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The Impact of a New Pediatric Epilepsy Diagnosis on Parents: Parenting Stress and Activity Patterns

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Abstract

The purpose of this study was to compare parenting stress and activity patterns in parents of children with new-onset epilepsy (NOE; $n = 30$) and parents of children without epilepsy (controls; $n = 29$). Participants completed parenting stress measures and Daily Phone Diaries (DPDs), a cued-recall procedure to track parents through their activities over a 24-hour period. No significant differences were found in parenting stress, with the exception of a higher proportion of parents of children with NOE experiencing Life Stress compared to parents of controls ($p < 0.05$). Results indicated parents of children with NOE spent more time in medical care ($F = 4.4, p < .05$) and less time in recreation outside of the home ($F = 5.6, p < .05$) compared to parents of controls. These findings have important implications for family adaptation to a new epilepsy diagnosis.

Keywords

ecological momentary assessment; activity pattern analyses; pediatric; healthy controls; controlled design; children; parenting stress; family adaptation

Introduction

It is well-known that having a child diagnosed with a chronic illness, such as epilepsy, is a significant stressor for both children and parents (1). Specifically, McCubbin and Patterson have posited that a child's illness is a critical event that places additional stress and burden on families, beyond those of normal development (Double ABCX model; (2)). This is especially true in pediatric epilepsy given the unstable pattern of seizures (3). In fact, studies indicate that 45–65% of parents of children with intractable epilepsy experience elevated levels of parenting stress (4,5), which have been shown to mediate the relationship between family factors and parenting variables (6). Furthermore, mothers of children with epilepsy have significant worries and stress around the epilepsy diagnosis, comorbidities, and treatments (e.g., effect of seizures on the brain, behavior problems) and management of disease (e.g., future seizures, lifestyle changes) (7,8) that maintain over time (9). However, little is known about parenting stress immediately after receiving an epilepsy diagnosis and its impact on the family.

Understanding the level of stress parents of children with new-onset epilepsy (NOE) experience

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after diagnosis is important because there is an intrinsic link between parent and child adaptation (10–14).

Austin and colleagues (1996) have extended the ABCX model and its application to pediatric epilepsy, with individual, parent, and family adaptation as the primary outcomes of the model (15). Family adaptation has been defined as how well the family unit functions as a whole (15). In contrast, parental adaptation is defined by how well a parent manages his/her own life, as well as the lives of his/her children, including the child with epilepsy. Overall, parents are responsible for maintaining normal family activities while balancing the needs of the child with epilepsy. For younger children with epilepsy, this is especially salient because parents play a key role in helping children adapt and adjust to a new diagnosis.

The stress of a new epilepsy diagnosis may play a significant role in the daily activities of families with children with epilepsy. For example, parents may initially spend more time with children with new chronic illnesses compared to siblings (16). In addition, the anxiety and depressive symptomology often experienced by parents of children with epilepsy (11,17,18) could affect other areas of daily functioning. Studies have shown that families of children with epilepsy report dissatisfaction with restriction in their social (e.g., eating out, entertainment) and recreational activities (19,20), as well as disturbances in sleep and frequent nighttime awakenings (21). Limitations of these prior studies include the use of a retrospective self-report measure and inability to capture the impact of epilepsy on families within the context of daily activities. Research in other chronic illness populations that examine daily activity patterns demonstrated that children and parents spend less time in recreation and more time in medical care compared to healthy controls (22). Spending less time in recreational activities (22,23) and disturbances in sleep (21) have important implications for family functioning and adaptation because such activities serve as buffers for everyday life stressors. Without these buffers, parents are likely to experience higher levels of stress and poor parental adaptation, which could impact child adaptation (24,25) and disease management. To date, no studies have examined the impact of a new diagnosis of epilepsy on family activity patterns.

Technological advances have made it possible to understand an individual's daily activities and mood within the context of their social environment in real-time. Methodologies to analyze activity patterns include the day reconstruction method (26), such as the Daily Phone Diary (DPD) (27,28), experience sampling method (29), and ecological momentary assessment (30). The computerized DPD is the only method that has been used in pediatric chronic illness populations (e.g., cystic fibrosis, asthma) to track parent activity patterns, including time spent in sleep and recreation over the previous 24 hours. This innovative methodology is ideally suited to examine activity patterns in parents of children with new-onset epilepsy (NOE), which will allow for identification of alterations in daily functioning.

The purpose of the current study was two-fold: 1) to examine parenting stress between parents of children with NOE and parents of children without epilepsy (e.g., matched control group) and 2) to examine how activity patterns differ between parents of children with NOE and controls. Based on prior studies, both in epilepsy and other chronic conditions, it was hypothesized that parents of children with NOE would report higher levels of parenting stress and a larger percentage would experience clinically elevated levels of parenting stress compared to parents of controls. It was also hypothesized that parents of children with NOE would spend less time in recreational activities and sleep than parents of controls. An additional exploratory aim of the study was to examine the relation between activity patterns and parenting stress in parents of children with NOE. It was hypothesized that parents with higher levels of parenting stress, including both generic and epilepsy-specific stress, would spend less time in recreation compared to those with lower levels of parenting stress.

Methods

Potential participants were approached and recruited from a pediatric new-onset epilepsy clinic in the Midwest if they met the following inclusion criteria: a) children being 2–12 years old, b) new diagnosis of epilepsy requiring treatment (e.g., diagnosed with at least 2 unprovoked seizures and prescribed an AED the day of recruitment), c) no comorbid medical conditions requiring daily medications, d) no significant developmental delays (e.g., Autism), and e) no prior treatment with antiepileptic medications. Parents completed a demographics form at this initial visit and were scheduled for their Daily Phone Diaries (e.g., 2 days) approximately two weeks after the diagnosis date. A set of DPDs included two days, including one weekday and weekend day. As a part of routine clinic care, patients were scheduled to return to the clinic one month after diagnosis and every three months thereafter. For purposes of the current study, participants completed two parenting stress questionnaires at the one-month clinic visit. This timeline was decided because it was felt that completion of parenting stress measures at the time of diagnosis would be too burdensome and insensitive to families.

Children without epilepsy (e.g., control group) were recruited using several strategies, including recruitment emails, brochures, and word-of-mouth. The largest recruitment method was based on sending a hospital-wide email (76%). Potential participants called or emailed staff if they were interested in participating. Basic demographic information was collected from potential participants, including child age, sex, date of birth, and race. Inclusion criteria for the control group included target children being 2–12 years of age and no children in the family having significant chronic illnesses requiring daily medications. Controls were matched to children with epilepsy based on same sex, race, and $\pm$ one year of the age of the child with epilepsy. If a match was found, participants were contacted by phone or email to set-up a time to describe the study in further detail and obtain written consent. After participants were consented, parents completed a demographics form and parenting stress measure. They were also scheduled for their DPDs, which occurred approximately 2 weeks later. All participants were reimbursed with a \$10 gift card to local stores for completion of a set of Daily Phone Diaries, as well as a \$10 gift certificate for completion of the background information form and parenting stress measure. The study was approved by the Institutional Review Board.

Measures

Background Information Form—Parents completed a Background Information Form at the initial visit which asked about the child's date of birth, gender, parent's age, socioeconomic status, occupation, and composition of the family. Data were available to calculate the Revised Duncan (TSEI2) (31) for each family, an occupation-based measure of socioeconomic status (SES) (32). This occupational-based measure is a contemporary indicator of SES (33). Scores range from 15 to 97 with higher scores representing greater occupational attainment. For two-caregiver households, the higher Duncan score was used in analyses.

Parenting Stress Index (PSI; (34))—The PSI is a 120-item parent self-report measure designed to assess the degree to which stress is related to parent functioning, the behavioral and temperamental qualities of the child, and the parent-child relationship. The PSI was developed for parents of children ages 1 month to 12 years. The PSI is comprised of 6 child domains (Distractibility/Hyperactivity, Adaptability, Reinforces Parent, Demandingness, Mood, and Acceptability) and 7 parent domains (Competence, Isolation, Attachment, Health, Role Restriction, Depression, Spouse). Individual subtest scores for each domain are calculated, as well as Child and Parent domain scores and a Total Score. An optional Life Stress score was also calculated, which assesses global stressors that may exacerbate parenting stress (e.g., major events, including marriage, death of a loved one, loss of wages). Parents scoring above the 85th percentile for these scales were considered to be experiencing high levels of

stress. Reliability coefficients for the Child and Parent domains and the Total Stress Scale were 0.90 or greater (34). Child and Parent domain total scores, Total Stress and Life Stress scores were used for the current analyses.

Family Stress Scale-Seizure Version (FSS-Seizure)—The FSS-Seizure is a 14-item epilepsy-specific scale of parenting stress, which was derived from structured interviews. Stress ratings are on a 5-point scale ranging from “not at all stressful” (1) to “extremely stressful” (5) for each item. Items are summed for a total epilepsy-specific stress score, which range from 14 to 70. The scale has good reliability (35). Prior research has shown that FSS scores (disease-specific) were more correlated with psychological distress measures compared to generic measures of parenting stress ($r = 0.40$ versus 0.29 ; (16)). The internal consistency coefficient for the current sample was 0.84 .

Daily Phone Diary (DPD)—The DPD uses a cued recall procedure to track parents through their activities over the past 24-hours and provides a fine-grained analysis of activity patterns, companions, and mood (22,28). For all activities lasting five minutes or longer, a parent reports the type of activity they engaged in, duration of the activity, and who was present. The interviewer assists the parent in reconstructing his/her day as accurately as possible by providing prompts, such as the time of day or information about the previous activity (“after you finished dinner, what did you do next?”). Each activity was recorded by the interviewer on a computer screen with clock hands which rotates through a 24-hour clock, a set of activities, companions, and a rating scale for mood ranging from 1 (Extremely Negative) to 5 (Extremely Positive). A set of 2 DPDs (1 weekday and 1 weekend day) was conducted with the primary caregiver by phone. The DPD has yielded reliable stability coefficients over a 3-week period ($r_s = .61-.71$, $p < .01$) and high levels of interrater reliability ($> 90\%$) (22). Strong convergence (77–80% (22)) was found for daily routines between the DPD and Self Observation Report Technique (36). The DPD, which was originally developed for a cystic fibrosis population, was adapted for parents of children with epilepsy. Activity codes for the DPD are presented in Table 1.

Statistical Analyses

Descriptive analyses, including means and standard deviations, were calculated for parenting stress and time spent in activity variables. Independent t-tests and Fisher’s Exact tests were conducted to examine group differences on sociodemographic variables, including age, gender, race, parent gender, parent marital status, and socioeconomic status (SES). Controlling for significant covariates, ANOVAs were utilized to examine group differences on composite parenting stress variables (e.g., Child Domain Score, Parent Domain Score, Total Domain Score, Life Stress Score). Fisher’s Exact Tests were conducted to examine group differences in the percentage of participants meeting clinical cut-offs for parenting stress. Controlling for significant covariates, a MANOVA was conducted to examine differences in time spent in activities between parents of children with NOE and controls. Finally, for the epilepsy group, Pearson correlations were employed to examine the relation between parenting stress (e.g., total PSI and FSS scores) and time spent in activities. Children with epilepsy were also grouped into categories: those who had seizures and those who did not experience seizures during the first month after diagnosis. Independent t-tests were conducted and effect sizes were calculated to examine differences in parenting stress by group (e.g. presence or absence of seizures).

Results

Participants

Thirty-two participants with NOE were approached for participation in the current study and 94% agreed to participate. Controls volunteered to participate in the study and were matched

to participants with epilepsy based on similar age, race, and sex. The final sample included thirty children with NOE and twenty-nine matched controls and their caregivers. Participant and caregiver characteristics are provided in Table 2. Children with NOE did not significantly differ from controls in age, sex, race, parent gender, or parent marital status. However, children with epilepsy had lower SES compared to controls.

Parenting Stress

No significant differences were found between parents of children with NOE and controls on parenting stress composite scales: Child Domain ($F(1, 56) = 0.51, p = \text{n.s.}$), Parent Domain ($F(1, 55) = 0.01, p = \text{n.s.}$), Total Domain ($F(1, 55) = 0.11, p = \text{n.s.}$), and Life Stress ($F(1, 56) = 0.25, p = \text{n.s.}$) (See Table 3). Fisher's exact tests indicated no significant differences between groups regarding percentage of parents who met clinical cut-off scores for the Child Domain ($p = 0.42$, Fisher's Exact Test, two-tailed), Parent Domain ($p = 1.0$, Fisher's Exact Test, two-tailed), or Total Parenting Stress ($p = 1.0$, Fisher's Exact Test, two-tailed) scores. However, a higher percentage of parents of children with NOE experienced elevated Life Stress scores compared to parents of controls ($p < 0.05$, Fisher's Exact Test, two-tailed). A post-hoc examination of these items revealed that more parents of children with NOE experienced life stressors, such as death of loved ones ($n=8$ vs. $n=4$), decreased income ($n=8$ vs. $n=4$), moving ($n=5$ vs. $n=0$) and relatives moving into their homes ($n=10$ vs. $n=5$), compared to parents of controls.

The mean epilepsy-specific stress score was 25.4. Item-level analyses revealed that parents of children with NOE experienced the highest levels of stress around finances ($M = 2.5$), disciplining their child with epilepsy ($M = 2.14$), concerns about education ($M = 2.14$), and their marital relationships ($M = 2.0$).

Activity Patterns

A main group effect for activity patterns was detected (Wilk's lambda = 0.64 ($F(13, 44) = 2.1, p < .05; \eta^2 = 0.89$) (See Figure 1). Parents of children with NOE spent more time in medical care ($F = 4.3, p < .05$) and less time in recreation outside of the home ($F = 5.2, p < .05$) compared to parents of controls.

Relations between Parenting Stress, Activity Patterns, and Seizures

Regarding the relations between parenting stress and time spent in activities for parents of children with NOE, no significant associations were found between generic parenting stress (e.g., Parenting Stress Index) and time spent in activities. A trend was noted for time spent in recreation outside of the home and generic parenting stress ($r = 0.37, p = .053$). Epilepsy-specific parenting stress was significantly correlated with recreation inside of the home ($r = 0.47, p < .01$). However, epilepsy-specific parenting stress was not significantly correlated with time spent in any other activities, including recreation outside of the home ($r = -0.05, p = \text{n.s.}$). No statistically significant differences were found between parents of children who experienced or did not experience seizures during the first month after diagnosis on parenting stress; however, small effect sizes were observed: PSI Total score ($t(26) = -0.67, p = \text{n.s.}$; effect size = -0.25) and FSS Total score ($t(26) = -0.64, p = \text{n.s.}$; effect size = -0.24).

Discussion

Parenting stress appeared to be similar in parents of children with NOE and controls, suggesting that soon after diagnosis, only a small percentage (7%) of parents of children with NOE are experiencing elevated stress in their parenting role. Prior research in pediatric epilepsy have found high levels of parenting stress (e.g., approximately 50%); however, these studies have primarily focused on children with intractable epilepsy and did not utilize a control group. One

potential reason for the normative levels of general parenting stress in this group may be that parents of children with NOE are feeling more anxious and worried about future seizures, but they are not experiencing stress in their parenting role. There is some evidence from the FSS that parents of children with NOE feel stressed about the management of epilepsy and its impact on the child and family (e.g., financial stress, educational concerns). One may also hypothesize that stressors related to parenting a child with a new chronic illness, such as epilepsy, may not develop until later when the prognosis and trajectory of the disease become more clear (e.g., adherence, side effects, continued seizures). For instance, preliminary data (e.g., effect sizes) suggest that parents of children who experienced seizures during the first month after diagnosis had higher levels of generic and epilepsy-specific parenting stress compared to parents of children who did not experience a seizure.

A higher proportion of parents of children with NOE exhibited clinically elevated levels of Life Stress compared to parents of controls. Although one may anticipate that this would be due to the new diagnosis of epilepsy, no questions on this scale asked about a new chronic illness diagnosis. Items on the Life Stress scale are related to major life events that were occurring for parents, including moving, death of a loved one, pregnancy, and financial difficulties. Given the level of life stress that parents of children with NOE were experiencing, it may be that they were experiencing stressors that were more immediate and significant compared to the stress associated with parenting a child with epilepsy. In fact, half the sample of children with epilepsy did not experience seizures during the first month after diagnosis. These data suggest the need to evaluate major family stressors because epilepsy management is likely to suffer when these stressors occur. For example, prior literature has demonstrated that adherence is lower in children of unmarried (e.g., divorced, single, separated) versus married parents and those with lower socioeconomic status (37); thus, if parents are separating/getting divorced or experiencing a drop in their income, it is likely that adherence to the treatment regimen will decrease and potentially result in increased seizures for the child. Seizure management interventions, such as “Be Seizure Smart” have been shown to improve family relationships, improve support and reduce concerns (38) and are thus likely to be beneficial to families experiencing higher levels of stress. Similarly, DiIorio and colleagues have recently developed a self-management program (“Web-ease”) for adults with epilepsy that improved adherence (39), which could potentially be adapted for children and adolescents with epilepsy and their families.

The current study is the first, to our knowledge, to compare activity patterns of parents of young children recently diagnosed with epilepsy and an age-sex-race matched control group. These data provide information on the impact of a new diagnosis of epilepsy on family life and activities. As expected and similar to studies in other pediatric populations (22,23), results indicated that parents of children with NOE spent more time in medical care and less time in recreation outside of the home compared to controls. This is not surprising given that parents of children with NOE must give medications once or twice a day, attend doctor’s appointment, get medications refilled, and call the healthcare team with information about seizures. Although no statistically significant differences were found for time spent in recreation inside of the home, parents of children with NOE spent less time in recreation outside of the home compared to parents of controls. Of note, combined recreation time for both groups was approximately 25%, suggesting that parents engage in equal amounts of total recreation. One potential reason for this finding is that parents of children with NOE may have shifted recreation time from outside to inside of the home due to worries about seizures and safety. This is supported by our data, which indicated that parents of children with NOE with higher stress spent more time in recreation inside of the home. Recent data from focus groups with parents of children with epilepsy also supports this hypothesis, as parents voiced that they could no longer spontaneously plan outdoor activities and spent more time in the home environment (40).

In contrast to the extant literature, no significant group differences were found in the amount of time parents spent sleeping. Cottrell and Khan (2005) found that parents of young children with epilepsy (e.g., 5 years and younger) slept an average of 4.5 hours per night, which is lower than parents of children with NOE in the current sample, who slept 8.4 hours. In addition, prior literature has suggested that parents of children with epilepsy wake up three times a night to check on their children, which impedes the ability to receive restful sleep (21). Our study did not systematically assess for nighttime wakings, but it is likely that nighttime wakings occurred more frequently for a younger sample of children compared to our sample, potentially resulting in less overall sleep. Combined, these data suggest that activity patterns are quite similar for parents of children 2–12 years of age, with the exception of where recreation occurs. Longitudinal studies examining activity patterns over time would shed light on whether differences in recreation inside and outside of the home are constant and how this might relate to social support received by families. For example, are families engaging in less recreation time with other couples or families because they are spending more time in the home environment?

Although this represents the first step in examining activity patterns and parenting stress soon after children receive a diagnosis of epilepsy, limitations were noted. The current study provides preliminary evidence (e.g. small effect sizes) that children who experience seizures during the first month of the diagnosis may have parents with higher levels of parenting stress; however, the epilepsy sample was quite small, reducing our power to detect differences. Second, other factors, such as the buffering effects of social support, were not evaluated in the current study. Prior research has indicated that social support is an important mediator between stress and adjustment in parents of children with chronic conditions (16). Future studies need to further examine factors, such as social support and epilepsy-specific variables (e.g., type of epilepsy, number of seizures) on parenting stress and activity patterns in a larger cohort of children with epilepsy. Another limitation was the cross-sectional nature of the current study, as it is likely that parenting stress shifts over time as stressors evolve. Examining both activity patterns and parenting stress over time would allow health care teams to identify critical points where parents may need additional support and resources to cope.

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Figure 1.
Activity Patterns by Group. Significance based on follow-up ANOVAs (* $p < .05$).

Table 1

Activity Code Definitions

Activity	Definition
Basic Child Care	Meeting the basic physical needs of the child (e.g., putting children to bed, giving baths) and facilitating child activities (e.g., driving to and from activities)
Medical Care	Caring for the child's health, including disease-specific treatment regimens (e.g. AED therapy, attending physician/clinic visits, and general health concerns (e.g., well visits, immunizations)
Household Tasks	Engaging in general household chores, including laundry, dishes, cleaning, and grocery shopping.
Meals	Preparing and consuming food (e.g., making dinner, eating lunch)
Recreation at home	Engaging in leisure, relaxation, or social activities inside the home (e.g., reading, watching TV/movie, having friends over)
Recreation outside the home	Engaging in leisure, relaxation, or social activities outside of the home (e.g., going to movies, shopping for clothes, visiting friends and family)
Work/Attending School	Engaging in paid employment in or outside of the home or attending school
Self-care	Caring for one's own physical needs, including bathing, dressing, and personal hygiene
Sleeping/Resting	Engaging in naps or sleeping at bedtime
Other	Includes all activities not encompassed in above categories, including time spent doing the DPD or one-time activities (e.g., decorating the house for holidays)

Table 2

Demographic characteristics

	Total Group (n = 59)	Epilepsy Group (n = 30)	Control Group (n = 29)	
Variable	Mean (SD)/Percentage	Mean (SD)/Percentage	Mean (SD)/Percentage	Group Differences (t- or Fisher Exact tests)
Child Age	6.5 (2.5)	6.4 (2.5)	6.6 (2.5)	n.s.
% Male	63	63	62	n.s.
% Race				
Caucasian	75	70	79	n.s.
African American	15	17	14	
Other	10	13	7	
Highest Duncan Score ^a	61.7 (23.2)	47.7 (20.3)	76.1 (16.1)	t = -5.9; p < .0001
Parent Marital Status				
Married	68	60	76	n.s.
Not Married ^b	32	40	23	
Caregiver				
Mother	55	26	29	n.s.
Father	4	4	0	
Epilepsy Type				
Partial		57		
Generalized		33		
Unclassified		10		

^aNote. Duncan scores are a measure of socioeconomic status, with higher scores representing higher occupational attainment;

^bNot Married = Separated, Single, Widowed, Divorced

Table 3
Parenting Stress

Parenting Stress Variables	Epilepsy Group		Control Group	
	Mean (Standard Error)	% meeting clinical cut-off	Mean (Standard Error)	% meeting clinical cut-off
PSI				
Child Domain ^a	94.7 (3.7)	14%	90.6 (3.6)	7%
Parent Domain ^a	106.7 (4.5)	7%	107.3 (4.5)	4%
Total Stress Score ^a	201.2 (7.4)	7%	197.4 (7.4)	4%
Life Stress Score ^a	10.2 (1.8)	*39%	8.7 (1.8)	14%
FSS	25.4 (SD = 8.0)		N/A	

^aNote. Estimated marginal means controlling for SES,

* Significant difference noted between groups, $p < .05$.