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

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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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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

response to medication (less than 6 months seizure free), and 6) pharmaco-resistance (failure to respond to at least 3 appropriately selected anti-epileptics).[30] In the present study, this severity scale was used in the analyses with lower scores indicating less severe epilepsy.

All data, except for disease characteristics, were obtained by means of the following validated questionnaires:

2.2.2. *Illness perceptions*

2.2.2.1. *Brief illness perceptions questionnaire (BIPQ)*[25]. Seven items measure cognitive illness representations (consequences, timeline, identity, personal and treatment control) and emotional representations (concern and emotion). An additional item asks the patient to mention factors that according to his/her opinion caused the illness. A 10-point Likert scale is used to answer each item with lower scores indicating more beneficial perceptions (i.e. for timeline: 0 = my epilepsy will last for a very short time to 10 = it will last forever), except for coherence, personal and treatment control, where higher scores represent more beneficial perceptions. In order to compute the total score, the scores of these items are reversed and therefore in all items a lower score reflects a less threatening view of the illness.

2.2.3. *Checklist individual strength (CIS) questionnaire*[31,32]

Fatigue is measured via 20 statements where the participant indicates on a 7-point Likert scale to what extent each particular statement applies to him/her. The subscales of this questionnaire are a) *subjective feeling of fatigue* (8 items), b) *concentration* (5 items), c) *motivation* (4 items), and d) *physical activity* (3 items). The total score is calculated by adding up the scores for each dimension. Higher scores indicate higher levels of fatigue severity. Normative values for healthy subjects were used to interpret the scores of our population.[31] As indicated, a cut-off of 35 for the main dimension (subjective feeling of fatigue) was used to define clinical levels of fatigue.[33]

2.2.4. *Athens insomnia scale (AIS)*[34,35]

This is an instrument designed to quantify sleep difficulty which consists of 8 items that refer to sleep induction, awakenings during the night, final awakening, total sleep duration, sleep quality, well-being, functioning capacity, and sleepiness during the day. Each item can be rated 0–3 (with 0 corresponding to "no problem at all" and 3 "very serious problem"). A total score is calculated by adding up the scores for each item. Higher scores indicate more sleep problems. A cut-off of 6 for the total score was used to define clinical levels of insomnia.[35]

2.3. *Statistical analysis*

With respect to patient characteristics, categorical data were described as numbers and percentages. Preliminary analyses were carried out, using Pearson's correlations, in order to examine the univariate relationships between all the variables used in the present study (Table 1). Second, in order to compare our scores with the normative samples two new dichotomous variables were created. A new variable for subjective fatigue was created based on the cut-off point of 35[31] in order to distinguish between normal and clinical levels of

Table 1 – Pearson's correlations between all variables.

	Gender	Severity	Consequences	Timeline	Personal control	Treatment control	Identity	Concern	Coherence	Emotional representation	Fatigue	Sleep problems
Gender	1											
Severity	0.023 (0.817)	1										
Consequences	0.288[b] (0.004)	0.238[a] (0.017)	1									
Timeline	0.368[b] (0.000)	0.343[b] (0.000)	0.649[b] (0.000)	1								
Personal control	0.210[a] (0.036)	0.370[b] (0.000)	0.364[b] (0.000)	0.460[b] (0.000)	1							
Treatment control	0.026 (0.800)	0.252[a] (0.011)	0.322[b] (0.001)	0.376[b] (0.000)	0.830[b] (0.000)	1						
Identity	0.264[b] (0.008)	0.210[a] (0.036)	0.394[b] (0.000)	0.439[b] (0.000)	0.469[b] (0.000)	0.417[b] (0.000)	1					
Concern	0.357[b] (0.000)	0.235[a] (0.018)	0.603[b] (0.000)	0.696[b] (0.000)	0.427[b] (0.000)	0.362[b] (0.000)	0.605[b] (0.000)	1				
Coherence	−0.010 (0.918)	0.221[a] (0.027)	0.436[b] (0.000)	0.396[b] (0.000)	0.307[b] (0.002)	0.322[b] (0.001)	0.470[b] (0.000)	0.508[b] (0.000)	1			
Emotional representation	0.355[b] (0.000)	0.207[a] (0.039)	0.749[b] (0.000)	0.461[b] (0.000)	0.366[b] (0.000)	0.204[a] (0.041)	0.559[b] (0.000)	0.574[b] (0.000)	0.312[b] (0.002)	1		
Fatigue	0.314[b] (0.001)	0.153 (0.129)	0.275[b] (0.006)	0.394[b] (0.000)	0.179 (0.074)	0.178 (0.076)	0.341[b] (0.001)	0.463[b] (0.000)	0.221[a] (0.027)	0.358[b] (0.000)	1	
Sleep problems	0.197[a] (0.050)	0.050 (0.621)	0.415[b] (0.000)	0.345[b] (0.000)	0.094 (0.355)	0.175 (0.081)	0.367[b] (0.000)	0.404[b] (0.000)	0.154 (0.126)	0.481[b] (0.000)	0.650[b] (0.000)	1

[a] Correlation is significant at the 0.05 level.
[b] Correlation is significant at the 0.01 level.

fatigue. In addition, another dichotomous variable based on the cut-off of 6[35] was created in order to distinguish between normal and clinical levels of sleep problems. After selecting only the participants who reported normal levels of fatigue, a one-sample T-test was performed with subjective fatigue being the test variable, and the mean for the normative sample (17.30) reported by Vercoulen et al. (1999) being the test value.[31] Similarly, after selecting only the participants who reported normal levels of sleep problems, a one-sample T-test was performed with sleep problems being the test variable, and the mean for the normative sample (2.28) reported by Soldatos, Dikeos & Paparrigopoulos (2003) being the test value.[35] Lastly, separate multiple hierarchical regression analyses were conducted for each outcome. Both for fatigue and sleep problems, in the first block, gender was entered in the analysis (model 1). In the second block, severity was entered (model 2). Lastly, in the third block, illness perceptions were added (model 3).

3. Results

3.1. Patients

The 100 participants in our study had a mean age of 13.9 ($SD = 2.21$) and 59% of them were boys. Regarding epilepsy severity, 6% of these patients fulfilled criteria for pharmacoresistance, 3% were less than 6 months seizure-free (symptomatic epilepsy with moderate response to medication), 24% were more than 6 months seizure-free (symptomatic epilepsy with adequate response to medication), 14% were well controlled by medication but with unknown prognosis, 30% had idiopathic generalized epilepsy, and 23% benign focal childhood epilepsy.

3.2. Comparisons of scores between youngsters with epilepsy and normative samples

As shown in Table 2, the mean score on subjective fatigue was significantly lower than the normative sample of healthy subjects.[31] In the present study, 11% of the respondents reached the clinical cut-off score. In addition, the mean score on sleep problems was significantly lower than the normative sample of healthy subjects.[35] In the present study, 33% of the respondents reached the clinical cut-off score.

Table 2 – Comparison of fatigue and sleep problems of this study with normative data and the number of respondents reaching the clinical cutoffs.

	Mean (SD)	Sig	Cutoff	Clinical level (%)
Subjective Fatigue				
Youngsters with epilepsy	14.89 (7.03)	0.002	≥35	11%
Normative sample	17.30 (10.10)			
Sleep problems				
Youngsters with epilepsy	0.73 (1.23)	0.000	≥6	33%
Normative sample	2.28 (2.56)			

3.3. Hierarchical regression analyses

3.3.1. Predicting fatigue

The results of the hierarchical regression analysis with fatigue as the dependent variable are shown in Table 3. The final model (model 3: $R^2 = 0.302$, adjusted $R^2 = 0.224$, $F = 3.850$, $df = 10$, $p < 0.001$) shows that thinking to have less personal control over your illness and thinking that epilepsy will have a high emotional impact on your life predicts higher levels of fatigue in youngsters with epilepsy.

3.3.2. Predicting sleep problems

As presented in Table 4, the final model (model 3: $R^2 = 0.365$, adjusted $R^2 = 0.293$, $F = 5.109$, $df = 10$, $p < 0.001$) shows that thinking to have less personal control over your disease, thinking that control over your disease is dependent on others and thinking that epilepsy will have a high emotional impact on your life will predict more sleep problems in youngsters with epilepsy.

4. Discussion

The present study investigated the extent to which gender, epilepsy severity and illness perceptions predict fatigue and sleep problems in youngsters with epilepsy. Overall, our findings provide support for the predictive power of illness perceptions on fatigue and sleep problems, concepts that have not being investigated extensively in the adolescent epilepsy literature.

In our study, preliminary analyses revealed significant positive association between sleep problems and fatigue ($r = 0.650$, $p < 0.001$). This relatively high correlation is however most probably rather due to a cause effect relationship than to large concept overlap. Although both outcomes may thus be related, they should not be treated as identical problems.[36,37]

The comparison between our patients with normative groups revealed that youngsters with epilepsy had significantly lower levels of fatigue and sleep problems than the normative group (Table 2). A possible explanation for this finding could be the fact that the normative groups were derived from adult populations. This finding is not in line with studies that suggest that children with epilepsy show much higher rates of sleep disorders than healthy controls, but it should be noted that in this study sleep problems were assessed using parental questionnaires, while in our study self-reports by youngsters were used.[38] It is quite clear that there is a need for normative fatigue data, derived from a study in healthy youngsters. While the percentage of youngsters reaching clinical levels in this study is thus probably an underestimation, one third of our study population reported clinical levels of sleep problems.

The results of the final multiple regression model with fatigue as the dependent variable ($R^2 = 0.302$, adjusted $R^2 = 0.224$, $F = 3.850$, $df = 10$, $p < 0.001$) shows that thinking to have less personal control over the disease and believing that epilepsy has a high emotional impact on life predict higher levels of fatigue in youngsters with epilepsy. This suggests

Table 3 – Summary of hierarchic regression analysis for variables associated with fatigue of adolescents with epilepsy (N = 100).

	Model 1			Model 2			Model 3		
	B (β)	SE B	p	B (β)	SE B	p	B (β)	SE B	p
Gender	13.012 (0.314)	3.974	0.00	12.870 (0.311)	3.948	0.00	7.789 (0.188)	4.402	0.08
Severity				2.166 (0.146)	1.418	0.13	1.073 (0.072)	1.485	0.47
Consequences							−2.020 (- 0.327)	1.074	0.06
Timeline							1.487 (0.213)	1.028	0.15
Personal control							−3.511 (−0.370)	1.774	0.05
Treatment control							3.432 (0.315)	1.953	0.08
Identity							−0.140 (−0.016)	1.180	0.91
Concern							1.974 (0.265)	1.110	0.08
Coherence							0.402 (0.045)	1.029	0.70
Emotional representation							2.262 (0.337)	1.130	0.05

Model 1: $R^2 = 0.099$, adjusted $R^2 = 0.089$, $F = 10.721$, df = 1, $p < 0.001$.
Model 2: $R^2 = 0.120$, adjusted $R^2 = 0.102$, $F = 6.599$, df = 2, $p < 0.001$.
Model 3: $R^2 = 0.302$, adjusted $R^2 = 0.224$, $F = 3.850$, df = 10, $p < 0.001$.

Table 4 – Summary of hierarchic regression analysis with gender, disease severity and illness perceptions as independent variables and sleep problems as the dependent variable in adolescents with epilepsy (N = 100).

	Model 1			Model 2			Model 3		
	B (β)	SE B	p	B (β)	SE B	p	B (β)	SE B	p
Gender	1.357 (0.197)	0.197	0.05	1.349 (0.196)	0.685	0.05	0.183 (0.027)	0.698	0.79
Severity				0.113 (0.045)	0.246	0.65	−0.040 (−0.016)	0.236	0.86
Consequences							- 0.034 (- 0.033)	0.170	0.84
Timeline							0.193 (0.166)	0.163	0.24
Personal control							−0.955 (−0.606)	0.281	0.00
Treatment control							0.877 (0.484)	0.310	0.01
Identity							0.176 (0.120)	1.187	0.35
Concern							0.143 (0.116)	1.176	0.42
Coherence							−0.178 (−0.119)	0.163	0.28
Emotional representation							0.502 (0.450)	1.179	0.01

Model 1: $R^2 = 0.039$, adjusted $R^2 = 0.029$, $F = 3.955$, df = 1, $p < 0.05$.
Model 2: $R^2 = 0.041$, adjusted $R^2 = 0.021$, $F = 2.066$, df = 2, *n.s.*
Model 3: $R^2 = 0.365$, adjusted $R^2 = 0.293$, $F = 5.109$, df = 10, $p < 0.001$.

that illness cognitions may have an exacerbating effect on symptoms or in other words amplify the severity of the patients' illness experience.

The final multiple regression model with sleep problems as the dependent variable ($R^2 = 0.365$, adjusted $R^2 = 0.293$, $F = 5.109$, df = 10, $p < 0.001$) shows that thinking to have less personal control over epilepsy, thinking to be dependent on others for the control of the disease and believing that epilepsy has a high emotional impact on your life predict more sleep problems in youngsters with epilepsy. This suggests that a passive, dependent or emotional way of coping with the disease may result in an aggravation of sleep problems.

In both regression analyses gender was initially a significant predictor, suggesting that being a girl significantly predicts higher levels of fatigue and more sleep problems. This relationship disappeared however, when illness perceptions were added to the analyses, suggesting that illness perceptions rule out the effect of gender. The literature delineating the link between gender and fatigue is however discordant, supported by some,[39] but not by others.[1]

Severity of epilepsy was not a significant predictor of fatigue or sleep problems. This could be related to the fact that the majority of our population either belonged to an idiopathic epilepsy group or were well controlled by anti-epileptics. There is however, also, evidence that all types of seizures can have the potential for adverse effects on sleep,[24] which may explain why disease severity is not a significant predictor of sleep problems in our study. Our findings differ from studies in adults with epilepsy which suggested that the most important causes of fatigue or sleep problems were energy consumption depending on the number and/or type of seizures and duration of epilepsy,[3,15,23] but these studies did not explore the effect of illness perceptions.

The present study has some limitations. To start with, the cross-sectional design does not allow us to draw firm conclusions about causality. The generalizability of our findings is also limited by the strict inclusion criteria that we set in order to avoid the effect of comorbid physical/mental conditions. One could also argue that we should have included more differentiated epilepsy-related factors in our study such as seizure type, age of seizure onset, seizure frequency and

duration of epilepsy, but the focus of this study was on the role of illness perceptions rather than on predictors that have already been studied extensively.

Furthermore, there are several other remarks that can be made with regard to this study. First, we did not include anti-epileptic drugs (AEDs) as predictors even though they are known to affect sleep. There is evidence that barbiturates, benzodiazepines and to a lesser degree phenytoin have detrimental effects on sleep, while gabapentin, levetiracetam and lamotrigine have a positive effect on sleep structure. In general, new generation AEDs have fewer detrimental effects on sleep structure than the older ones, but measuring the direct effects of AEDs on sleep and fatigue remains very difficult because of the many factors that coexist and may affect this relationship (i.e. type of seizures, polypharmacy, concurrent sleep disturbances, anxiety, stress etc.).[40] We would like to emphasize however, that there were no AED changes for at least 6 months prior to the time of measurement and that sleep disturbances were routinely sought after during follow-up visits in the epilepsy clinic, especially those possibly related to AEDs (medication or dosage changes).

Next, sleep disorders such as obstructive sleep apnea (OSA) and periodic limp movements in sleep (PLMS) can often coexist with epilepsy, may interfere with sleep and some an extent also with fatigue. In addition, they may affect seizure control.[41,42] Although some general information regarding these disorders could be drawn from items from the AIS questionnaire such as sleep induction, awakenings during the night, overall quality of sleep and sleepiness during the day, in the present study we did not aim to diagnose these specific sleep disorders, but mainly focused on the general sleep quality of our patients. Future studies should also take existing sleep disturbances into account.

Lastly, we did not measure sleep problems or behaviors of parents nor did we take into account their view on their child's sleep problems or fatigue since our aim was to assess these concepts by means of a personal report by the youngsters rather than by proxy perceptions. Nevertheless, it has been reported that parents have strong concerns about nocturnal seizures as well as sudden unexplained death.[42] Parent-child co-sleeping has reached rates up to 38%[43] and daytime dysfunction and habitual sleep efficacy have been found to be the two parental sleep domains with the greatest divergence between epilepsy and control cohorts. In addition, parents of children with epilepsy appear to be more fatigued than controls.[42] It should however be noted that the majority of these studies dealt with children with epilepsy that are 10 years old or younger and that patient inclusion criteria differed from ours (i.e. co-morbid conditions such as autism spectrum disorders and attention deficit hyperactivity disorder were included). The influence of parental concerns on sleep and fatigue in youngsters should however be further explored in future studies.

5. Conclusions

The findings of this study suggest that illness perceptions are important targets for interventions that aim to reduce fatigue and sleep problems in youngsters suffering from epilepsy. Most existing interventions focus on seizure reduction rather than on the reduction of feelings of distress or on other psychological factors such as illness perceptions.[44] There are a few promising efforts to develop and implement interventions for adolescents with epilepsy that combine cognitive-behavioral approaches and self-management theory,[44–46] but these studies do not specifically target fatigue or sleep problems. As a consequence offering psychological interventions, based on self-regulation theory,[47] that aim to change maladaptive illness cognitions in youngsters suffering from epilepsy is an important target for the future.

Conflict of interest statement

There is no conflict of interest.

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REFERENCES

1. Gray SE, Rutter DR. Illness representations in young people with chronic fatigue syndrome. *Psychol Health* 2007;**22**:159–74.
2. Kothare SV, Kaleyias J. Sleep and epilepsy in children and adolescents. *Sleep Med* 2010;**11**:674–85.
3. Şenol V, Soyuer F, Arman F, Öztürk A. Influence of fatigue, depression, and demographic, socioeconomic, and clinical variables on quality of life of patients with epilepsy. *Epilepsy Behav* 2007;**10**:95–104.
4. Vereker MI. Chronic fatigue syndrome: a joint paediatric-psychiatric approach. *Arch Dis Child* 1992;**67**:550–5.
5. Cairns R, Hotopf M. A systemetic review describing the prognosis of chronic fatigue syndrome. *Occup Med* 2005;**55**:20–31.
6. De Gucht V, Fischier B. Somatization: a critical review of conceptual and methodological issues. *Psychosom* 2002;**43**:1–9.
7. De Gucht V, Maes S. Explaining medically unexplained symptoms: toward a multidimensional, theory-based approach to somatization. *J Psychosom Res* 2006;**60**:349–52.
8. Fukuda K, Straus SE, Hickie I, Sharpe MC, Dobbins JG, Komaroff A. The chronic fatigue syndrome: a comprehensive approach to its definition and study. International Chronic Fatigue Syndrome Study Group. *Ann Intern Med* 1994;**121**:953–9.
9. Godfrey E, Cleare A, Coddington A, Roberts A, Weinman J, Chalder T. Chronic fatigue syndrome in adolescents: do parental expectations of their child's intellectual ability match the child's ability? *J Psychosom Res* 2009;**67**:165–8.
10. Gregory AM, Sadeh A. Sleep, emotional and behavioral difficulties in children and adolescents. *Sleep Med Rev* 2012;**16**:129–36.
11. Marques M, De Gucht V, Maes S, Leal I. Protocol for the "four steps to control your fatigue (4-STEPS)" randomised controlled trial: a self-regulation based physical activity intervention for patients with unexplained chronic fatigue. *BMC Public Health* 2012;**12**:202. http://dx.doi.org/10.1186/1471-2458-12-202.

12. Whiting P, Bagnall A, Sowden A, Cornell J, Murlow C, Ramirez G. Interventions for the treatment and management of chronic fatigue syndrome: a systematic review. *J Am Med Assoc* 2001;**286**:1360–8.
13. Nijhof SL, Bleijenberg G, Uiterwaal CSPM, Kimpen JLL, Van de Putte E. Effectiveness of internet-based cognitive behavioural treatment for adolescents with chronic fatigue syndrome (FITNET): a randomised controlled trial. *Lancet* 2012;**379**:1412–8.
14. Racaru VM, Cheliout-Heraut F, Azabou E, Essid N, Brami M, Benga I, Pinard JM. Sleep architecture impairment in epileptic children and putative role of anti-epileptic drugs. *Neurol Sci* 2013;**34**:57–62.
15. Samaitiene R, Norkuniene J, Tumiene B, Grikiniene J. Sleep and behavioral problems in rolandic epilepsy. *Pediatr Neurol* 2013;**48**:115–22.
16. Benavente-Aguilar I, Morales-Blanquez C, Rubio EA, Rey JM. QOL of adolescents suffering from epilepsy living in the community. *J Paediatr Child Health* 2004;**40**:110–3.
17. Plioplys S. Depression in children and adolescents with epilepsy. *Epilepsy Behav* 2003;**4**:39–45.
18. Cramer JA, Westbrook LE, Devinsky O, Perrine K, Glassman MB, Camfield C. Development of the QOL in epilepsy inventory for adolescents: the QOLIE-AD-48. *Epilepsia* 1999;**40**:1114–21.
19. Heimlich TE, Westbrook LE, Austin JK, Cramer JA, Devinsky O. Brief report: adolescents' attitudes toward epilepsy. Further validation of the child attitude toward illness scale (CATIS). *J Pediatr Psychol* 2000;**25**:339–45.
20. Jellesma FC, Rieffe C, Terwogt MM, Westenberg PM. Do parents reinforce somatic complaints in their children? *Health Psychol* 2008;**27**:280–5.
21. Baki O, Erdogan A, Kantarci O, Akisik G, Kayaalp L, Yalcinkaya C. Anxiety and depression in children with epilepsy and their mothers. *Epilepsy Behav* 2004;**5**:958–64.
22. Ettinger AB, Weisbrot DM, Krupp LB, Coyle PK, Jandorf L, Devinsky O. Fatigue and depression in epilepsy. *Epilepsy* 1998;**11**:105–9.
23. Cortesi F, Giannotti F, Ottaviano S. Sleep problems and daytime behavior in childhood idiopathic epilepsy. *Epilepsia* 1999;**40**:1557–65.
24. Elkhayat HA, Hassanein SM, Tomoum HY, Abd-Elhamid IA, Asaad T, Elwakkad AS. Melatonin and sleep-related problems in children with intractable epilepsy. *Pediatr Neurol* 2010;**42**:249–54.
25. Broadbent E, Petrie KJ, Main J, Weinman J. The brief illness perception questionnaire. *J Psychosom Res* 2006;**60**:631–7.
26. Diefenbach MA, Leventhal H. The common-sense model of illness representation: theoretical and practical considerations. *J Soc Distress Homeless* 1996;**5**:11–38.
27. Leventhal H. Findings and theory of the study of fear communications. *Adv Exp Soc Psychol* 1970;**5**:119–86.
28. Leventhal H, Meyer D, Nerenz D. The common sense representation of illness danger. In: Rachman S, editor. *Medical psychology*. New York: Pergamon Press; 1980. p. 7–30.
29. Rizou I, De Gucht V, Papavasiliou A, Maes S. Illness perceptions determine psychological distress and quality of life in youngsters with epilepsy. *Epilepsy Behav* 2015;**46**:144–50.
30. Berg AT. Identification of pharmacoresistant epilepsy. *Neurol Clin* 2009;**27**:1003–13.
31. Vercoulen JHMM, Alberts M, Bleijenberg G. The checklist individual strength (CIS). *Gedragstherapie* 1999;**32**:131–6.
32. Beurskens AJHM, Bultmann U, Kant I, Vercoulen JHMM, Bleijenberg G, Swean GMH. Fatigue among working people: validity of a questionnaire measure. *Occup Environ Med* 2000;**57**:353–7.
33. De Vree B, Van der Werf S, Prins J, Bazelmans E, Vercoulen J, Servaes P. Meetinstrumenten bij chronische vermoeidheid. *Gedragstherapie* 2002;**35**:157–64.
34. Soldatos CR, Dikeos DG, Paparrigopoulos. Athens insomnia scale: validation of an instrument based on ICD-10 criteria. *J Psychosom Res* 2000;**48**:555–60.
35. Soldatos CR, Dikeos DG, Paparrigopoulos TJ. The diagnostic validity of the Athens insomnia scale. *J Psychosom Res* 2003;**55**:263–7.
36. Krupp LB, Jandorf L, Coyle PK, Mendelson WB. Sleep disturbance in chronic fatigue syndrome. *J Psychosom Res* 1993;**37**:325–31.
37. Lichstein KL, Means MK, Noe SL, Aguillard RN. Fatigue and sleep disorders. *Behav Res Ther* 1997;**35**:733–40.
38. Stores G, Wiggs I, Campling G. Sleep disorders and their relationship to psychological disturbance in children with epilepsy. *Child Care Health Dev* 1998;**24**:5–19.
39. van de Putte EM, Engelbert RHH, Kuis W, Kimpen JLL, Uiterwaal CSPM. Chronic fatigue syndrome and health control in adolescents and parents. *Arch Dis Child* 2005;**90**:1020–4.
40. van Golde EGA, Gutter T, de Weerd AW. Sleep disturbances in people with epilepsy; prevalence, impact and treatment. *Sleep Med Rev* 2011;**15**:357–68.
41. Nunes ML. Sleep and epilepsy in children: clinical aspects and poly-somnography. *Epilepsy Res* 2010;**89**:121–5.
42. Larson AM, Ryther RCC, Jennesson M, Geffrey AL, Bruno PL, Anagnos CJ, Shoeb AH, Thibert RL, Thiele EA. Impact of pediatric epilepsy on sleep patterns and behaviors in children and parents. *Epilepsia* 2012;**53**:1162–9.
43. Jenni OG, Fuhrer HZ, Iglowstein I, Molinari L, Largo RH. A longitudinal study of bed sharing and sleep problems among Swiss children in the first 10 years of life. *Pediatrics* 2005;**115**:233–40.
44. Blocher JB, Fujikawa M, Sung C, Jackson DC, Jones JE. Computer-assisted cognitive behavioural therapy for children with epilepsy and anxiety: a pilot study. *Epilepsy Behav* 2013;**27**:70–6.
45. Wagner JL, Smith G. Psychosocial intervention in pediatric epilepsy: a critique of the literature. *Epilepsy Behav* 2006;**8**:39–49.
46. Wagner JL, Smith G, Ferguson P, van Bakergem K, Hrisko S. Feasibility of a pediatric cognitive-behavioral self-management intervention: coping openly and personally with epilepsy (COPE). *Seizure* 2011;**20**:462–7.
47. Maes S, Karoly P. Self-regulation assessment and intervention in physical health and illness: a review. *Appl Psychol* 2005;**54**:267–99.