents a critical opportunity for health-care teams to intervene and support families with children with NOE.

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1. Introduction

One of the most stressful life experiences for a family is the diagnosis of a chronic illness, such as epilepsy [1]. The diagnosis of a chronic illness often reflects a critical event that creates more burden and stress for families beyond that of normal development [2]. Prior research has demonstrated that when children are diagnosed with a chronic condition, such as epilepsy, families report increased stress, as well as changes to daily routines. Such stress and alterations in the family routine may serve as barriers to families adapting and adjusting to a new chronic illness diagnosis [3].

Caregivers of children with epilepsy may experience unique stressors compared to caregivers of children with other pediatric chronic conditions, especially initially after diagnosis. First, seizures are unpredictable, which can increase feelings of anxiety and helplessness in both children and their caregivers [1,4]. For example, Ellis, Upton, and Thompson suggest that post-diagnosis, anxiety and fear about future seizures may dictate the way families spend their time (i.e., trying to avoid places where seizures have occurred, co-sleeping because of fear of having a seizure at night) [5]. Second, children with

new-onset epilepsy (NOE) are required to attend frequent clinic appointments and take antiepileptic drugs (AEDs). Antiepileptic drugs are typically taken twice a day and have known side effects, including drowsiness, cognitive slowing, and behavioral disturbances that may require families to restructure routines and activities. The way caregivers spend and allocate their time after having a child diagnosed with a chronic illness has been found to be a key factor in how families are able to adapt to pediatric chronic illnesses [6,7]. Specifically, cross-sectional research in other pediatric conditions, including cystic fibrosis and asthma, demonstrates that caregivers spend more time in medical care and less time in recreation than caregivers of children without a chronic illness [7–9]. Specific to epilepsy, caregivers were reported to experience more nighttime awakenings [10] and more time in medical care and less time in recreation outside of the home (versus home-based recreation) than control groups [11]. These shifts in daily activities are important because sleep and recreation often serve as buffers for everyday-life stressors. If caregivers are engaging in fewer buffering activities, they likely experience more stress and consequently poorer parental adaptation, which can ultimately impact adaptation of the whole family unit [12,13].

The Daily Phone Diary (DPD; [6,14]) is the only ecological momentary assessment that has been used to examine the activity patterns of children with chronic conditions (e.g., cystic fibrosis, asthma, HIV) over a 24-hour time period [6–8,14–16]. This innovative methodology, which allows us to examine the types of activities, length of time

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spent in activities, companions during activities, and mood while conducting activities, provides rich information regarding the daily life of individuals. It is well suited to examining how activity patterns may shift over time for caregivers of children with chronic conditions, such as epilepsy.

This study builds upon our prior work which utilized Daily Phone Diaries to examine differences in activity patterns between caregivers of 30 children with NOE two weeks after diagnosis and caregivers of 29 age- and gender-matched controls. Results demonstrated that caregivers of children with a new diagnosis of NOE spent more time in medical care and less time in recreation outside of the home than caregivers of the matched comparison group. Notably, the total amount of recreation for both groups was equivalent [11]. The primary aim of the current study was to extend our prior work by examining the activity patterns of this cohort longitudinally and comparing the activity patterns of the caregivers of children with NOE over the 5.5 months following diagnosis to a matched comparison group [11].

For this longitudinal analysis, it was hypothesized that initial time spent in recreation and sleep would be lower for caregivers of children with NOE compared to controls, but this would increase over the 6-month study period as caregivers of children with NOE adjusted to the diagnosis. It was also hypothesized that caregivers of children with NOE would spend more time in medical care than the comparison group over time. An exploratory aim was to examine the relationship between seizures (absence vs. presence) and time spent in sleep and recreation of caregivers of children with NOE. It was hypothesized that caregivers of children experiencing seizures will spend fewer minutes in sleep and recreation compared to caregivers of children with NOE not experiencing seizures.

2. Method

2.1. Participants and procedure

Thirty-two potential participants with new-onset epilepsy (NOE) and 29 matched healthy children and their caregivers were invited to participate in the current study. Participants in the group with NOE were part of a larger NIH-funded study evaluating adherence to medical regimens and were recruited over a five- to six-month period. Children with NOE were recruited from a new-onset seizure disorder clinic at a Midwestern children's medical center. Eligibility for the larger study included the following inclusion criteria: (a) aged 2–12 years of age; (b) new epilepsy diagnosis; (c) no diagnosis of pervasive developmental disorder (i.e., autism); (d) no other chronic medical illnesses that require daily medication, with the exception of seasonal allergies; and (e) no previous use of antiepileptic medications (AEDs). The comparison group was recruited primarily through a hospital-wide employee e-mail distribution (76%), with the remaining 24% recruited by word of mouth. One hundred ninety-three interested caregivers responded and were then questioned by a research assistant about their child's age, sex, and race. Inclusion criteria for the comparison group included the following: (a) the child is between 2 and 12 years of age, (b) the child has no siblings with a chronic illness, and (c) his/her demographics matched those of a participant in the group with NOE. Families received a \$10 gift card to local stores for completing the Background Information Form and for completing each of the three DPD sets (i.e., a total of \$40 for the entire study).

The overall recruitment rate for participants that initially agreed to participate in the study was 97% for the total sample (94% for the group with NOE, 100% for the healthy group). The final sample included 30 children with NOE and their primary caregivers and 29 children without epilepsy and their primary caregivers (i.e., healthy comparison group).

The study was approved by the hospital's Institutional Review Board. Eligible participants were approached by a trained research assistant to provide a detailed explanation of the study and answer questions. After

informed consent was obtained, caregivers completed a Background Information Form and scheduled a time to complete their first set of DPDs. In order to reduce participant burden and stress immediately after receiving an epilepsy diagnosis, families did not complete any additional questionnaires at this visit.

Once children with NOE were recruited for the study, research assistants examined the list of healthy comparisons who demonstrated an interest in the study. Healthy comparisons were matched to children with NOE based on age (± 6 months), gender, and similar number of siblings. If a suitable matched comparison was found, the research assistant contacted caregivers, and an appointment was made to answer questions about the study and obtain informed consent. Caregivers then completed a Background Information Form and scheduled their first set of DPDs.

In total, both groups completed three sets of DPDs (e.g., one weekday and one weekend day in each set). The first set of DPDs (Time 1) was conducted about 2 weeks after diagnosis (the halfway point between diagnosis and the first follow-up clinic appointment). The second set of DPDs (Time 2) was conducted 2.5 months post-diagnosis (halfway between the first and second follow-up clinic appointments). The final set of DPDs (Time 3) was conducted approximately 5.5 months post-diagnosis (halfway between the second and third follow-up clinic appointments).

2.2. Measures

2.2.1. Background Information Form

At the initial visit, caregivers completed a Background Information Form, which included questions about family composition and child and parent demographic information. In addition, information was collected from each family to determine their revised Duncan score, an occupation-based measure of SES. Scores range from 15 to 97, with higher numbers equating to higher SES [17]. In two caregiver families, the higher Duncan score was used.

2.2.2. Daily Phone Diary (DPD)

The DPD is a computerized system with which interviewers utilize a cued-recall procedure to record all activities that lasted 5 min or longer over a 24-hour period [9,14]. In order to help caregivers recreate an accurate activity pattern of the last 24 h, interviewers used prompts to elicit the activities that occurred and the order in which they were completed. A list of the activity categories is presented in Table 1. For example, an interviewer may ask a caregiver the following question, "Once you put your daughter to bed, what did you do next?" In addition to obtaining the order in which these activities occur, interviewers recorded how long the activity took (in minutes), who was present during the activity (specific family members as well as friends, coworkers, etc.), and the valence of mood associated with the activity (on a scale of 1 = *extremely negative* to 5 = *extremely positive*). While the DPD has been used with several pediatric populations, including those with cystic fibrosis [8,9,14,15,18], asthma [8], and HIV [16], it was adapted for use with children with epilepsy and their families for the current study. Prior studies have found excellent interrater reliability (>90%) for two independent raters' successful categorization of activity patterns [19] and strong stability coefficients ($r_s = 0.61\text{--}0.71$, $p < .01$) over a 3-week period [20]. Additionally, strong convergent validity was documented between the DPD and home interviews and nightly rating scales [6], as well as objective adherence data [8,15], suggesting that it is a valid measurement tool.

2.3. Statistical analyses

Means, standard deviations, and percentages were calculated from the raw data to examine time spent in all 10 broad activity categories collected through the DPD. A multivariate analysis of variance (MANOVA) was conducted on the total sample at Time 1 to compare

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