



Parental knowledge, attitudes, and behaviors towards children with epilepsy in Belgrade (Serbia)



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ABSTRACT

Objective: The aim of our study was to assess knowledge, attitudes, and behaviors of parents whose children were diagnosed with epilepsy.

Methods: This cross-sectional study included 213 consecutive parents who accompanied their children, diagnosed with epilepsy, at regular checkups in the outpatient department of the Child and Adolescent Neurology and Psychiatry Clinic in Belgrade. Data were obtained through a questionnaire before completion of the child's neurological checkup, while clinical parameters of children with epilepsy were taken from medical records.

Results: Almost all respondents knew that epilepsy is not an infectious disease (99.5%), while the least proportion of parents (31.9%) knew that epilepsy is not, for the most part, hereditary. Parents felt that their family and friends should know that their child is suffering from epilepsy (average score: 4.3 out of 5). Also, parents felt the most confident in taking care of their child during seizures (4.7 out of 5), while they felt the least confident in letting their child go on school trips for several days (3.4 out of 5). Parental longer schooling (i.e., higher education level) was an independent predictor of higher epilepsy knowledge. Taking less number of medications was an independent predictor of more supportive parental behavior towards children with epilepsy.

Conclusion: Some epilepsy-related issues still require improvement in parental knowledge. Ensuring education and support at community and school levels for both parents and children with epilepsy should be the principal goal of health-care service.

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1. Introduction

Public awareness and attitudes towards epilepsy differ across cultures [1–6]. It has been noted that traditional beliefs and lack of knowledge strongly influence attitudes towards epilepsy [1–3,5]. Keeping in mind that this chronic neurological disorder occurs in 0.5 to 1.0% of children under the age of 16 [7], we have found that the burden of epilepsy most commonly involves informal caregivers. Moreover, epilepsy in children has wide repercussion on social, emotional, and overall family functioning [8–10], particularly in families where younger children are affected and in those with single parents [11].

It has been highlighted that parental engagement in pediatric epilepsy care in terms of communication and shared decision-making represents a crucial factor in the management of this neurological disorder [12]. Still, young persons and their parents feel that medication management of epilepsy is the only priority in a health-care setting

[13]. Although parents may face difficulties in family functioning [8], it has been observed that parental reporting of various symptoms correlates with that of the child [14]. Specifically, analysis of agreement between children and parents indicated that there is a substantial concordance in reporting symptoms of anxiety and depression [14]. This finding suggests that parents are able to accurately recognize and define problems their children experience. In addition, research has shown that parents were able to describe and differentiate types of seizure and their characteristics [15].

Taking care of a child with epilepsy results in a higher amount of stress compared with taking care of a healthy child [16]. Because of parental strain, higher level of worries, and perception of vulnerability and anxiety for the future of their children [17], it is possible that mothers and fathers of children with epilepsy exhibit particular emotional and behavioral patterns in terms of higher level of child protection and interpretations of their child's daily challenges. Moreover, we hypothesized that addressing this issue could reveal particular sociocultural aspects of the local community because identification of specific misconceptions and problems of parents related to epilepsy in their children would potentially help achieve better treatment and well-being of the family as a whole and, ultimately, improve overall

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quality of life. Therefore, the aim of our study was to assess knowledge, attitudes, and behaviors of parents whose children were diagnosed with epilepsy.

2. Material and methods

2.1. Participants

In the period from June 1 to July 31, 2013, all parents who accompanied their children who were diagnosed with epilepsy at regular checkups were recruited in the outpatient department of the Child and Adolescent Neurology and Psychiatry Clinic, Belgrade. A total of 231 consecutive parents were approached, and 213 agreed to participate (response rate: 92.2%). In case that both parents came with the child for checkup, only one randomly selected parent per family was included in the survey. Diagnosis of epilepsy was made by a pediatric neurologist. Inclusion criteria for the study were as follows: being older than 18 years of age and being able to speak and understand Serbian. Exclusion criteria were as follows: having a child with intellectual and other (visual, hearing, orthopedic) impairments and having a child with diagnosed progressive neurodegenerative disorder. The survey was approved by the Institutional Review Board. The parents signed an informed consent prior to enrollment in the study.

2.2. Instrument

Data were obtained through a questionnaire before completion of the child's neurological checkup, while clinical parameters of children with epilepsy were taken from medical records. The questionnaire, designed for the study, comprised 5 sections: parental sociodemographic characteristics (sex, age, marital status, education level, employment status, number of household members, parental monthly income, place of residence, and number of children in the household), demographic and clinical characteristics of children with epilepsy (sex, age, age at onset, length and quantity of pharmacotherapy, type, and frequency of seizures), knowledge, attitude, and behaviors related to epilepsy.

The knowledge, attitude, and behavior sections for this questionnaire were developed using previously published studies exploring parents', caregivers', teachers' and health professionals' knowledge and attitudes on the subject [18–21]. To check the understanding and interpretation of the translated items by the Serbian population, the questionnaire was tested on five parents of children with epilepsy. Results of this pilot survey were discussed among the group of researchers and clinicians with the aim of generating a version of the questionnaire that was semantically and conceptually clear and understandable to persons who speak the Serbian language fluently. Suggestions of parents who participated in the pilot survey were also implemented in the final version of the questionnaire.

The knowledge section comprised 12 items regarding age at onset of seizures (in the first year/until age of 18/at any age) and circumstances indicative of epilepsy diagnosis (one unprovoked seizure/at least two unprovoked seizures/loss of consciousness during seizures). The following questions (offering yes/no answers) referred to whether or not epilepsy was a communicable disease or a psychiatric or a hereditary disorder as well as whether or not all persons lose consciousness during seizures and whether or not all the affected patients have similar symptoms. Additionally, the parents were asked whether the affected children may be vaccinated, have a lower intelligence quotient, and have difficulties with learning. The final two questions in this section were related to the use of medication: whether or not withdrawal of seizures after the use of pharmacotherapy means that the person is cured and whether or not, after skipping therapy, double dose of medications should be taken. Each correct answer in this set of items was awarded 1 point. Therefore, the total knowledge score represented a range between 0 points as the minimum and 12 points as the maximum.

Parents' attitude was assessed by 7 statements presented in a block. Statements referred to parents' attitudes towards perceptions of their child's epilepsy by family, friends, and the community. Answers were graded using the Likert scale, where the minimal mark 1 denoted "I strongly disagree with this statement" and the maximal mark 5 denoted "I strongly agree with this statement". The sum of marks for each statement represented the attitude score (ranging from 7 to 35).

Similarly, parents' behavior in relation to their children's epilepsy was evaluated using a block of 7 statements. The statements reflected parental behavior in terms of ongoing seizures and their permission to let the child participate in different school and nonschool activities. Answers were graded using the Likert scale, where the minimal mark 1 denoted "I strongly disagree with this statement" and the maximal mark 5 denoted "I strongly agree with this statement". The sum of marks for each statement represented the behavior score (ranging from 7 to 35).

Additionally, the parents were asked whether or not they were familiar with epilepsy before their child was diagnosed as well as how they perceive their own knowledge of epilepsy and how they inform themselves about epilepsy-related issues.

2.3. Data analysis

Attitude and behavior scores were presented as means with corresponding standard deviations (SD), skewness, and kurtosis. Skewness shows how much data weight towards one extremity of the scale. Kurtosis refers to the convexity or flatness of the data distribution. Differences in examined variables were assessed by using the Mann–Whitney *U* test for 2 independent samples. In case of multiple categories per variable (such as employment status: employed/unemployed/retired) the Kruskal–Wallis nonparametric test for comparing more than two samples was used. Spearman's correlation test was applied to investigate relationships between selected parameters.

Internal consistency of the attitude and behavior sections in the questionnaire was evaluated using Cronbach's alpha coefficient [22], which ranged from 0 to 1. Values of alpha coefficient above 0.7 denote excellent internal consistency.

Multiple linear regression models were designed to assess the predictive value of sociodemographic characteristics of parents on their knowledge, attitudes, and behaviors. Dependent variables were knowledge, attitude, and behavior scores. Independent variables were all characteristics of parents that could potentially influence overall knowledge, attitudes, and behaviors (gender, age, marital status, year of schooling, number of members in the household, monthly income, and number of children in the household). Additionally, demographic and clinical characteristics of children with epilepsy were tested in multiple linear regression models to evaluate predictors of parental attitude and behavior. In these models, dependent variables were parental attitude and behavior scores, while independent variables were child's age and gender, age at onset of epilepsy, length of pharmacotherapy, existence of partial seizures, number of seizures per month, number of medications, and existence of well-controlled seizures.

A probability level of $p < 0.05$ was considered significant. The SPSS 17.0 statistical software package (SPSS Inc., Chicago, IL, U.S.A.) was used to perform the statistical analysis.

3. Results

Of the 213 study respondents, 77% were women. The mean parental age was 43 ± 8.2 years (age span: 24 to 69). Other sociodemographic characteristics of respondents are presented in Table 1. In addition, Table 1 displays demographic and clinical characteristics of children with epilepsy. The mean age of children was 13.4 ± 6.1 years. The average age at epilepsy onset was 6.4 years. Epilepsy was considered well controlled in 84.5% of the individuals.

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