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Continuing Psychosocial Care Needs in Children with New-Onset Epilepsy and Their Parents

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Abstract

Problem—Children with new-onset epilepsy and their parents have many psychosocial care needs, including concerns and fears and needs for information and support. No prospective studies address psychosocial care needs at 12 and 24 months after seizure onset. It is unknown if psychosocial care needs are associated with children's attitudes toward having epilepsy or with parental responses to their child's epilepsy. Our study addresses this knowledge gap.

Method—Members of 143 families took part. Children were 8 to 14 years of age and had at least two seizures. Parents and children completed Psychosocial Care Need Scales at 3, 6, 12, and 24 months after the first seizure. Children also completed the Child Attitude Toward Illness Scale, and parents completed the Parent Response to Child Illness scale. Data were analyzed using descriptive statistics and correlations.

Results—Although psychosocial care needs were highest at the 3-month data collection for both parents and children, some worries and concerns and needs for information and support persisted for 24 months. In children more psychosocial care needs were associated with more negative attitudes toward having epilepsy. In parents, high psychosocial care needs were associated with a more negative impact on family life.

Implications—A substantial number of parents and children have unmet psychosocial care needs that are associated with more negative child attitudes and a negative impact on family life, even 24 months after the onset of seizures. Nurses should assess both children and parents for these needs at every encounter with the health care system in order to address their needs.

A diagnosis of pediatric epilepsy precipitates a crisis, forcing parents to accept a new vision for their child (Ellis, Upton, & Thompson, 2000). High levels of anxiety frequently accompany this process (Chapieski, Brewer, Evankovich, Culhane-Shelburne, Zelman, & Alexander, 2005). Parental overprotection and altered discipline can result, and child behavior problems frequently follow (Mitchell, Scheier, & Baker, 1994; Rodenburg, Meijer, Dekovic, & Aldenkamp, 2005; Rodenburg, Stams, Meijer, Aldenkamp, & Dekovic, 2005; Sheeran, Marvin, & Pianta, 1997; Williams, Stell, Sharp, DelosReyes, Phillips, Bates et al., 2003). Lack of knowledge and misconceptions about epilepsy have been associated with parental anxiety in several studies (Austin et al., 2008; Chapieski et al., 2005; Shore et al., 1998); whereas other studies have shown that education about epilepsy is effective in reducing parental anxiety (Austin, McNelis, Shore, Dunn, & Musick, 2002; Shore, Perkins, & Austin, 2008). Children take their cues from their parents and develop worries and concerns about their epilepsy (Austin, Dunn, Perkins, & Shen, 2006; McNelis, Musick, Austin, Dunn, & Creasy, 1998).

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More needs for information about child epilepsy were associated with greater worry about having epilepsy and more negative attitudes toward having epilepsy (McNelis, Buelow, Myers, & Johnson, 2007; McNelis et al., 1998).

In a longitudinal study of parents of children with new-onset seizures, we found that many parents continued to experience uncertainty six months after their child's seizures began (McNelis et al., 1998; Shore et al., 1998). They sought a cause for the diagnosis such as a brain tumor or past injuries and wondered about the long-term prognosis. Parents also continued to worry about the effects of seizures and treatment in three areas: on their child's brain (brain damage, death, cognitive deficits), on the child's mental health, and on the family. These parents were concerned about how to manage their child's seizures, including worries related to the medical diagnosis, negative responses of others to the epilepsy, lifestyle restrictions, and mental health problems. When parents with new-onset seizures were asked what they needed, parents requested information about their child's diagnosis and treatment. They wanted support beyond that provided by family and friends, specifically support from health care professionals (Austin, Oruche, Dunn, & Levstek, 1994). These findings were echoed in a study of parents and children with chronic epilepsy (McNelis et al., 1998; Shore, et al., 1998). They reported similar concerns regarding need for information and fears and concerns, strongly suggesting that many parents and children have unmet needs over a period of years.

Several child outcomes are related to their parents' reaction to their disorder. Studies have shown that the quality of the parent-child relationship is associated with child psychopathology in families having a child with epilepsy (Rodenburg et al., 2005). In a comprehensive review of the literature, Ellis and colleagues (2000) found that parent-child relationships were poorer in children with epilepsy than in families of children with other chronic disorders. These relationships were related to child outcomes such as quality of life and behavior problems. In a longitudinal study of 88 children with epilepsy and their families, Mitchell and colleagues (1994) found that not only seizure history and duration of epilepsy were consistent predictors of child outcomes, but parental attitudes about epilepsy were highly related to child outcomes as well. Poor child outcomes were associated with exaggerated fears and protective attitudes in their parents (Mitchell et al., 1994). In addition, compared to parents of children with other disorders, parents of the children with epilepsy have been found to have relationships that are less supportive, less affectionate, and less performance-oriented (Rodenburg et al., 2005). Other studies have found associations between parent attitudes and the child's perception of stigma (Carlton-Ford, Miller, Nealeigh, & Sanchez, 1997; Mitchell et al., 1994).

Child Need for Information: In our past research and that of others, children with epilepsy had many concerns and fears about their diagnosis. For example, in focus groups with children with epilepsy, McNelis and colleagues (2007) found that children were afraid to talk to their parents because they did not want to worry them. Austin and colleagues (1993) found that children reflected their parents' fears including those related to procedures, dying, and becoming mentally ill. Others have found that children feel that having epilepsy is stigmatizing and keep their condition a secret from their friends (MacLeod & Austin, 2003).

For the purposes of this study, psychosocial care needs were conceptualized as psychological needs of parents and children within the social context of adaptation to child epilepsy. We based this conceptualization on a review of the literature and interviews with parents and we reported these findings in a previous article (Austin, Oruche, Dunn, & Levstek, 1994.) No study has evaluated psychosocial care needs beginning near the time of seizure onset and up to two years later in children with recurring seizures and their parents. Additionally, no research has examined relationships between (a) parents' psychosocial care needs and their responses to their children's epilepsy, and (b) children's psychosocial care needs and their attitudes toward having epilepsy. Our research addresses this gap in the literature.

Our study was designed to answer the following questions:

1. What are the psychosocial care needs of parents of children with recurring seizures at 3, 6, 12, and 24 months after diagnosis?
2. What are the psychosocial care needs of children with recurring seizures at 3, 6, 12, and 24 months after diagnosis?
3. What are the relationships between parent psychosocial care needs and their responses to their child's epilepsy?
4. What are the relationships between child psychosocial care needs and their attitude toward having epilepsy?

Methods

Our research was part of a larger longitudinal study of mental health problems in children with new-onset seizures. Parents and children were interviewed within 6 weeks of the child's first seizure, and subsequently at 3, 6, 12, and 24 months after that event. Parents of children who experienced a first seizure episode were recruited from clinics, private neurology practices, EEG laboratories, and emergency rooms in two large metropolitan areas (Indianapolis, Indiana, and Memphis, Tennessee). Children were 4 to 14 years of age at the time of the first recognized seizure. Families were excluded if their child had another chronic health condition, an IQ lower than 70, a sibling with a chronic health condition, or a known precipitant for their seizure (e.g., head trauma). To be eligible for enrollment, both the major caregiving parent and the child with epilepsy were required to participate.

The study was approved by the institutional review boards at Indiana University/Purdue University, Indianapolis and LeBonheur Children's Hospital, Memphis. Informed consent was obtained from participating parents and assent was obtained from the children. Research assistants with experience in the health care system collected data via structured telephone interviews from parents and children who were 8 years of age or older.

Instruments

Parent Measures—Parent psychosocial care needs were measured with three sections of the Parent Report of Psychosocial Care Scale (Austin, Dunn, Huster, & Rose, 1998; Shore et al., 1998). This scale was developed through content analysis from data obtained in open-ended interviews with parents of children with epilepsy (Austin, Oruche, Dunn & Levstek, 1994). The generated items were reviewed by experts in family adaptation to epilepsy and the scale was revised. Psychometric properties of the scales are described in our previous work (Austin et al., 1998). The parent scale consisted of three subscales: Needs for Information, Needs for Support, and Worries and Concerns.

Parents responded to six questions asking their needs for information and eight items regarding their needs for support in relation to their child's seizure condition. Responses were on a scale of 1 (*no need*) to 3 (*strong need*). The alpha coefficients ranged from .91 to .94. A third section of this scale was used to measure parents' concerns about their children's seizure condition. Parents rated their level of concern on five items using responses from 1 (*not at all*) to 4 (*very much*). Alphas coefficients were .82, .84, .84, and .84 for parent concerns at 3, 6, 12 and 24 months respectively. For parent needs for information, alpha coefficients were .92, .92, .93, and .92 and .92, .93, .94, .93 for needs for support at the same data collection points.

Parents' responses related to seizures in their child were measured with the Parent Response to Child Illness scale (PRCI). The PRCI is a 35-item scale with five subscales: child support, child autonomy, family life/leisure, condition management, and child discipline. Internal

consistency reliability was reported at .75, .87, .77, .64, and .76 respectively. Test-retest reliability from 3- and 6-month data collections were .62, .47, .51, .72, and .71, respectively. The associations between parent positive mood and all of the subscales were in the predicted direction, providing support for validity. Readers are referred to a recent report by Austin and colleagues (2008) for more information about this instrument.

Child Measures—Child psychosocial care needs were measured by the three subscales of the Child Report of Psychosocial Care (Austin, Dunn, Huster, & Rose, 1998; McNelis et al., 1998). Like the parent version, the Child Report of Psychosocial Care contains three subscales. It was developed through the process described above with the exception that children were interviewed using open-ended questions to identify needs and concerns.

The *Need for Information* and the *Need for Support* subscales contain 12 items pertaining to areas in which children need information (6 items) or help (6 items) in relation to their seizure condition. Each question in this subscale begins with the stem: “At this time would you like ...” Children responded with either *Yes* or *No*. The coefficient alphas ranged from .75 to .88. The third subscale, *Concerns and Fears*, measures how often children worried about phenomena associated with their seizure disorder. They responded on 5-point scales: 1 (*never*), 2 (*not often*), 3 (*sometimes*), 4 (*often*), and 5 (*very often*) with higher scores reflecting higher need. Alpha coefficients for child concerns were .77, .78, .85, .84, at 3, 6, 12, and 24 months, respectively.

Child attitude toward epilepsy was measured with the Child Attitude Toward Illness Scale (CATIS) developed by Austin and colleagues (1993). The CATIS consists of 13 items that measure children’s feelings about having epilepsy. Each item is followed by a 5-point response format specific to that item. For example, the item “How good or bad do you feel that it is to have epilepsy?” has the following responses: 5 (*Very good*), 4 (*Good*), 3 (*Not sure*), 2 (*A little bad*), and 1 (*Very bad*). Internal consistency reliability ranged from .79 to .87.

Sample

The sample consisted of members of 143 families who took part in the larger study. Families were included in this study if their child experienced more than one seizure, and if they provided data at one or more data collection points. There were 142 mothers, 4 fathers, and 98 children who met these criteria. For three children, both parents provided data at different data collections. The majority of the children were Caucasian (78%) and female (55%). The average parent was in his or her middle thirties (mean 34.8 years for mothers, 36.5 years for fathers), Caucasian, and had two years of education beyond high school. The mean child age was 8.7 years at baseline. Although all seizure types were included, most had either generalized tonic-clonic seizures (35%) or complex partial seizures (24%). In general, seizures were well controlled in the children.

Data Analysis—Descriptive statistics were used to answer research questions 1 and 2. The percentages of parents and children who indicated some needs or strong needs for psychosocial care are presented in Tables I and II. Spearman correlation coefficients were calculated to answer research questions 3 and 4. Data were analyzed with SAS version 9.1.

Results

Results for each of the four research questions are discussed below.

1. *What are the psychosocial care needs of parents of children with recurring seizures at 3, 12, and 24 months after diagnosis?* (See Table I.) Parents’ needs for information and support were highest at 3 months. Although these needs were lower at 24 months, they still were high.

For example, at 12 months more than 50% of parents still had concerns for all areas except counseling. Moreover, at 24 months more than a third of the parents still had concerns for all items. Possible causes for seizures, handling future seizures, and fears about the future had the highest percentages at 24 months after the child's first seizure.

2. *What are the psychosocial care needs of children with recurring seizures at 3, 12, and 24 months after diagnosis?* (See Table II.) The percentage of children who reported needs for both information and support is slightly lower at all points in time when compared to those of their parents. In general, children's need for information was greater than their need for support. At both 12 and 24 months, children reported need for information on 40% to 64% of the items. At both 12 and 24 months, children reported need for support on 32% to 64% of the items.

3. *What are the relationships between parent psychosocial care needs and their response to child epilepsy?* (See Table III.) Multiple significant relationships were found between parent psychosocial care needs and their responses to their child's epilepsy. Although there was not a significant association between parent psychosocial care needs and parents emotional support of their child, significant associations were found between each of the four remaining parent responses. The strongest relationships were noted between psychosocial care needs and parent encouraging child autonomy and between parent psychosocial care needs and family life and leisure.

4. *What are the relationships between child psychosocial care needs and child attitude toward having epilepsy?* (See Table IV.) The correlations between child concerns and needs and child attitude toward illness were highly significant in all areas, and they continue through the first 24 months after diagnosis.

Discussion

The purpose of this study was to describe the levels of psychosocial care needs (i.e., need for information, need for support, and concerns about epilepsy) in children with new-onset seizures and their parents during the first two years after seizure onset. In addition, relationships were explored between parent psychosocial care needs and their responses to their child's seizures and between children's psychosocial care needs and their attitude toward having epilepsy.

Our major finding was that high proportions of parents and children have information and support needs that remain surprisingly high during the first two years despite the fact that in this sample the children's seizures were relatively well-controlled. It was striking that, even after two years, one-third to one-half of parents reported needs for information and support and continued to experience fears and concerns about their children's epilepsy. For example, 54% of parents were worried about their child's future at two years and 46% reported that they still needed support and encouragement. This finding is congruent with those from other studies (McNelis et al., 2007). In one recent study, parents reported receiving most of their information from physician's offices and the Internet (Lu, Wirrell, & Blackman, 2005). However, our results indicate that these sources are insufficient to meet all of parents' perceived needs.

Children also reported psychosocial care needs at all time periods. Although children's concerns and needs were not quite as high as those of their parents, up to 40% of children reported concerns and needs for information and support two years after their first seizure. It may not be surprising that parents have more concerns and needs for information and support than their children. Parents have more responsibility for management of the disorder, more life experience, and more awareness of the financial aspects of having a child with a chronic condition. Children frequently assume that their parents are doing a good job of taking care of their health needs.

One possible interpretation of our findings is that they are an indicator of unmet needs that persist from the period of diagnosis throughout the subsequent two years. There is limited support in the literature for this view. One study used the Parent and Child Reports of Psychosocial Care as part of the evaluation of a psychoeducational intervention (a one-time program presented over two days). The children with epilepsy at this program were diagnosed a year or more prior to attendance. Although the psychosocial care needs of both parents and adolescents attending the program decreased after the intervention, the improvements in the parents were more dramatic when contrasted with those in their children (Shore et al., 2008). However, children reported fewer needs than their parents did prior to the intervention. Both parents and children continued to show some improvement in psychosocial care needs at 1 month and 6 months after the intervention took place. A feasibility study of the Be Seizure Smart program also used the Psychosocial Care Scales as outcome measures and similar patterns of improvement were found (Austin et al., 2002).

It is also possible that needs evolve over time and that as parents learn about and change with their child and his or her condition, they require more advanced instruction and a different type of support. A comprehensive family model that addresses parents' and children's changing needs is needed to guide interventions for children with epilepsy and their parents.

The relationships between psychosocial care needs and parents' responses to their child's illness are striking. Although parents appear to emotionally support their children regardless of their own concerns and needs, greater confidence in their ability to manage their seizure condition, and fewer changes in family life and leisure activities are associated with fewer psychosocial care needs. Our findings suggest that greater unmet needs and concerns might reduce the parents' ability to manage the disorder; it might be that when parents have less confidence in their ability to manage the epilepsy, it could negatively affect their children's ability to manage their own condition as they get older. Furthermore, because less adaptive family life and leisure activities were associated with greater unmet parental psychosocial care needs, unmet need for care has ramifications for the entire family. We know from previous work (Austin, Risinger, & Beckett, 1992; Mitchell et al., 1994; Rodenburg et al., 2005) that family mastery (characterized by cooperation, organization, and effective problem solving) is strongly related to child outcomes. This study suggests that addressing parent psychosocial care needs early in the course of a child's epilepsy might promote family mastery.

The relationships between concerns and needs of the children and their attitude toward having epilepsy were very strong at all points in time. This finding suggests that nursing interventions to address identified concerns and needs have the potential to improve child attitude towards epilepsy. Our feasibility study found improved attitudes in both children and their parents after they received tailored information about epilepsy based on an assessment including the Psychosocial Care Scales (Austin, McNelis, Shore, Dunn, & Musick, 2002).

Limitations and Strengths

Our sample may not have adequately represented all families of children with new-onset recurring seizures. Families in our study were predominantly Caucasian and had relatively high levels of education. We did not include parents of children with low IQ, a frequent comorbidity. Furthermore, the seizure disorders of the children in our study were relatively well controlled. However, our study also had strengths. We followed the families for two years and collected data at four points in time. Our sample was collected from two metropolitan areas and multiple types of care delivery systems. One of the study's greatest strengths was identifying and obtaining information from children and their families during the first two years after the onset of the seizure disorder.

Nursing Implications. Our findings document that both parents and children have needs for information and support that are not being met; moreover, many of these needs do not decrease appreciably over time. These unmet needs may influence their day-to-day ability to manage the condition and its social implications. For this reason, comprehensive care of the children with epilepsy and their families requires nursing assessment of psychosocial care needs at every encounter. The parent and child versions of the psychosocial care need scale could be used as an assessment tool. Given that encounters with health care professionals may be infrequent and brief, parents need additional sources of reliable information and support related to their child's seizure disorder that can be accessed whenever they perceive a need. Further research is needed to test interventions for this vulnerable population.

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Table I

Percent of parents of children with recurrent seizures who have each need at each visit.

Item	3 mo <i>n</i> = 138	6 mo <i>n</i> = 139	12 mo <i>n</i> = 135	24 mo <i>n</i> = 122
Need for Information				
Information on seizures	80	67	63	49
Treatment Information	73	74	67	48
Possible causes	86	78	75	59
Handling future seizures	72	70	65	50
Activity restrictions	60	59	53	39
Injury protection	67	58	50	40
Need for Support				
Support and encouragement	68	69	56	47
Handling responses of others	49	54	47	36
Discuss fears about future	68	68	57	54
Discuss fears about seizures	70	65	50	41
Discuss mental health concerns	57	57	49	40
Handling child's response	61	60	49	39
Have child talk with other kids	71	63	57	49
Have child receive counseling	48	42	44	37

Table II

Percent of children with recurrent seizures who have each need at each visit.

Item	3 mo <i>n</i> = 59	6 mo <i>n</i> = 65	12 mo <i>n</i> = 81	24 mo <i>n</i> = 85
Need for Information				
About seizure condition	68	55	54	46
About medication	56	48	49	40
About possible causes of seizures	75	71	63	64
About handling future seizures	76	72	60	56
About activity restrictions	62	48	51	45
About keeping safe during a seizure	78	72	62	62
Need for Support				
To talk to someone about feelings	49	38	41	40
To talk to someone about how to tell friends	28	29	32	35
To talk to someone about any concerns or fears	34	38	38	33
To talk to someone about the future	59	43	46	47
To talk to other kids with a seizure condition	71	66	59	64
To talk to someone about seizures at school	53	51	49	49

Table III

Spearman correlations among parent needs and parent responses at 24 months

	Child Support	Child Autonomy	Child Discipline	Family Life/Leisure	Condition Management
Overall Needs	-0.04	-0.27***	-0.27***	-0.24**	-0.20**
Need for Information	-0.01	-0.21**	-0.23**	-0.19**	-0.23**
Need for Support	-0.08	-0.29**	-0.29***	-0.25***	-0.15
Parent Concerns	-0.11	-0.25***	-0.13	-0.36***	-0.11

*
 $p < 0.1$ **
 $p < 0.05$ ***
 $p < 0.01$

Table IV

Spearman correlations among child needs with child attitudes

	3 months	6 months	12 months	24 months
Overall Needs	-.43***	-.28**	-.33***	-.34***
Need for Information	-.30**	-.14	-.23**	-.40***
Need for Support	-.42***	-.36***	-.37***	-.20*
Child Concerns	-.69***	-.62***	-.63***	-.54***

*
 $p < 0.1$ **
 $p < 0.05$ ***
 $p < 0.01$