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Development and Validation of the Pediatric Epilepsy Medication Self-Management Questionnaire

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Abstract

Study aims were to describe the development and validation of a Pediatric Epilepsy Medication Self-Management Questionnaire (PEMSQ) for caregivers of children 2–14 years. It was expected that PEMSQ scales would have 1) internally consistent factors and 2) moderate associations with adherence and seizures. Participants included caregivers of 119 children with epilepsy ($M_{age}=7.2$ yrs, 36% female, 72% Caucasian) who completed the PEMSQ, demographics questionnaire, and AED adherence was assessed (e.g., electronic monitors, self-report). Factor analysis was conducted and internal consistency and construct validity were assessed. The final PEMSQ is 27-items with four scales (Epilepsy and Treatment Knowledge and Expectations, Adherence to Medications and Clinic Appointments, Barriers to Medication Adherence, and Beliefs about Medication Efficacy) accounting for 88% variance. Cronbach's alphas ranged from 0.68–0.85. Significant associations were found between PEMSQ scales, adherence, and seizures. The PEMSQ represents the first self-management measure validated for caregivers of children with epilepsy, with clinical and research utility.

Keywords

psychometric; reliability; validity; family management; adherence; children; seizures; efficacy; barriers; disease knowledge

Introduction

Self-management of chronic illnesses, including epilepsy, refers to a patient or family's active involvement in the daily activities they assume to control the illness and its symptoms, minimize its impact on health and quality of life, and cope with the disease (1–5). Specific to epilepsy, self-management refers to the activities required to control seizures and reduce side effects, including taking antiepileptic drugs, engaging in healthy lifestyle behaviors (e.g., good sleep hygiene), active participation in decision making with the healthcare team, and managing stress. The concept of self-management is important

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because epilepsy management primarily occurs in the home environment, not clinic settings. Thus, it is critical to assess what families understand about their disease and treatment regimen, their beliefs about the efficacy of treatment, and facilitators and barriers to adherence. The term *self-management* will be used throughout the manuscript to refer to both self and family-management of epilepsy (4).

While the adult epilepsy literature provides a strong foundation for theories and measures of self-management (6–8), as well as interventions targeted at self-management (9–12), little is known about self-management of pediatric epilepsy. The first step required to assess self-management of pediatric epilepsy is the development of a tool to measure the construct. Once a validated tool exists, researchers can determine predictors of self-management and how self-management affects health and psychosocial outcomes for children with epilepsy.

Because management of epilepsy begins the day of diagnosis, children with new-onset epilepsy and their families are primary targets for assessment and intervention around epilepsy management. Thus, the aim of the present study was to describe the development and validation of a Pediatric Epilepsy Medication Self-Management Questionnaire for caregivers of children newly diagnosed with epilepsy between 2–14 years of age. The primary objective was to assess the reliability and validity of the Pediatric Epilepsy Medication Self-Management Questionnaire. Specifically, it was expected that the Pediatric Epilepsy Medication Self-Management Questionnaire would have 1) factors with high internal consistency (e.g., Cronbach's $\alpha > 0.70$) and 2) moderate associations with an objective and self-reported adherence measure (construct validity). Other secondary study objectives included examining child age, socioeconomic status, months since epilepsy diagnosis, race, gender, marital status, and seizure type differences on the Pediatric Epilepsy Medication Self-Management Questionnaire.

Methods and Procedures

Participants and Procedures

Study participants included 119 children with epilepsy and their primary caregivers seen at the New Onset Epilepsy clinic at Cincinnati Children's Hospital Medical Center (CCHMC). Study inclusion criteria included 1) children 2–14 years of age, 2) absence of significant developmental disorders (e.g., autism, Down syndrome) or comorbid chronic illnesses (e.g., diabetes), 3) willingness to comply with study procedures and 4) provision of written informed consent/assent. Families participating in this study were part of a larger longitudinal study examining adherence to AED therapy over a two-year period.

Caregivers of children with epilepsy who met inclusion criteria were approached by study personnel during their scheduled clinic visit. After obtaining consent, caregivers completed a demographics questionnaire and were given a MEMS TrackCap and bottle to begin electronically monitoring adherence to their prescribed treatment. Caregivers were made aware that the bottle monitored medication taking. As a part of routine clinical care, patients returned to clinic approximately one-month post-diagnosis and every three months thereafter for follow-up appointments. Research study visits coincided with follow-up clinic appointments for the longitudinal study, at which time the primary caregivers completed a series of questionnaires, including the Pediatric Epilepsy Medication Self-Management Questionnaire. Because children in this study were at varying stages of the longitudinal protocol, the last assessment point in which the measure of interest was completed (e.g., Pediatric Epilepsy Medication Self-Management Questionnaire), was used in current analyses. Caregivers received a \$10 gift card for completing the questionnaires and \$10 for bring back the MEMS TrackCaps for a total of \$20. The protocol and consent forms were approved by the CCHMC Institutional Review Board.

Measures

Demographic Background Questionnaire—Primary caregivers completed a background questionnaire documenting the child's race/ethnicity, age, caregiver marital status, and caregiver level of education. Adequate data were available to calculate the Revised Duncan (TSEI2; (13) for each family, which is an occupation-based measure of SES (14). 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.

Pediatric Epilepsy Medication Self-Management Questionnaire—This instrument was developed by the current investigators to assess how caregivers manage their children's seizures for children 2–14 years of age. Item content for the original 40-item measure was based on expert advice from pediatric epileptologists and nurse practitioners, as well as the extant pediatric literature regarding disease management. There were a core set of items that included the assessment of communication with healthcare providers, barriers and facilitators of treatment adherence, beliefs about medications, expectations regarding treatment, and comfort with the treatment regimen. Two response sets were used on the questionnaire: “Strongly disagree” to “Strongly agree” or “never” to “always”. Caregivers of children and adolescents between 2 and 14 years of age completed the measure.

Electronic Monitoring—The Medication Event Monitoring Systems (MEMS® 6 TrackCap) made by AARDEX Corporation is an electronic monitoring system that measures the dosing histories of patient prescribed oral medications. It was used to monitor adherence to AEDs for the current study. It has two components: a standard plastic vial with a threaded opening and a closure for the vial that contains a micro-electronic circuit to register the dates and times the bottle is opened and closed. The MEMS TrackCap stores times and dates for up to 3518 events for a period of 36 months and the data can be transferred to a Windows-based computer. Data from the MEMS TrackCap were downloaded at all follow-up clinic visits. It is important to note that the MEMS® cap did not account for the number of capsules taken at each day; it was assumed that patients extracted the correct number of capsules. Adherence was calculated for the 30 days preceding completion of the PEMSQ with rates ranging from 0–100%.

Self-Reported Adherence—Caregivers were also asked to complete an ad-hoc question regarding how many AED doses their child missed in the past week. This question was used to calculate self-reported adherence [(# of doses prescribed per week - # of doses missed)/# of doses prescribed per week], which ranged from 0–100%.

Seizure History—Seizures experienced between clinic visits was collected with the following two methods. First, a chart review was conducted to assess when caregivers called the healthcare team to inform them that a seizure had occurred. In addition, all families were given a seizure calendar to chart seizures. Combined, this information was used to calculate the presence or absence of seizures in the 3 months prior to completion of the Pediatric Epilepsy Medication Self-Management Questionnaire.

Statistical and Data Analyses

Descriptive statistics (means and standard deviations) were used to characterize demographic variables. Exploratory factor analyses using principal axis factoring with promax rotation were performed on the 40-item pool. Items were deleted for several reasons, including low factor loadings ($\leq .40$; (15)) and high cross-loadings (i.e. when the original loading was below 0.50 and a cross-loading was > 0.40 on another scale). After determination of a meaningful factor structure, internal consistency coefficients using Cronbach's alpha were calculated for each scale. Although coefficients of $r > 0.70$ are

recommended (16), Ware and colleagues (1980) have suggested that alpha coefficients ≥ 0.60 are considered acceptable for newly developed scales (17). To examine construct validity, Pearson's product moment correlation coefficients were calculated to determine the relationship between objective adherence measured via MEMS TrackCaps, self-reported adherence and Pediatric Epilepsy Medication Self-Management Questionnaire subscales. Validity was assessed via independent samples t-tests between children who had experienced seizures in the 3-months preceding the assessment compared to those who had not experienced a seizure on Pediatric Epilepsy Self-Management scales. Secondary exploratory analyses included calculating Pearson correlations to examine the relationship between child age, socioeconomic status, months since epilepsy diagnosis, and Pediatric Epilepsy Medication Self-Management Questionnaire scales, as well as multivariate analyses of variance (MANOVA) to examine race, gender, marital status, and epilepsy type differences in seizure management. Analyses were performed using SAS (version 9.1, 2002–2003, Cary, NC) and SPSS statistical software (version 14.0, 2006, Chicago, IL).

Results

Participants

Of the 127 potential participants, 122 agreed to participate, indicating a recruitment rate of 96% for the longitudinal study. Of the 122 participants, three participants did not return for follow-up to the epilepsy clinic; thus, no research data were available for these children. The final sample included 119 participants. A summary of demographic characteristics of participants are presented in Table 1.

Factor Analysis

An exploratory factor analysis was conducted to examine 40 items on the Pediatric Epilepsy Medication Self-Management Questionnaire for 119 participants. Eigenvalues over one and scree plot data supported the use of a four to six factor solution. Each of these solutions was examined with respect to the pattern of item loadings, cross loadings, and conceptual meaning. A four-factor solution was chosen because it separated a moderate number of items into factors that were statistically distinct and interpretable. Initial items were removed if item loadings were less than 0.40 or significant cross loadings occurred. This resulted in a final instrument with 27 items for caregivers of children 2–14 years of age.

Pediatric Epilepsy Medication Self-Management Questionnaire Scales and Items

The Pediatric Epilepsy Medication Self-Management Questionnaire (PEMSQ) is a 27-item measure consisting of four scales: Epilepsy and Treatment Knowledge and Expectations (8 items), Adherence to Medications and Clinic Appointments (8 items), Barriers to Medication Adherence (8 items), and Beliefs about Medication Efficacy (3 items). These four scales make up a Total Self-Management score. The scales, corresponding items, and item loadings of the factor analysis are presented in Table 2. The percentage variance accounted for by the 27-item measure was 88%. Internal consistency coefficients (e.g., Cronbach's alpha) for each scale were moderate to strong and are presented in Table 3. Internal consistency was lowest for the Beliefs about Medication Efficacy Scale ($\alpha = 0.63$) and highest for Epilepsy and Treatment Knowledge and Expectations ($\alpha = 0.93$). Factor intercorrelations ranged from .23 to 0.85 (see Table 4).

The Epilepsy and Treatment Knowledge and Expectations scale assessed caregivers' perceptions of their understanding of epilepsy and antiepileptic drug therapy, their expectations about managing the disease and their ability to manage the disease in conjunction with their healthcare teams. The Adherence to Medications and Clinic Appointments scale assessed caregivers' perceptions of adhering to the prescribed treatment

regimen and attending regularly scheduled follow-up clinic appointments. The Barriers to Medication Adherence scale assessed caregivers' perceptions of things that make it difficult (e.g. barriers) for their child to take medications as prescribed. The Beliefs about Medication Efficacy scale assessed caregivers' perceptions of how well they believe the medication will work to treat seizures. Finally, the Total Self-Management scale is a compilation of the 4 core scales. All scores are based on raw values, which are added together to make up the score for a particular scale. Items on the Barriers to Medication Adherence scale are reverse scored for consistency. Scores range from 8–40 for the Epilepsy and Treatment Knowledge and Expectations, Adherence to Medications and Clinic Appointments, and Barriers to Medication Adherence scales. Scores ranged from 3–15 for the Beliefs about Medication Efficacy and 27 – 135 for the Total Self-Management Scale. Higher scores represent better self-management.

Construct Validity

Significant associations were found between objective, electronically-monitored adherence and Pediatric Epilepsy Self-Management scales: Adherence to Medications and Clinic Appointments scale ($r = 0.22, p < .05$), Barriers to Medication Adherence Scale ($r = 0.27, p < .01$), Total Self-Management Scale ($r = 0.24, p < .01$). In addition, self-reported adherence was significantly associated with Adherence to Medications and Clinic Appointments scale ($r = 0.28, p < .01$), Barriers to Medication Adherence Scale ($r = 0.35, p < .0001$), Beliefs about Medication Efficacy scale ($r = 0.35, p < .0001$), and Total Self-Management Scale ($r = 0.32, p < .001$). Specifically, as both self-reported and objectively measured adherence to AED therapy increased, self-management related to medication and clinic appointment adherence increased, barriers decreased (higher scores represented less barriers), beliefs about medication efficacy increased and total self-management scores increased.

Independent samples t-tests indicated a significant difference in the Epilepsy and Treatment Knowledge and Expectations scale between children who had seizures versus those who did not have seizures in the three months preceding the assessment, $t(116) = 2.45, p < 0.05$. Specifically, caregivers of children who experienced seizures had lower knowledge and expectation scores ($n=28; M=33.8, SD=6.8$) than those who had not experienced a seizure ($n=90; M=36.2, SD=3.7$). No significant group differences were found for the other PEMSQ scales.

Sociodemographic and Disease Differences

No significant correlations were found between child age, socioeconomic status and Pediatric Epilepsy Self-Management scales. However, significant positive correlations were revealed between time since diagnosis and several Pediatric Epilepsy Self-Management scales, including Epilepsy and Treatment Knowledge and Expectations ($r = 0.25, p < .01$), Beliefs about Medication Efficacy ($r = 0.32, p < .0001$), and Total Self-Management ($r = 0.23, p < .05$). These data suggest that the longer a child has epilepsy, the more their caregivers know about epilepsy and its treatments and the more they believe medications will be effective. No significant gender (*Hotelling's T* = .03, $F(4, 114) = 0.86, p = 0.49$), race (e.g., white versus minority status; *Hotelling's T* = .05, $F(4, 114) = 1.48, p = 0.21$), marital status (e.g., married versus non-married; *Hotelling's T* = .03, $F(4, 114) = 0.74, p = 0.57$), or epilepsy type (e.g., partial, generalized, unclassified; *Hotelling's T* = .06, $F(8, 224) = 0.83, p = 0.58$) differences were found on any Pediatric Epilepsy Self-Management scales.

Discussion

The Pediatric Epilepsy Medication Self-Management Questionnaire is the first measure to assess aspects of self-management that are likely salient to a pediatric epilepsy population,

including understanding of the epilepsy and its treatment, adherence to AEDs, beliefs about the efficacy of treatment, and barriers to treatment. Preliminary results demonstrate that the PEMSQ has strong psychometric properties, including good internal consistency among scales and construct validity with objective and subjective measures of adherence. Thus, the PEMSQ likely has both clinical and research utility in neurology practices.

The PEMSQ is comprised of four scales, including Epilepsy and Treatment Knowledge and Expectations, Adherence to Medications and Clinic Appointments, Barriers to Medication Adherence, and Beliefs about Medication Efficacy. The first step regarding epilepsy management is understanding the disease and recommended treatments, as well as expectations. While the pediatric chronic illness literature has unequivocally stated that knowledge is not sufficient to improve self-management and adherence behaviors (18–21), it is still recognized as a necessary component of self-management. In fact, studies in pediatric epilepsy have demonstrated that caregivers report needing more information about their child's disease (22) with only 29% of caregivers of children with epilepsy knowing the name or dose of their child's current medication. Thus, this scale in particular, can help guide clinicians regarding education efforts to address deficits in a caregivers' knowledge about epilepsy or epilepsy treatment.

The second scale represents one of the most important aspects of self-management for children with epilepsy, adherence to both AEDs and clinic appointments. Items on this scale elucidate caregivers' perceptions regarding their agreement with the treatment plan and ability to follow treatment recommendations, as well as their confidence in AED treatment. This scale was significantly and positively correlated with both subjective and objective measures of adherence, suggesting strong clinical validity. Similarly, the Barriers to Medication Adherence scale suggested that lower adherence rates, measured both subjectively and objectively, was related to more barriers. Specifically, this scale identifies potential reasons that self-management may be difficult for families. For example, commonly reported barriers, such as forgetting (23) or competing activities (20), could be identified and teams are encouraged to problem-solve around such barriers. Newer technologies, such as cell-phone reminders and text-messaging services, or organizational strategies (e.g., pillboxes) may prove useful around forgetting to take AEDs.

The final scale on the PEMSQ is the Beliefs about Medication Efficacy scale, which assesses perceptions about how well caregivers believe the medication will treat seizures. This perception may play a key role in how patients manage epilepsy. For example, two adult studies demonstrated that adherence improves when AED therapy is perceived to be beneficial (24,25). In contrast, personal negative views about treatment efficacy may compromise AED adherence in children (26,27). The perceived importance of AED therapy and the stigma associated with an epilepsy diagnosis also influence self-reported adherence behaviors. Thus, the Beliefs about Medication Efficacy scale may serve as a useful tool to provide further insight into the health-related beliefs that influence epilepsy management.

Additional analyses considered whether pediatric epilepsy self-management varied by age, socioeconomic status, gender, race, caregiver marital status, epilepsy type, seizure absence/presence, and time since diagnosis. As expected, children who had epilepsy for a longer duration had caregivers who perceived themselves to be more knowledgeable about epilepsy and its treatments and believed AEDs were an effective treatment. In addition, children who experienced seizures in the three months prior to completion of the PEMSQ had caregivers who perceived less knowledge and lower expectations about epilepsy and its treatment. This implied that when children are experiencing seizures, caregivers are likely to be more anxious and less confident about their ability to manage epilepsy.

Within a clinical setting, the PEMSQ can be utilized in a number of ways to inform clinical care. For example, the measure is relatively brief (e.g., 27 items) and allows a caregiver to describe critical aspects of family management of pediatric epilepsy. This may serve to not only guide clinical decision-making but provide a tool to improve caregiver/patient-provider communication around current family concerns. For example, if a caregiver scores lower regarding their beliefs about medication efficacy, it may provide clinicians an opportunity to discuss why the caregiver doesn't believe the medication will work and/or make decisions with the caregiver about changing to a new medication. Further, from a provider perspective, the PEMSQ is of low cost, easy to score and interpret, and therefore presents minimal burden for use within a clinical setting.

Although the PEMSQ represents the first pediatric epilepsy self-management measure developed and validated for caregivers of children and young adolescents with epilepsy, the study has some limitations, including 1) children were within the first two years of their diagnosis, 2) data collection occurred at one site, 3) youth were below 14 years of age, and 4) epilepsy management was focused on medications and did not include lifestyle behaviors (e.g., sleep hygiene). Children with intractable epilepsy or those who are older adolescents likely have different perceptions regarding epilepsy management. In fact, assessing adolescent's own perceptions about disease management is an important direction for future research because caregiver and adolescent perspectives often differ around this issue. This study represents initial psychometric evaluation of the PEMSQ. Additional studies should address test-retest reliability and confirm both the factor structure.

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Table 1

Demographic data on children with epilepsy and their caregivers (n = 119)

	N	M (SD)	%
Child Age (years)		7.2 (2.9)	
Child Sex			
Girls	43		36
Boys	76		64
Child Race/Ethnicity			
White: Non-Hispanic	86		72
White: Hispanic	4		3
Black	20		17
Asian	1		1
Biracial/Multiracial	8		7
Seizure Type			
Partial	69		58
Generalized	30		25
Unclassified	20		17
Prescribed Antiepileptic Drug			
Carbamazepine/Carbatrol	53		44
Valproic Acid	44		37
Levetiracetam	9		8
Oxcarbazepine	3		2
Ethosuximide	2		2
Gabapentin	1		1
Lamotrigine	1		1
Topiramate	6		5
Time Since Diagnosis (months)		12.57 (8.7)	
Participating Caregiver			
Mother	101		85
Father	14		12
Great Aunt/Other	4		3
Marital Status			
Married	78		66
Separated/Divorced	17		14
Single/Never Married	23		19
Widowed	1		1
Duncan score*		53.02 (20.1)	

* Based upon Duncan TSEI2 for head of household, a measure of occupational attainment. The mean TSEI2 score reflects occupations such as property managers, physician's assistants, mail carriers, sheriffs/law enforcement and fire prevention occupations.

Table 2**Pediatric Epilepsy Self-Management Questionnaire: Exploratory Factor Loadings**

Item	Epilepsy and Treatment Knowledge and Expectations	Adherence to Medications	Barriers to Medication Adherence	Beliefs about Medication Efficacy
Understood what side effects to look for	0.87	−0.01	0.14	−0.03
Confident about seizure freedom	0.77	−0.10	−0.17	−0.03
Confident about managing side effects	0.75	0.17	0.01	0.03
Health care providers are easy to contact	0.71	0.12	−0.10	−0.13
Know who to contact with questions	0.69	0.26	−0.04	−0.04
Health care team listens	0.65	0.34	−0.08	−0.07
Understand risks of discontinuing medications	0.64	0.19	−0.07	0.08
Doctors/Nurses fully explained diagnosis	0.62	−0.11	0.23	0.27
Child receives medications most of the time	−0.24	0.69	−0.16	−0.05
Important for child to receive treatment as directed	0.02	0.64	0.11	0.39
Will see my child takes medications as prescribed	0.12	0.63	−0.08	0.24
Transportation available to bring child to appointment	0.36	0.57	0.09	−0.05
Usually follow medical advice prescribed for child/self	0.27	0.54	0.02	−0.02
Family members agree with treatment plan	0.15	0.48	−0.08	0.01
It is important to assure my child takes meds daily	0.24	0.47	−0.01	0.25
No difficulty bring child to follow-up appointments	0.23	0.43	−0.03	−0.21
Medications are difficult to swallow	−0.14	0.23	0.70	−0.18
Ran out of medication	0.15	−0.24	0.61	−0.04
Embarrassed to take medications in front of others	0.05	0.02	0.54	−0.04
Difficult to get medication from pharmacy	−0.04	−0.14	0.51	0.15
Dislikes taste of medicine	−0.19	0.17	0.46	−0.22
Activities interfere with taking medications	−0.07	−0.13	0.44	0.11
Forget to give medications	0.03	−0.18	0.44	0.04
Child refused to take medication	0.10	0.01	0.43	−0.33
Medication is necessary for my child's condition	−0.02	0.22	0.03	0.73
Medication chosen will control seizures	0.31	−0.01	−0.03	0.59
Medications fit into our daily schedule	−0.18	−0.12	−0.04	0.46

Note: Bold-faced and shaded text represents the factor loading of the item on its intended scale.

Table 3

Pediatric Epilepsy Self-Management Questionnaire: Means (SD) and Reliability Coefficients

Scale	Mean (SD)	Cronbach's Alpha
Epilepsy and Treatment Knowledge and Expectations	35.52 (4.79)	0.93
Adherence to Medications and Clinic Appointments	36.24 (4.14)	0.87
Barriers to Medication Adherence	36.25 (3.81)	0.76
Beliefs about Medication Efficacy	12.51 (2.42)	0.63
Total Self-Management	120.53 (11.22)	0.85

Table 4

Pediatric Epilepsy Self-Management Questionnaire: Scale Interrelations

Pediatric Epilepsy Self-Management Questionnaire Scales				
	Epilepsy and Treatment Knowledge and Expectations	Adherence to Medications	Barriers to Medication Adherence	Beliefs about Medication Efficacy
Epilepsy and Treatment Knowledge and Expectations				
Adherence to Medications	0.71***			
Barriers to Medication Adherence	0.23*	0.25**		
Beliefs about Medication Efficacy	0.37***	0.39***	0.25**	
Total Self-Management	0.85***	0.84***	0.59***	0.61***

Note.

* $p < .05$,

** $p < .01$,

*** $p < .001$