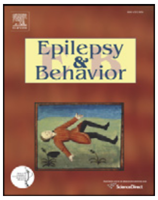
Epilepsy & Behavior 27 (2013) 497–503

Contents lists available at SciVerse ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh



Parenting and restrictions in childhood epilepsy

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ARTICLE INFO

Article history:
Received 4 September 2012
Revised 22 January 2013
Accepted 29 January 2013
Available online 19 April 2013

Keywords:
Epilepsy
Children
Restrictions
Overprotective parenting
Indulgent parenting
Moderation effect

ABSTRACT

Purpose: From the overprotection literature, the predictive and interactional (moderation) effects of controlling and indulgent parenting on restrictions in children with epilepsy were examined.
Methods: Parents of 73 children with epilepsy completed questionnaires on parenting, restrictions, and functional status. Predictive and moderation effects were tested using multiple regression analysis. Moderation was tested with interactive computational methods.
Results: Restrictions were significantly ($R^2 = .38$, $F\Delta = 6.59^{***}$, $p < .001$) predicted from seizure frequency ($\beta = .24^{*}$, $p < .05$), functional status ($\beta = -.42^{***}$, $p < .001$), and interaction between controlling and indulgent parenting ($\beta = .28^{**}$, $p < .01$). Moderation occurred predominantly for high values of control: controlling parents who were not indulgent imposed fewer restrictions. In contrast, controlling parents who were indulgent imposed more restrictions.
Conclusion: Parents who were controlling and more indulgent imposed more restrictions. Clinicians should ask parents about parenting and restrictions. Future research should examine whether the current study's findings can be replicated.

1. Introduction

Epilepsy is the most common neurological condition in childhood and is characterized by recurrent seizures. Children with epilepsy are at a high risk for psychopathology [1], and psychopathology, in turn, is associated with restrictions in children with epilepsy [2]. Restrictions are a generic aspect of chronic conditions that children with epilepsy share with children having other types of chronic conditions (e.g., asthma or diabetes) [1].

Although some restrictions in epilepsy are required (e.g., bathing/swimming under supervision) [3], many restrictions can be considered as unnecessary and may hamper autonomy and independence and negatively affect psychosocial adjustment and quality of life [4,5]. In line with these findings is the observation that attaining autonomy is hampered in children with epilepsy [6,7].

Restrictions imposed to children with epilepsy appeared to be strongly correlated to neurologic variables including seizure frequency and functional independence. Carpay et al. [8] found that for children with at least one seizure in the previous year, 83% of the parents reported at least one restriction due to epilepsy. Restriction scores were associated with physicians' advice about restrictions and with parental concern about the child's epilepsy. Carpay et al. suggested that imposing restrictions would probably not reflect seizure-related risks but rather overprotective parenting.

The operationalization of parental overprotection has been seen as ambiguous [9,10]. Levy's [11] original work provided the blueprint for this ambiguity, defining overprotection as both excessive and lack of control. In the literature, two separate lines of investigation sprouted: on the one hand, overprotection is regarded as *excessive* and *over-controlling* parenting [12] and on the other, *indulgent* parenting is regarded as a consequence of the vulnerable child syndrome (VCS) [13]. Indulgent parenting associated with VCS refers to parental difficulties with limit-setting behaviors due to parental anxiety that their child will be harmed [9,10]. After reviewing the overprotection research, Thomasgard and Metz characterized parental overprotection as (1) highly supervising and vigilant parenting, (2) having difficulties with separation from the child, (3) parenting that maintains

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1525-5050/$ – see front matter © 2013 Elsevier Inc. All rights reserved.
http://dx.doi.org/10.1016/j.yebeh.2013.01.026

dependent behavior, and (4) highly controlling parenting [10]. Parental overprotection reflects parenting that is not age-appropriate and thus, not in concordance with the child's developmental level. Thus, the picture that arises from the literature is that overprotection relates, on the one hand, to a controlling element (i.e., excessive physical or social contact, infantilization, excessive parental control, intrusiveness/prevention of independent behavior) and, on the other, to an anxious element, as claimed by the VCS theory. As a consequence, it is assumed that parents may develop an overprotective parenting style that is both controlling and indulgent in nature [4].

In children with chronic conditions, parental overprotective behaviors are considered as adaptive (protective) parenting behaviors, which might generate positive effects for child adjustment, including the child's recovery and prevention from physical harm or failure [4,7,14]. However, the rather excessive overprotective behaviors may hamper the development of chronically ill children. These behaviors can be considered as well-intentioned but inadequate parental helping (miscarried helping, [15]) and may interfere with the child's growing need for autonomy [15,16].

From the overprotection literature, the idea that overprotection generates negative effects on child outcome mainly with regard to child independence and autonomy can be derived [4,10]. A review on family factors in children with epilepsy showed that children with epilepsy and psychopathology perceived their mothers as more overprotective when compared to children with epilepsy without psychopathology [17]. Chapieski et al. [7] found that maternal anxiety was associated with maternal overprotection but that maternal anxiety predicted the adjustment of children with epilepsy better than overprotection.

Summarizing the findings from the literature, it may be assumed that parental concern [4,7,8] about a child's well-being may result in imposed restrictions due to overprotective behavior (for the purpose of this study: controlling behaviors) and indulgent parenting and so may hamper the child's growing need for autonomy. An interesting point that follows from this discussion is how these parenting factors interact with each other in the context of childhood epilepsy.

Examining controlling and indulgent parenting in relation to restrictions in children with epilepsy would add to the existing research since these factors have been discussed but have never been investigated for associations with restrictions. It was demonstrated that seizure frequency and functional status are related to restrictions in children with epilepsy [2]. Functional status is a construct that was defined to measure condition severity in the way it impacts on age-appropriate child development with regard to physical, social, and personal activities [18,19]. Testing seizure frequency and functional status simultaneously with controlling behaviors and indulgent parenting within one model additionally adds to our knowledge because it not only reveals which factors predict restrictions to the greatest extent, but it also allows the determination of whether and how controlling and indulgent parenting interact with each other in predicting restrictions.

As parenting behaviors are known to have an impact on child adjustment in epilepsy [20], we suppose that these factors may also be related to parentally imposed restrictions due to epilepsy. Consequently, we aim to examine whether parental perceptions of child's functional status and controlling and indulgent parenting are related to parentally imposed restrictions due to epilepsy. In this respect, this study is exploratory in nature as, to our knowledge, there is no empirical evidence about the nature of these interactions. Child age and child gender were added as covariates in the model as earlier research showed that the impact of epilepsy on child autonomy seems to be more severe for girls [21]. Child age was included as a covariate because parents may be more inclined to impose restrictions on younger children. Based on our assumptions, we used a model that predicts relations between imposed restrictions in children with epilepsy and child factors (age and gender), epilepsy factors (seizure frequency and functional status), and parenting factors (controlling and indulgent parenting) (see Fig. 1).

2. Method

2.1. Sample

Parents of children with epilepsy referred to the outpatient clinic of the tertiary epilepsy center Kempenhaeghe (The Netherlands) completed questionnaires concerning parenting, parental perceptions, and restrictions. The study was approved by the institutional review board of the Kempenhaeghe Institute, and informed, written consent was obtained from all participating parents. The criteria for inclusion in the study were families of children aged between 4 and 18 years with an IQ above 70 and without psychiatric disorders; parents had to read and understand the Dutch language adequately. An exception was made to include children with attention deficit and hyperactivity disorder (ADHD), which is very common in children with epilepsy [22,23].

The number of potential family inclusions was 135 of whom only 91 children met the inclusion criteria. About 33% of the families did not participate in the study because of not fulfilling the inclusion criteria (i.e., low IQ/severe mental retardation: five children), refusal to participate, and nondelivered questionnaires. No information about nonparticipating families was available, unfortunately. Of 91 parents, 73 parents completed the restriction questionnaire. Since restrictions were the dependent variable in this study, the data of these 73 parents were used. Sixty-five mothers (89%) and eight (11%) fathers completed the questionnaires. All children (4 to 15 years, M = 8.7 years) were of Dutch origin. Demographic information and seizure information were obtained from the children's medical files (Table 1). The definition of the type of epilepsy was based on the International League Against Epilepsy criteria [24] (study variables were operationalized before 2010, so the 1989 classification was used).

2.2. Measures

2.2.1. Restrictions

Restrictions were measured with The Hague Restrictions in Childhood Epilepsy Scales (HARCES) [8], consisting of 10 items: two global items that measure the amount of supervision and 8 items that measure the degree of freedom affected in multiple domains of daily life or activities (e.g., "Does the epilepsy influence the freedom of your child to go swimming?"). The HARCES has to be answered on a 4-point Likert scale, ranging from 'none' (1) to 'a lot' (4) for the global items and ranging from 'never' (1) to 'always' (4) for the items concerning daily life or activities. The calculated alpha for this study was .90.

2.2.2. Seizure frequency

Information on seizure frequency was obtained from clinical records. On the basis of the approach of Austin et al. [21], scores ranging from 1 to 5 were assigned, referring to no seizures (1), yearly seizures (2), monthly seizures (3), weekly seizures (4), and daily seizures (5). Mean frequency score was 3.4 (SD = 1.16).

2.2.3. Functional status

Parental attributions of epilepsy-related behavioral problems were measured with the Functional Status II (R) (FSII (R)) [18,25]. Parents rated firstly a general behavioral scale consisting of 14 items (e.g., "Does he/she sleep well?"), ranging from 'seldom or never' (0), 'now and then' (1), to 'almost always' (2). For the items rated 'seldom or never' or 'now and then', parents have to rate whether the problem is due to the child's condition or not on a Likert scale ranging from 'not at all' (0), 'partly' (1), to 'fully' (2). If parents rate that the behavioral problems are 'not at all' related to the condition (0), the original score on the general behavioral scale is rated as if there was no problem (2). A higher score indicates better functional status. The alpha for the present study was .82.