



## Knowledge and attitudes about epilepsy: A survey of high school students in Germany



Paula Jansen<sup>a</sup>, Martina P. Neininger<sup>b</sup>, Matthias K. Bernhard<sup>a</sup>, Wieland Kiess<sup>a</sup>,  
Andreas Merckenschlager<sup>a</sup>, Thilo Bertsche<sup>b</sup>, Astrid Bertsche<sup>a,\*</sup>

<sup>a</sup> University Hospital for Children and Adolescents, Centre for Paediatric Research, Liebigstr. 20a, 04103 Leipzig, Germany

<sup>b</sup> Dept. of Clinical Pharmacy, Institute of Pharmacy, Drug Safety Center, Leipzig University, Brüderstr. 32, 04103 Leipzig, Germany

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### ABSTRACT

**Purpose:** Attitudes concerning epilepsy improved over the last few decades, but children with epilepsy still suffer from stigmatisation. Data about unaffected children's knowledge of and attitudes about epilepsy is scarce.

**Methods:** We developed a questionnaire regarding epilepsy for high school students attending 8th–10th grade. The survey was performed from October 2015 to March 2016 in 5 different federal states of Germany.

**Results:** 1092 students [mean age (Q25/75): 14.5 (14/15) years] participated. 542/1092 (50%) of the respondents knew that people could die from a seizure. 216/1092 (20%) thought emotional strain could cause epilepsy. Asked for measures they would perform in case of a seizure, 235/1092 (24%) participants would hold the person to the ground, and 182/1092 (19%) would put a solid object into the person's mouth. 28/1092 (3%) would not like to be friends with a person with epilepsy, and 237/1092 (22%) would not like to go on a date with a person with epilepsy.

Answers of 342/1092 (31%) students of a school located nearby a specialised epilepsy centre differed in some questions. The latter students were more familiar with epilepsy and showed better knowledge concerning causes, symptoms and treatment of epilepsy. In a question about special characteristics of people with epilepsy, 63/342 (18%) [other schools: 52/750 (11%)] answered people with epilepsy were friendlier and 76/342 (22%) [other schools: 49/750 (11%)] answered they were more sociable compared to people without epilepsy.

**Conclusion:** To improve knowledge and attitudes and reduce misconceptions further education seems necessary.

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### 1. Introduction

Over the last few decades, many studies investigating affected and unaffected persons have dealt with knowledge of and attitudes toward epilepsy. Many of them examined the view of adults [1–9], whereas only a few studies focused on the view of children and

adolescents [10–14]. A recent German study showed that most school children suffering from epilepsy were able to describe their seizures well. Most children had rather good knowledge about medication but gaps in knowledge about safety precautions were frequent. One in ten children believed epilepsy is contagious and one in four children felt disadvantaged compared to other children [13]. An Italian study revealed immense gaps of knowledge about epilepsy in unaffected students [12]. Only about half of American students remembered having heard about epilepsy [10]. Knowledge of and attitudes toward epilepsy of unaffected Czech students were significantly improved by an educational video or an educational drama [11]. Public knowledge of and attitudes toward epilepsy have improved over the years [7,8,15], but fear and misunderstanding still impact the quality of life for people with epilepsy [16–18].

Children and adolescents with epilepsy still consider social stigmatisation as one of the worst parts of suffering from epilepsy

Abbreviation: SEC school, school located next to a specialised epilepsy centre.

\* Corresponding author at: University Hospital for Children and Adolescents, Centre of Social Paediatrics (SPZ), Centre for Paediatric Research, Liebigstr. 20a, 04103 Leipzig, Germany.

E-mail addresses: [paula.jansen@medizin.uni-leipzig.de](mailto:paula.jansen@medizin.uni-leipzig.de) (P. Jansen), [martina.neininger@medizin.uni-leipzig.de](mailto:martina.neininger@medizin.uni-leipzig.de) (M.P. Neininger), [matthias.bernhard@medizin.uni-leipzig.de](mailto:matthias.bernhard@medizin.uni-leipzig.de) (M.K. Bernhard), [wieland.kiess@medizin.uni-leipzig.de](mailto:wieland.kiess@medizin.uni-leipzig.de) (W. Kiess), [andreas.merkenschlager@medizin.uni-leipzig.de](mailto:andreas.merkenschlager@medizin.uni-leipzig.de) (A. Merckenschlager), [thilo.bertsche@medizin.uni-leipzig.de](mailto:thilo.bertsche@medizin.uni-leipzig.de) (T. Bertsche), [astrid.bertsche@medizin.uni-leipzig.de](mailto:astrid.bertsche@medizin.uni-leipzig.de) (A. Bertsche).

[14]. Adolescents' experiences and handling of epilepsy are influenced by the attitude of their social environment [19]. Thus, it is important to examine the group of unaffected adolescents more closely to find ways to reduce stigma and improve treatment.

## 2. Methods

### 2.1. Setting

We performed a questionnaire survey to examine the attitudes and knowledge of high school students (8th–10th grade) concerning epilepsy. In order to get a representative view of German high school students, we aimed at including three to four schools in each of the following regions: southwest (Baden-Wuerttemberg), northwest (Lower Saxony, North Rhine-Westphalia), and east (Saxony, Saxony-Anhalt). We aimed at including different school types of secondary education in Germany and invited about the same number of grammar schools ( $n=34$ ) and other schools (middle school, secondary school, comprehensive school;  $n=31$ ). In this manuscript, all school types are summarised as "high schools".

Of the 65 invited schools, 11 different high schools in the following federal states of Germany agreed to participate: three in Baden-Wuerttemberg, two in Lower Saxony, two in North Rhine-Westphalia, three in Saxony, and one in Saxony-Anhalt. Six participating schools were grammar schools, five other school types. One of the schools was located next to a specialised epilepsy centre (SEC school).

### 2.2. Questionnaire

An expert panel consisting of neuropaediatricians and clinical pharmacists developed a questionnaire asking for familiarity with epilepsy, knowledge on epilepsy, attributed attitudes and demographic items (for details see English version of the questionnaire in the supplement). The questions had pre-set answers to tick. Additionally, free-text answers were possible in most of the questions. The questionnaire was pretested for comprehensibility with 6 students in the targeted age group. The short introduction of the survey said that the survey was conducted in the context of epilepsy research. Students were informed about the anonymous evaluation of the data and that participation was voluntary. The questionnaire was filled in in class and completion took about 20 min, no talking was allowed between the students.

### 2.3. Study design

The study was approved by the Ethics committee of Leipzig University. Besides, according to the different federal laws, the school authorities or headmasters of the schools gave their approval to conducting the study. The parents had to give informed consent to their children taking part in the questionnaire. The headmasters of the schools had the responsibility to ensure that

only students whose parents had given their informed consent participated in the study.

### 2.4. Statistics

Statistical analysis was conducted by IBM SPSS Statistics Version 23 (IBM Corporation, Armonk, New York, USA) and Microsoft Office Excel Version 2013 (Microsoft Corporation, Redmond, Washington, USA). Frequencies are reported as numbers and percentages, and continuous data as median and Q25/Q75. We performed chi-square tests and considered a  $p$ -value of  $<0.05$  to indicate significance. Odds Ratios (OR) [(SEC schools confirmed/SEC schools not confirmed)/(other schools confirmed/other schools not confirmed)] are shown for comparisons between students of the SEC school and of other schools. Data that indicated no significant difference between the SEC school and the other schools are shown combined for all participating students.

## 3. Results

### 3.1. Characteristics of respondents

During the study period, 1092 questionnaires were completed. The characteristics of the respondents are summarised in Table 1.

### 3.2. Familiarity with epilepsy

Respondents had heard of epilepsy before in 1062/1092 (94.0%) cases, and 336/1092 (30.8%) knew a person suffering from epilepsy. Asked where they had got to know epilepsy, students from a school located nearby a specialised epilepsy centre (SEC school) chose different predefined answers concerning the contexts in which they got to know epilepsy (Fig. 1). In an open question for other contexts in which the students gained knowledge about epilepsy, the most frequent answer of the respondents of the SEC school was the place they live at [97/143 (67.8%)]. The most frequent answer of the students of the other schools was individual experiences [41/148 (27.7%)].

The number of students who had witnessed a seizure was higher in the SEC school than in the other schools [SEC school: 188/342 (55.0%) vs. other schools: 97/750 (12.9%), OR: 8.22,  $p < 0.001$ ].

### 3.3. General knowledge of epilepsy

In a pre-set answer, the approximate prevalence of epilepsy (1%) was estimated correctly by 387/1092 (35.4%) of the respondents. It was underestimated by 360/1092 (33.0%) of the respondents, and 124/1092 (11.4%) overestimated it.

The distribution of pre-set answers regarding causes of epilepsy and symptoms of seizures is shown in Table 2. The open-ended question relating to other causes of epilepsy led to 103 answers: They could be subdivided in 60 answers with possible causes for seizures, e.g. accidents 30/60 (50%) and nervous system disorder 6/

**Table 1**  
Demographic characteristics.

		all schools	SEC school	other schools
number of students: n		1092	342	750
gender: n (%)	female	618 (56.6)	195 (57.0)	423 (56.4)
	male	443 (40.6)	136 (39.8)	307 (40.9)
	not specified	31 (2.8)	11 (3.2)	20 (2.7)
age (years)	mean (Q25/Q75)	14.5 (14/15)	14.6 (14/15)	14.4 (14/15)
	range	12–18	12–18	12–18
suffer from epilepsy themselves: n (%)		5 (0.5)	1 (0.3)	4 (0.5)

Characteristics of participating students; SEC school: school nearby a specialised epilepsy centre.

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