



## Parenting stress does not normalize after child's epilepsy surgery



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### ABSTRACT

**Purpose:** This study aimed to investigate parenting stress expressed by parents before and two years after their children's epilepsy surgery.

**Methods:** *Subjects:* Parents of 31 consecutively included surgery patients with epilepsy and parents of 31 healthy sex- and age-matched control children were the subjects of this study. *Materials and procedure:* The questionnaire 'Parenting Stress Index', which distinguishes a Parent domain (stress leading parents to feel themselves inadequate) from a Child domain (child features felt by parent to cause stress) was completed before surgery of the patients and two years thereafter. At both time points, intelligence examination of the child was part of a comprehensive neuropsychological assessment, as were evaluations of recent stress-enhancing life events and epilepsy severity.

**Results:** Prior to surgery, total parenting stress was significantly higher in parents of patients than in parents of controls. Two years after surgery, total parenting stress had decreased significantly in parents of patients. The scores on parent-related subscales Role Restriction and Spouse and on the child-related subscale Distractibility/Hyperactivity, all relatively high before surgery, decreased significantly. Still, parents of patients experienced significantly more stress compared with parents of controls mainly because of persistently higher stress scores in parents of patients on the subscale Role Restriction (Parent domain) and on five of six subscales in the Child domain. Intelligence of the child was associated with parenting stress: the lower the child's intelligence, the higher the stress score on the subscale Distractibility/Hyperactivity and the lower the stress score on the subscale Mood. Stress decreased more in parents of patients who became seizure-free after surgery than in parents of patients with recurrent seizures.

**Conclusions:** Parenting stress decreases but does not normalize in the first two years after epilepsy surgery. Parents should be offered counseling on epilepsy-related intricacies contributing to parenting stress, immediately after diagnosis as well as after epilepsy surgery, notwithstanding the resulting seizure status of the child.

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### 1. Introduction

Parenting-related stress is since long acknowledged as an important determinant of dysfunctional parenting [1,2]. Dysfunctional parenting

affects the child's behavior, the latter affects parenting stress, and the increased parenting stress increases dysfunctional parenting [3]. Current models of parenting stress, i.e., of 'the aversive psychological reaction to the demands of being a parent', agree that complex processes underlie parenting stress [1–3]. Testing and cross-validating their multidimensional model of parenting stress, Östberg and Hagekull demonstrated a pattern of direct and indirect effects on parenting stress in mothers of infants and preschool children. Everyday problems with, e.g., feeding and sleeping, excessive crying, and illness were among the direct contributors to mothers' parenting stress [2]. Irregularity of the child's rhythmicity in biologically determined needs contributed indirectly to mothers' parenting stress, i.e., through her perceiving the child as fussy or difficult [2].

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Parents of a child with a chronic illness or handicap are at increased risk of parenting stress, as having such a child places considerable (extra) physical and emotional strains on parents (as well as on healthy siblings and even extended relations) [4]. Childhood epilepsy, particularly pharmacologically intractable epilepsy, is a risk factor par excellence for parenting stress [5–10].

However, data on the severity of parenting stress in parents of children with epilepsy vary widely. Explanations for the disparate estimates are as yet unclear. At one month after diagnosis, parents of children with new-onset epilepsy could not be distinguished from parents of healthy control children on generic and epilepsy-specific parenting stress scales [7]. Importantly, the children whose parents participated in that study [7] had been developing normally until the diagnosis. So, the course or severity of the epilepsy appears to be important, as markedly increased parenting stress has been reported in mothers with children suffering from pharmacologically intractable epilepsy who were on a ketogenic diet, were treated with vagal nerve stimulation, or had unsuccessful epilepsy surgery [8].

If candidates are carefully selected, epilepsy surgery, which aims at removing the cause of the seizures, is a successful treatment for pharmacological intractable epilepsy in childhood [11]. We are not aware of any study that compared parenting stress before epilepsy surgery with that after epilepsy surgery in children. Ideally, cessation of seizures and usually also tapering off antiepileptic medication after successful surgery will decrease parenting stress. However, our clinical impression is that parenting stress can also persist probably due to cognitive and behavioral comorbidities which, in most cases, remain after epilepsy surgery. In fact, despite successful surgery, parenting stress may even increase. For instance, parents who fostered unrealistic expectations with respect to their child's cognitive and behavioral functioning after the surgery may be disappointed and may experience increased stress. Alternatively, cessation of the seizures may deprive parents of certain rewards derived from the medical care and close attention that had been offered when managing their child's epilepsy. After unsuccessful surgery, disappointment and grief and, of course, the necessity of continued specialized care may be at odds with a decrease of parenting stress. It is, however, equally possible that parents, feeling that they have done everything that was medically possible, resign to the situation and may experience a decrease of stress.

The main purpose of the present study was to know whether epilepsy surgery in children influences parenting stress, and, if so, to what extent. We compared parenting stress in parents of patients before and two years after epilepsy surgery with that in parents of healthy-matched control children at baseline and two years later. Finally, we explored associations between parenting stress in parents of patients and the following variables: time (baseline versus two years later); postsurgical seizure status (seizure freedom versus seizure recurrence); severity of the seizures prior to surgery as estimated by the parents (on the assumption that the degree of severity influences the burden of everyday care); and the child's intelligence level prior to surgery (because the child's cognitive development is a major factor in parenting) [12,13]. To ensure that the effects of these variables were not attributable to other variables, such as age at surgery, gender of the patient, number of stress-enhancing life events, and education status and occupational status of the parents, we checked the relationships of the latter with parenting stress.

## 2. Methods

### 2.1. Design

The study was part of a countrywide project addressing the effects of epilepsy surgery on cognitive, affective, and psychosocial functioning in children [14,15]. Parenting stress was examined shortly before epilepsy surgery (baseline) of the patients and two years thereafter (follow-up). The two years' follow-up was chosen because by this time, in many

children, antiepileptic drugs have (almost) been tapered off, seizure-related visits to outpatient departments have reduced or stopped, and the parents have had time to adapt to their child's new – mostly seizure-free – condition. Control parents participated with the same time interval.

### 2.2. Subjects

Recruitment took place between January 2008 and December 2010. As soon as the Dutch Collaborative Epilepsy Surgery Programme (DuCESP) had accepted a child as a candidate for epilepsy surgery, the neurologist introduced the project to the parents and, if relevant, to the child, after which we sent the parents a written request to participate. Upon reception of the agreement to participate, age- and gender-matched control children were recruited. Parents of 46 patients fulfilled the requirement of the present study (child's age ranged from two to 16 years at inclusion). Parents of four patients did not return the questionnaires. One parent whose Dutch reading skills were insufficient to complete the questionnaires was excluded. Two more parents were excluded because their children were reoperated on within the follow-up time. In four cases, it was not the same parent who completed the questionnaire before and after surgery, rendering the comparison of perceived stress with respect to their child unreliable. As this was also the case in four control parents, four more parents of patients had to be excluded. Data obtained from the parents (29 mothers) of 31 patients [mean age at first assessment: 8.5 years, standard deviation (SD): 4.2 years; 13 girls; average intelligence: 65 (SD = 22) prior to surgery and 71 (SD = 26) two years thereafter] were analyzed. Groupwise, participating and nonparticipating parents did not differ in terms of their children's intelligence quotient (IQ), gender, and age at surgery. Thirteen patients attended regular schools, 12 received special education, and six children were too young for compulsory education. Data from 31 parents (29 mothers and 2 fathers) of healthy children matched for age and gender to the patients [mean age at first assessment: 8.4 (SD = 4.1) years] allowed us to compare parenting stress in parents of patients with that in parents of healthy children and to control for retest effects. The control children [mean IQ: 108 (SD = 18) at baseline and 117 (SD = 16) two years later] had no history of neurological disease, were recruited from regular schools located in affluent and less affluent neighborhoods, and participated at a similar time interval as did the patients. All patients and control children were living at home with their family. The Institutional Review Board of the University Medical Center Utrecht had approved of the study. Parents of all children and also all children above the age of 12 years provided written informed assent.

### 2.3. Instruments

#### 2.3.1. Parenting Stress Index (PSI)

The Parenting Stress Index (PSI) adapted for The Netherlands (Nijmeegse Ouderlijke Stress Index) measures psychological stress arising from parenting [16,17]. The self-report questionnaire is normed for parents of children in the age range of two to 16 years. When completing the questionnaire, the parent has to focus on one and the same child so that a measure of child-specific rather than general parenting stress is obtained. Separating a Child domain (six subscales) from a Parent domain (seven subscales), the instrument allows one to discern whether the stress is related to the parent feeling unfit for the task of parenting this child or to particular features of this child (see Appendix 1). The PSI consists of 123 items referring to how parents consider their child's behavior and their own functioning within the family. The parents respond on six-point Likert-type scales ('fully agree' to 'fully disagree'). Raw scores are converted to seven-point Likert-type standard stress scores ranging from very low (scale value = 1) to very high (scale value = 7) with mean scale value of 4. Test construction, concept

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