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Cognitive-behavioral correlates of proxy reports on cognitive capabilities in pediatric patients with epilepsy

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ABSTRACT

Purpose: To validate the Cognitive Problems in Children and Adolescents Questionnaire (KOPKIJ, German: **Ko**gnitive **P**robleme bei **K**indern und **J**ugendlichen), a proxy report measure for recognizing cognitive problems in pediatric patients with epilepsy.
Methods: Anonymized data sets from 279 pediatric epilepsy patients were standardized in regard to the KOPKIJ results of 352 healthy children and adolescents. The KOPKIJ was related to objective routine neuropsychological assessment (NPY), and to two subjective measures, the Child Behavior Checklist questionnaire (CBCL), a proxy rating by the parents, and a questionnaire for self-perceived health-related quality of life in children and adolescents (KINDL).
Results: Following principal component analysis of the KOPKIJ's normative data, three scales "basic functions", "academic skills", and a "total score" were differentiated, which indicated problems in 35%, 33%, and 32% of the children. Low IQ was evident in 23%, objective impairments in at least one major cognitive domain in 64% of the patients. Behavior (CBCL) and quality of life (KINDL) were impaired in 40% and 21% of the patients. Separate regression analyses revealed that objective cognitive performance (IQ, language, visual-spatial functions) explained ~30%, behavior (CBCL) and coping with the disease (KINDL) about ~40%, and clinical features (age at onset) 5–8% of the variance of the KOPKIJ scales.
Conclusion: The parents' impressions of children's cognition obtained via the KOPKIJ only in part reflect the neuropsychological cognitive status of children and adolescents with epilepsy. They appear rather determined by the children's behavioral problems, which in real life situations indeed often co-occur with cognitive impairments. Aspects of the epilepsy only marginally influence the parents' ratings of their children's cognition.

1. Introduction

Cognitive and behavioral problems are very common in children and adolescents with epilepsy [1]. They often exist from the beginning of the disease if not before [2], and need to be monitored along with the course of the disease and its treatment in order to identify the driving factors behind cognitive and behavioral issues [3]. Cognitive deficits in children and adolescents can either be assessed via objective neuropsychological tests, or alternatively by subjective questionnaires or rating scales which are given to patients or proxies. These different types of measures, however, are not necessarily equivalent and thus not interchangeable [4]. Apart from the fact that patient or proxy reports often do not match with objective assessment, the superordinate question always is as to whether objective and subjective data reflect actual behavior in everyday life fulfilling the criterion of ecological validity [5–7].

At our epilepsy center we have worked with the KOPKIJ, a German questionnaire, since its publication in 2006 (see Supplementary material which provides an English translation of the KOPKIJ). The KOKIJ [**Ko**gnitive **P**robleme bei **K**indern und **J**ugendlichen (cognitive problems in children and adolsecents)] is a first-contact questionnaire answered by parents or caregivers, which is thought to give a quick overview of the cognitive weaknesses and strengths of a given child or adolescent [8]. This questionnaire is different from other instruments generally used in pediatric patients, because it was specifically designed for patients with psychiatric and neurological disorders. Preliminary data on the standardization and validation of the KOPKIJ have been published as part of the German publication of the questionnaire [8].

Following the question of what parents refer to when evaluating their child, we assessed the validity of the KOPKIJ in

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a larger number of 279 children and adolescents with epilepsy by relating their KOPKIJ results to objective neuropsychological performance, to subjective proxy report of behavioral problems, and to self-perceived quality of life of the child. These latter measures were chosen in addition to objective testing, because the parents' perception of their children's cognitive situation may well refer to more than what is being assessed in a laboratory setting by use of standardized tests.

2. Methods

2.1. Patients

Included were pediatric epilepsy patients with complete data sets in regard to an objective neuropsychological assessment and the three relevant subjective measures (KOPKIJ, CBCL, and KINDL). Data from 279 of 964 children and adolescents with a behavioral assessment between 2006 and 2016 fulfilled this selection criterion. The data were acquired during routine neuropsychological assessments, extracted from the neuropsychological database of the Department of Epileptology, University of Bonn, and anonymized for scientific evaluation. The resulting sample comprised 279 patients with epilepsy between 6 and 17 years of age. About half (46%) of the patients were female, the mean age at epilepsy onset was 7 years, the mean duration of epilepsy 5 years. Of the 225 patients for whom information on the type of epilepsy was available most of the patients had the diagnosis of a structural (65%) or cryptogenic epilepsy (of unknown origin) (32%). A minority of 3% had a genetic epilepsy. Structural epilepsies were mostly evaluated in regard to possible surgery, epilepsies of unknown origin were in part evaluated for possible surgery and in part for differential diagnosis. Genetic epilepsies are generally rarely seen since the clinic in Bonn is in the first line known as an epilepsy surgical center.

Fourteen percent of the patients were off-drug, 36% were on antiepileptic drug monotherapy, and 50% on polytherapy. Seizure frequencies, however, were documented in the neuropsychological database for 183 of the patients. The median frequency per month was 5, the range 0–300. However since frequencies were not provided for different seizure types, this information needs to be relativized (see Table 1 for patient data).

Table 1 lists not only patient data but in addition data from the healthy controls who served for the normalization and standardization of the KOPKIJ and whose data were used to perform a principal component analysis of the tool.

2.2. Instruments

An overview of the applied tools and measures is given in Table 2. In addition to the KOPKIJ, two subjective measures (CBCL, and KINDL) and the results of the objective neuropsychological assessment were used.

Table 1
Demographics and clinical data.

	Patients	Normative control group
Gender	N = 279	N = 352
Male	150 (54%)	165 (47%)
Female	129 (46%)	187 (53%)
Age (years)	N = 279	N = 352
M (SD)	12.03 (2.6)	11.80 (2.5)
Range	6–17	6–17
School	N = 279	N = 352
Special	13%	0%
Elementary	29%	30%
Secondary	41%	60%
High School	17%	10%
Onset Epilepsy (age in years)	N = 252	/
M (SD)	7.33 (4.02)	
Range	0–15	
Type of Epilepsy (%)	N = 225	
structural	65%	
genetic	3%	
unknown	32%	
Duration of Epilepsy (years)	N = 252	/
M (SD)	4.79 (3.72)	
Range	0–16	
Number of Seizures: (seizure types not differentiated)	N = 183	/
M (SD)	30 (5)	
Median	5	
Range	0–300	
Number of AEDs	N = 210	/
M (SD)	1.70 (0.68)	
Range	1–4	
None	14%	
Monotherapy	36%	
Polytherapy	50%	

Data displayed as N = number of patients; M = mean; SD = standard deviation.
AEDs = anti-epileptic drugs.