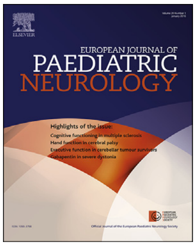
EUROPEAN JOURNAL OF PAEDIATRIC NEUROLOGY 20 (2016) 93–99

Official Journal of the European Paediatric Neurology Society



Original article

The contribution of illness perceptions to fatigue and sleep problems in youngsters with epilepsy

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ARTICLE INFO

Article history:
Received 26 May 2015
Received in revised form
10 September 2015
Accepted 4 October 2015

Keywords:
Illness perceptions
Fatigue
Sleep problems
Epilepsy

ABSTRACT

Purpose: The present study aims to explore the extent to which gender, epilepsy severity and illness perceptions predict fatigue and sleep problems in youngsters with epilepsy.

Method: Structured interviews were conducted in 100 young patients (Mage = 13,9, SD = 2.21; 41% girls) and data were analyzed by means of multiple hierarchical regression analyses.

Results: Most patients (91%) were well controlled by anti-epileptics; 3% had infrequent seizures and 6% were pharmacoresistant. At a multivariate level it appeared that youngsters with epilepsy who believe that they have less personal control over their illness and who feel that the illness has a high emotional impact on their lives reported higher levels of fatigue. In addition, more sleep problems were reported by youngsters who think they have less personal control over the disease, who believe that treatment controls epilepsy and report that the disease has a high emotional impact on their lives.

Conclusion: Given the importance of illness perceptions, it is suggested that they are targets for future interventions that aim to reduce fatigue and sleep problems in youngsters with epilepsy.

1. Introduction

Fatigue and sleep problems are frequently reported as a burden by youngsters with epilepsy, but there are few studies that have explored the cause of these symptoms.[1–4] As there is evidence that illness perceptions next to disease characteristics may be important determinants of somatic symptoms,[1] the present study investigates the influence of illness

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http://dx.doi.org/10.1016/j.ejpn.2015.10.001

cognitions on fatigue and sleep problems in youngsters with epilepsy.

Fatigue and sleep problems appear to share some common features. They can both be considered as symptoms of a psychological problems and/or physical illness, as side effects of medication (i.e. antiepileptic drugs), or as a separate entity (i.e. chronic fatigue syndrome). Due to the fact that (a) these symptoms have a multidimensional nature, b) their appearance may be transient but may also become chronic, and c) their etiology cannot be fully explained by organic findings, it is very difficult to define, diagnose and measure them in an adult population, and even more difficult in youngsters with epilepsy.[1,4–12] Especially in epilepsy, fatigue and sleep problems can have seizure-provoking effects, but at the same time, frequent seizures may in turn lead to their appearance. Without intervention, this vicious cycle of events may lead to impairment in all aspects of daily functioning.[2,13–15]

Research in children and adolescents with epilepsy points at the fact that girls and older children/adolescents tend to report a worse overall quality of life and more feelings of distress.[16,17] In addition, girls, older adolescents and those with more severe epilepsy tend to report more negative attitudes toward their epilepsy than boys, younger adolescents and those with moderate or mild epilepsy.[18,19] Research in non-epileptic adolescents suggests that girls usually report higher levels of fatigue and sleep problems than boys.[13,20]

Furthermore, there are several studies showing that disease severity, type of seizure, unpredictability, recurrence and high frequency of seizures, longer duration of disease and some anti-epileptic drugs are linked to depression and reduced quality of life in adolescents with epilepsy.[21] Higher fatigue scores have been reported in adult patients with a longer duration of epilepsy and in tertiary epilepsy patients.[22] Another study suggested that the most important causes of fatigue in adult epilepsy patients were a) energy consumption due to the number of seizures and b) the type of seizures, namely, generalized tonic-clonic seizures.[3] Sleep disorders in adolescents with epilepsy have been linked with paroxysmal activity density, longer duration of epilepsy and higher seizure frequency.[15,23] All types of seizures are believed to have the potential to cause adverse effects on sleep.[24] Lastly, it has been shown that behavioral problems in children are more directly related to the existence of a concomitant sleep disturbance than to the severity of their epilepsy.[14]

Leventhal's Self-Regulation Theory (SRT) particularly focuses on the role of illness perceptions or beliefs in illness behavior and the experience of symptoms. Important attributes of illness perceptions are according to this theory: *identity* (the name or label given to the illness or symptoms), *timeline* (the perceived time trajectory of the illness), *consequences* (the expected future effects and outcomes of the illness), *cause* (the supposed etiology of the illness) and *cure or control* (the extent to which the patients believe that they may recover or have personal control over the illness). Finally, *emotional representations of the illness* incorporate anticipated negative emotional reactions such as anger, fear, and distress due to the presence of the disease.[1,25–28] Although there is evidence suggesting that illness perceptions also play an important role in the way children or adolescents experience and cope with a chronic disease,[1] as well as to their quality of life and psychological distress[29] to our knowledge there is no research on the link between illness perceptions and fatigue and/or sleep problems in youngsters with epilepsy.

The present study explores whether, after controlling for gender and epilepsy severity, illness perceptions explain important parts of the variance in fatigue and sleep problems in youngsters with epilepsy. We hypothesize that a) female gender and more severe types of epilepsy will be positively related to fatigue and sleep problems and b) perceptions of control will be negatively related to fatigue and sleep problems, while all other illness cognitions will reveal an opposite relationship.

2. Material and methods

2.1. *Study design and patient recruitment*

The present cross-sectional study was approved by the Ethical Research Committee of Pendeli's Children Hospital. Participants were recruited between March 2009 and January 2012 according to the following inclusion criteria: 1) age: 10–18 years old, 2) at least one epileptic seizure during the preceding year, 3) normal IQ, 4) no other chronic illness, physical disability, or mental disorder, 5) no surgical procedures during the preceding year, and 6) no medication change in the last 6 months.

Four hundred medical records of youngsters were consecutively examined at the Epilepsy Clinic and reviewed for their eligibility for the study. After examination of the medical records by a neurologist, 200 youngsters who fulfilled the inclusion criteria were approached during their prescheduled visits. The first 100 who agreed to participate were included in the present study.

Initially, parents were informed about the goals and procedures of the study by the treating neurologist. Subsequently a meeting with the parents and the young patient was planned to explain the study in more detail. The first 100 of them who agreed to participate and signed an informed consent form and were included in the study. Next, all questionnaires were completed by the patient, without presence of the parents, in the context of an interview. The interviewer did not know any of the patients prior to this meeting and always asked the exact same questions following a protocol. The interview lasted approximately 60–70 min.

2.2. *Measures*

2.2.1. *Disease characteristics*

Data regarding disease characteristics were derived from the medical records and included type of epilepsy, duration, age of onset, time of last seizure, total number of seizures and medication. The severity of epilepsy was evaluated on an ordinal scale with 6 categories. Starting from the least severe epilepsy, the categories were: 1) benign focal childhood epilepsy, 2) idiopathic generalized epilepsy, 3) epilepsy well controlled by medication but with unknown prognosis (unknown etiology of epilepsy), 4) symptomatic epilepsy with adequate response to medication (more than 6 months seizure free), 5) symptomatic epilepsy with moderate