



Psychometric evaluation of the Epilepsy-related Fears in Parents Questionnaire

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ABSTRACT

Objective: The aim of the article was to examine the psychometric properties of the Epilepsy-related Fears in Parents Questionnaire (EFPO).

Method: Internal consistency, factor structure, and construct validity were analyzed based on data from 291 parents participating in the baseline assessment of a quasi-experimental study on the efficacy of the FAMOSES (modulares Schulungsprogramm Epilepsie für Familien) parents' program. The control group of this study was used to calculate the test–retest reliability, while the responsiveness of the questionnaire was evaluated by comparing matched groups of FAMOSES participants and control parents.

Results: An exploratory factor analysis revealed two factors of epilepsy-related fears, “Fears about short-term consequences of the child’s epilepsy” (8 items) and “Fears about the future development of the child and the child’s epilepsy” (9 items). Both showed good reliability (*Cronbach’s* $\alpha = .89$ and $.91$, resp.; test–retest reliability: *ICC* = $.77$ and $.80$, resp.), and construct validity was confirmed by correlations with epilepsy-related variables and psychosocial outcomes, e.g., with the Impact on Family Scale ($r = .48$ and $.61$, resp.). The FAMOSES parents' program significantly reduced epilepsy-related fears ($p < .05$ for both subscales).

Conclusion: The EFPO proved to be a reliable, valid, and responsive instrument for the assessment of parental fears about their child’s epilepsy and can be recommended for use in future studies.

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1. Introduction

Having a child with epilepsy (CWE) poses a significant burden to parents. Besides having to manage the medical requirements of their child’s condition, they have to cope with the emotional consequences of having a chronically ill child. In this context, concerns and fears are a common problem affecting the families’ everyday lives in various ways: parents are concerned about possible consequences of their child’s seizures, e.g., injuries, or they worry about their child’s future and are uncertain whether to let their child participate in social and physical activities, e.g., sports or school trips [1–4]. Thus, parental fears can lead to restrictions and overprotective parenting behavior, which in turn has an impact on the child and the development of his or her autonomy [5–7]. Moreover, higher parental anxiety is associated with lower health-related quality of life in their CWE [8]. For the parents themselves, fears about their child’s epilepsy possibly contribute to the elevated levels of general anxiety that have often been found and put them at risk of the development of anxiety disorders [9].

As a part of comprehensive epilepsy care, it is therefore essential to take the parents’ epilepsy-related fears into account, especially as parents of CWE not only feel a need for information about the disorder but also wish for opportunities to express fears and worries regarding their child’s condition [10,11]. One means to address parents’ fears are educational programs that aim at improving knowledge and usually include group discussions and opportunities to exchange experiences with other participants in order to facilitate coping with the disorder and the emotions associated with it [12].

In the context of the evaluation of educational programs and other psychosocial interventions, parental epilepsy-related fears should therefore be assessed. However, no standardized questionnaires on fears about epilepsy in parents have been published, so most studies on childhood epilepsy use generic anxiety rating scales such as the State–Trait Anxiety Inventory (STAI) [9,13]. Although general anxiety and epilepsy-related fears are related constructs, they correlate only moderately [5]. For this reason, it is necessary to develop and test instruments to assess parental fears specifically related to epilepsy. The psychometric testing of these instruments might also lead to new insights into the nature of epilepsy-related fears. For adult patients with epilepsy, for example, different facets of fears about epilepsy have been found, such as social fears or fear of stigmatization and fear of physical harm [14,15].

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The aim of this article was to report the psychometric properties of a questionnaire assessing epilepsy-related fears of parents of CWE. It was developed in the context of the evaluation of the educational program FAMOSES (*modulares Schulungsprogramm Epilepsie für Familien*, modular service package epilepsy for families), which, among others, aims at the reduction of parental fears about epilepsy [16–18]. For this reason, we will also give a brief outline of how the FAMOSES parents' program addresses participants' fears and report on the efficacy of this approach.

2. Methods

2.1. The Epilepsy-related Fears in Parents Questionnaire (EFPQ)

The EFPQ was developed for a pilot study of the educational program FAMOSES [17,19]. Based on scales assessing epilepsy-related fears in adult patients with epilepsy [20–22], 17 items were constructed (see Table 2). These items refer to fears about seizures and epilepsy that were rated on a five-point Likert scale (“not at all” to “very much”).

For the purpose of this article, the German original version of the questionnaire (see Table S1 in the Supplementary Material) was translated by the authors. All psychometric results refer to the German version. In the pilot study, the questionnaire was found to have a high internal consistency (Cronbach's $\alpha = 0.92$) and a high test-retest-reliability over three months (intraclass correlation coefficient, ICC = 0.84) [17].

2.2. Study sample

The data for the psychometric testing of the EFPQ were collected in a quasi-experimental study carried out with the primary aim to evaluate the efficacy of the FAMOSES parents' program. For this, a treatment group of parents of CWE answered questionnaires directly before participating in the FAMOSES parents' course (baseline) and a second time six months later (follow-up). A control group also answered the questionnaires twice at an interval of about six months but did not take part in FAMOSES.

The data of all parents from both groups who completed the EFPQ at baseline ($n = 291$) were used for a factor analysis and to determine the internal consistency of the EFPQ. Test-retest reliability was calculated for the participants of the control group with complete values on all EFPQ items at baseline and follow-up ($n = 71$).

To analyze the efficacy of the FAMOSES parents' program, and hence, the responsiveness of the EFPQ, treatment and control group were matched based on demographic and disease-related data at baseline, resulting in group sizes of $n = 148$ (treatment group) and $n = 74$ (control group, matching ratio 2:1). For these parents, missing item values were imputed [16].

Written informed consent was obtained from all parents, and the study plan was approved by the ethics committee of the Department of Psychology at Bielefeld University.

2.3. The FAMOSES parents' program

The FAMOSES parents' program is one part of the educational program FAMOSES, which is described elsewhere in more detail [18]. In an interactive group setting, epilepsy-related fears are addressed in different ways: trainers give profound information about epilepsy and its prognosis; they encourage the parents to express their feelings regarding epilepsy and to exchange their experience of coping with their child's disorder with the other participants. Moreover, discussions about options to support the child should contribute to reducing fears regarding the child's future. Thus, the parents shall realize that they are not alone with their problems, which should help them deal with their emotions and strengthen their social network.

2.4. Further instruments

For the evaluation of the FAMOSES parents' program, the parents were asked to answer several, mostly epilepsy-specific questionnaires. Besides the EFPQ, these included scales on knowledge about epilepsy, parental coping with the epilepsy, information seeking and sharing of information, and an 11-item short form of the Impact on Family Scale (IOFS), assessing the burden of having a chronically ill child [23–26]. Although most of the instruments have been newly developed, they showed good psychometric properties [16]. Additionally, demographic data of parents and their children as well as disease-related data of the children were assessed (e.g., age at onset of epilepsy, comorbidities).

2.5. Statistical analyses

The psychometric analyses of the EFPQ comprised an exploratory factor analysis (EFA) and measures of reliability as well as construct validation. The EFA was performed to test the factorial structure of the questionnaire. Because of the ordinal answers, which were mostly not symmetrically distributed, a robust weighted least squares estimator (WLSMV) was used [27]. To determine the number of factors, the

Table 1

Demographic characteristics of the sample for psychometric analyses of the EFPQ and demographic and clinical characteristics of their children with epilepsy.

Demographic characteristics of the parents	$n = 290^a$
Respondent, n (%)	
Mother/foster mother/aunt ^b	235 (81.0%)
Father	36 (12.4%)
Mother and father	19 (6.6%)
Age (years), mean \pm SD [$n = 289$] ^c	38.99 \pm 7.02
(Range)	(21–64)
Marital status, n (%)	
Living with spouse/partner	238 (82.1%)
Single parent	52 (17.9%)
Education, n (%)	
Without school leaving certificate	6 (2.1%)
Secondary general school (9 or 10 years)	46 (15.9%)
Intermediate school leaving certificate (10 years)	121 (41.7%)
Higher education entrance qualification	117 (40.3%)
Employment, n (%)	
Employed	190 (65.5%)
Unemployed	8 (2.8%)
Housewife/man	64 (22.1%)
No information/other ^d	28 (9.7%)
Demographic characteristics of parents' children with epilepsy	$n = 291$
Gender, n (% female)	134 (46.0%)
Age (years), mean \pm SD	8.54 \pm 4.33
(Range)	(0.42–20.92)
Educational institution, n (%)	
Kindergarten	76 (26.1%)
School	179 (61.5%)
Other	15 (5.2%)
None	21 (7.2%)
Clinical characteristics of parents' children with epilepsy	
Age at onset of epilepsy (years), mean \pm SD [$n = 283$] ^c	4.35 \pm 3.77
(Range)	(0.00–15.83)
Treatment with anticonvulsant medication, n (% yes)	281 (96.6%)
Identity card for severely disabled persons, n (%)	131 (45.0%)
Comorbidity, n (% yes)	132 (45.7%)
Baseline seizure frequency (in the past six months), n (%) [$n = 288$] ^c	
No seizures	55 (19.1%)
1–2 seizures	50 (17.4%)
3–5 seizures	51 (17.7%)
1–2 seizures per month	29 (10.1%)
≥ 1 seizure per week	33 (11.5%)
≥ 1 seizure per day	70 (24.3%)

^a Demographic information was missing for one mother.

^b All children are living with the respondent.

^c Due to missing information.

^d Other: self-employed, vocational training, retired, student, parental leave, marginal employment.

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