Parent and Self-Report of Sleep-Problems and Daytime Tiredness Among Adolescents With Inflammatory Bowel Disease and Their Population-Based Controls

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Study Objectives: To evaluate the frequency of sleep problems and daytime tiredness among adolescents with inflammatory bowel disease (IBD) in comparison with their healthy peers.

Design: Parent and self-reports of sleep problems and daytime tiredness.

Setting: Questionnaire-based postal survey.

Intervention: N/A.

Participants: One hundred sixty Finnish adolescents with IBD; 236 adolescents matched for age, sex, and place of residence; and the parents of both groups.

Measurements and Results: Sleep Self-Report and sleep questions of the Child Behavior Check-List, and Youth Self-Report. The parents of adolescents with IBD reported in their index child more trouble sleeping ($P < 0.01$), more nightmares ($P < 0.01$), sleeping more than most children during the day/night ($P < 0.001$), and overtiredness ($P < 0.001$) than did the parents of control subjects. In contrast, adolescents with IBD themselves did not report more problems than their peers. However, in the group of patients with self-reported severe IBD symptoms, both the parents and the adolescents reported trouble sleeping and overtiredness more often (P values < 0.01) than in the group with mild symptoms or control subjects. Adolescents with severe IBD reported more often that their symptoms affected the quality of their sleep ($P < 0.001$) than did adolescents with mild disease.

Conclusions: Adolescents with severe IBD symptoms have disturbed sleep and are overtired more often than are adolescents with mild IBD symptoms or control subjects. Thus, in adolescents with severe IBD symptoms, evaluating sleep is important in characterizing the disease burden. Both parent and adolescent reports are needed for comprehensive assessment of sleep in the young.

Keywords: Sleep in pediatric IBD, parent and youth-self report

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INFLAMMATORY BOWEL DISEASE (IBD), NAMELY CROHN DISEASE (CD) AND ULCERATIVE COLITIS (UC), IS MOST TYPICALLY DIAGNOSED IN LATE adolescence and early adulthood.[1] The incidence of pediatric IBD is on the rise in many Western countries. In Finland, the incidence almost doubled from 1987 to 2003,[2] and the same trend has been observed elsewhere.[3-6] Primary causes of IBD or factors underlying the increasing incidence and geographic variation remain obscure.[7] Symptoms of IBD, such as uncontrollable bowel function, rectal bleeding, diarrhea, abdominal pain, weight loss, fatigue, and, in CD, aphthous ulcers and fever, may be severe and may disturb sleep.

Surprisingly, very few studies have investigated the quality of sleep and daytime tiredness in patients with IBD. A recent report on sleep disturbances compared adults with inactive IBD (n = 16) with patients with irritable bowel syndrome (IBS) (n = 9) and healthy control subjects (n = 7).[8] Patients with IBD did not differ significantly from patients with IBS with respect to sleep parameters assessed by a single night of polysomnography and questionnaires. However, sleep quality of both patient groups was lower than that of the control group. The 3 groups did not differ with respect to daytime dysfunction.[8] Another questionnaire-based study of sleep disturbances among adult patients with inactive IBD (n = 80) showed prolonged sleep latency, frequent sleep fragmentation, higher rate of using sleeping pills, decreased daytime energy, increased tiredness, and poor overall sleep quality in IBD compared with healthy control subjects (n = 15).[9] In this study, patient-reported sleep quality correlated with disease severity. Of the patients with IBD, 66% assessed their sleep as poor during the active state of the disease, and 49% believed disturbed sleep affected their inflammatory disease.[9] Likewise, in a study focusing on extraintestinal symptoms in adults with IBD (n = 55), patients with IBD were noted to have significantly more sleep disturbances than control subjects, and diarrhea predicted sleep disturbances in these patients.[10] In all of these studies, only adult patients were included. The sample sizes were small, and population-based control groups were lacking.

Data on sleep disturbances in young patients with IBD are sparse. We found only 1 preliminary study on sleep disturbances among young patients with IBD (n = 41) in Israel, published as an abstract.[11] This questionnaire-based study concluded that moderate and severe sleep disturbances are frequent among young patients with IBD. No correlation was found between sleep disturbance and disease characteristics of IBD (e.g., disease type, disease activity, or medication). No precise informa-

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tion was given about the method of collecting data on sleep or disease activity.

For other inflammatory conditions, such as juvenile rheumatoid arthritis (JRA), sleep quality and daytime tiredness have been explored in a few studies.[12-16] These findings reveal that sleep is disrupted in children with JRA. For example, comparable child and parent questionnaires, the Sleep Self-Report (SSR) and the Children's Sleep Habit Questionnaire (CSHQ), were used in a retrospective study of 25 children with active JRA to assess sleep and its relationship to pain, dysfunction, and disease activity.[15] Parents of patients with JRA reported significantly higher total scores on the CSHQ and on the subscales assessing nighttime waking, parasomnias, sleep anxiety, sleep-disordered breathing, and morning wakening/daytime sleepiness than did parents of healthy control subjects. However, the total score on the CSHQ did not correlate with disease severity; this was in contrast with the total score on the SSR, which correlated highly with pain but not with other arthritis-related variables.[15]

Lack of knowledge about the quality and quantity of sleep in pediatric patients with IBD warrants studies in these patients. Sleep disturbances may increase the risk for psychosocial symptoms or disorders such as tiredness and depression.[17] Thus, more research is needed on sleep in adolescents with IBD and the association between sleep and IBD symptom severity.

The first objective of the current study was to evaluate sleep problems, quality of sleep, and daytime tiredness among adolescents with IBD in comparison with population-based control subjects. The second objective was to evaluate the effect of the severity of IBD symptoms on sleep problems, quality of sleep, and daytime tiredness. This questionnaire-based study includes both parent and self-reports.

MATERIALS AND METHODS

Subjects

The postal addresses of 300 patients aged 10 to 18 years diagnosed with IBD in Finland from 1994 to 2006 in the 5 University hospitals (Helsinki, Kuopio, Tampere, Turku, and Oulu) according to the files of the Social Insurance Institution of Finland were retrieved from the database of the Population Register Center. This database includes information on all patients entitled to reimbursement for IBD-related medical costs. Patients with a recent diagnosis (medical reimbursement less than 8 months) were excluded. Postal addresses were available for 287 such patients. In addition, postal addresses for 3 population-based control subjects per patient (n = 861) were randomly selected from the same source. Controls were matched for age, sex, and place of residence. We have previously shown that such a selection of control subjects represents the average population well.[18] Subject recruitment has been described more thoroughly in our recent report on psychosocial symptoms in adolescents with IBD.[19]

Standardized questionnaires (see below) were sent to the 287 patients, the 861 control subjects, and the patients' and control subjects' parents. After 1 reminder was sent, completed Youth Self-Report questionnaires were received from 160 (56%) and SSR questionnaires from 159 (55%) adolescents with IBD. Parents of patients with IBD returned 159 (55%) CBCL questionnaires. Of the adolescents with IBD, 52% had UC, 33% had CD, 12% had unspecified colitis (IC), and 3% did not answer this question. The mean age of the patients at disease onset was 10 (SD 3.3, range 1-15) years, and the mean duration of the disease at the time of the study was 5.2 (SD 3.3, range 0.7-13) years (see Väistö et al., 2010[19]).

Among control subjects, 1 reminder was sent to adolescents and their parents if none of the 3 matched controls of a patient had replied. After 1 reminder was sent, completed YSR and SSR self-reports were received from 236 (27%), and parent reports from 232 (27%) of these subjects.

The mean age of the patient group was 15.4 (SD 2.2) years and of the control group 15.2 (SD 2.2) years. The patient group included 85 boys (53%) and the control group 115 boys (52%).

Sleep Questionnaires

Parents and the adolescents filled in standardized questionnaires assessing psychosocial symptoms and competence, including questions on sleep and overtiredness (CBCL and YSR, respectively).[20,21] The questionnaires were translated into Finnish. The results related to questions on psychosocial symptoms and competence have been reported elsewhere.[19] In this study, we utilized the 5 problem items dealing with sleep and tiredness in both the CBCL and YSR (Table 1). The items are rated on a scale from 0 to 2 (0 = not true, 1 = sometimes true, 2 = often true).

Additionally, for a more detailed self-report of sleep habits, adolescents completed a structured SSR questionnaire.[22] The SSR questionnaire is a standardized subjective retrospective measure of sleep habits for school-aged children.[22] The questionnaire is divided into 2 sections. The first section includes 3 background questions on sleeping (Who in your family sets the rules about when you go to bed? Do you think you have trouble sleeping? Do you like to go to sleep?). In the second section, single items are allocated to 3 subscales to describe Bedtime (12 items), Sleep Behavior (7 items), and Daytime Tiredness (4 items) (Table 1). Response options are "Often" (5-7 times per week), "Sometimes" (2-4 times per week), and "Seldom or never" (0-1 time per week). Items are rated on a 3-point scale, and, for each subscale, sum-scores are formulated. Questions 4, 5, 6, 8, 11, and 26 are scored inversely. The minimum and maximum sum-scores consequently are from 12 to 36 for Bedtime, from 7 to 21 for Sleep Behavior, and from 4 to 12 for Daytime Tiredness. A higher score indicates more sleep problems.

We included 2 extra questions for adolescents with IBD: "Do IBD symptoms affect the quality of your sleep?" and the open question: "If yes, how?" Adolescents were advised to answer these according to their sleep habits over the preceding 6-month period.

Disease Activity and Background Data

The patients also received a background inquiry in which they were asked to report their age at disease onset, diagnosis of the disease (UC, CD, or IC) and the severity of their IBD symptoms during the preceding week using the numeric visual-analog scale (VAS) from 1 to 7. The severity of the symptoms was shown visually as a line from asymptomatic to extremely severe. The patients were asked to score their symptom sever-

ity on the scale from 1 (asymptomatic) to 7 (extremely severe). Patients with IBD were divided into the following 2 groups according to reported severity of IBD symptoms: patients with mild IBD symptoms (VAS scores 1-3: asymptomatic, mild, rather mild symptoms) and patients with severe IBD symptoms (VAS scores 4-7: moderate, severe, very severe, extremely severe symptoms). The VAS from 1 to 7 was used in earlier studies about quality of life and psychosocial functioning in Finnish patients with IBD.[18,19,23]

Ethics

The Ethics Committee of the Helsinki University Central Hospital approved the study protocol.

Data Analysis

Statistical analyses were performed using SPSS 17.0 software for Windows (SPSS, Inc., Chicago, IL). Mean group differences for sum-scores "Bedtime," "Sleeping Behavior," and "Daytime Tiredness" were statistically tested with a nonparametric Mann-Whitney U-test. The χ^2 test was used for the questions "Do you think you have trouble sleeping?" and "Do IBD symptoms affect the quality of your sleep?" For trend analyses of sleep items in CBCL and YSR, the linear-by-linear test (χ^2 test's variation) was used. A nonparametric median test for k-independent samples was applied to roughly analyze differences in SSR subscales, SSR total score, and YSR/CBCL items between age groups of 10 to 12 years (n = 18), 13 to 16 years (n = 81), and 17 to 19 years (n = 61) in patients with IBD. Statistical significance was set at $P \leq 0.05$.

RESULTS

Sleep and Daytime Tiredness Among Adolescents With IBD and Control Subjects

Parent reports

According to parents, 25% of adolescents with IBD had trouble sleeping sometimes or often, significantly more than in the control group (13%) ($P < 0.01$). Parents of patients with IBD reported in their index child significantly more nightmares ($P < 0.01$) and more sleeping during the day/night, ($P < 0.001$), as compared with parents of control subjects. Furthermore, adolescents with IBD were significantly more often overtired ($P < 0.001$) than adolescents in the control group according to parent reports (Table 2).

Adolescent self-reports

According to the YSR, no significant difference was present in frequency of trouble sleeping between adolescents with IBD and control subjects. Instead, control adolescents reported sleeping "less than most kids" more frequently than did adolescents with IBD. In addition, adolescents with IBD did not report more overtiredness than their controls (Table 2).

Of the SSR questionnaires, 86% in the patient group and 89% in the control group were completed by the adolescents themselves; the rest were completed with the help of another person. The proportion of self-completed SSR questionnaires did not differ significantly in the groups of patients and control subjects ($P = 0.332$).

Table 1—List of sleep-related items in the CBCL and YSR questionnaires and items in the SSR questionnaire

CBCL
- Nightmares (Q47)
- Overtired without good reason (Q54)
- Sleeps less than most kids (Q76)
- Sleeps more than most kids during day and/or night (Q77)
- Trouble sleeping (Q100)

YSR
- I have nightmares (Q47)
- I feel overtired without good reason (Q54)
- I sleep less than most kids (Q76)
- I sleep more than most kids during day and/or night (Q77)
- I have trouble sleeping (Q100)

SSR

Bedtime
- Do you go to bed at the same time every night on school nights?
- Do you fall asleep in the same bed every night?
- Do you fall asleep alone?
- Do you fall asleep in your parents', brother's, or sister's bed?
- Do you fall asleep in about 20 minutes?
- Do you fight with your parents about going to bed?
- Is it hard for you to go to bed?
- Are you ready for bed at your usual bedtime?
- Do you have a special item (doll, blanket, etc) that you bring to bed?
- Are you afraid of the dark?
- Are you afraid of sleeping alone?
- Do you stay up late when your parents think you are asleep?

Sleep behavior
- Do you think you sleep too little?
- Do you think you sleep too much?
- Do you wake up at night when your parents think you are asleep?
- Do you have trouble falling back to sleep if you wake up during the night?
- Do you have nightmares?
- Does pain wake you up at night?
- Do you sometimes go to someone's bed during the night?

Daytime sleepiness
- Do you have trouble waking up in the morning?
- Do you feel sleepy during the day?
- Do you take naps during the day?
- Do you feel rested after a night's sleep?

CBCL refers to Child Behavior Checklist; YSR, Youth Self-Report; SSR, Sleep Self-Report; Q, question number.

Altogether, 11% of patients (n = 16) and 13% of control subjects (n = 31) reported having a sleep problem in the SSR questionnaire item "Do you think you have trouble sleeping?" (The difference between groups was not significant, $P = 0.429$). Almost all patients (93.3%) and control subjects (95.3%) reported liking to go to sleep in the evenings ($P = 0.133$).

No difference emerged between the groups in the scores of the subscales (Bedtime, Sleep Behavior, Daytime Sleepiness) or the total sum-scale of the SSR (all $P > 0.27$).

Table 2—Frequencies of sleep-related problems in patients and control subjects as reported by parents using the CBCL and adolescents using the YSR[a]

	Patients (n = 160)			Control subjects (n = 236)			
CBCL	Not true	Sometimes true	Often true	Not true	Sometimes true	Often true	P Value
Q47: Nightmares	107 (68)	49 (31)	2 (1)	187 (81)	44 (19)	1 (0)	< 0.01
Q54: Overtired	76 (48)	70 (44)	12 (8)	159 (69)	67 (29)	5 (2)	< 0.001
Q76: Sleeps less	117 (74)	37 (23)	5 (3)	189 (82)	33 (14)	8 (4)	0.112
Q77: Sleeps more during day/night	118 (74)	34 (21)	7 (4)	210 (91)	15 (7)	6 (3)	< 0.001
Q100: Trouble sleeping	116 (74)	35 (22)	5 (3)	201 (87)	22 (10)	7 (3)	< 0.01
YSR							
Q47: Nightmares	89 (56)	67 (42)	3 (2)	126 (54)	97 (41)	12 (5)	0.342
Q54: Overtired	69 (44)	80 (51)	9 (6)	105 (45)	102 (44)	27 (12)	0.483
Q76: Sleeps less	115 (72)	40 (25)	4 (3)	141 (60)	80 (34)	15 (6)	< 0.01
Q77: Sleeps more during day/night	114 (72)	28 (18)	17 (11)	181 (77)	41 (18)	12 (5)	0.072
Q100: Trouble sleeping	125 (80)	26 (17)	6 (4)	181 (77)	39 (17)	15 (6)	0.366

Data are shown as number (%). P Values were determined with a linear-by-linear test (χ^2 variation) for statistical significance between patients and control subjects. CBCL refers to Child Behavior Checklist; YSR, Youth Self-Report; Q, question number.

Table 3—Frequencies of sleep problems in adolescents with mild or severe inflammatory bowel disease as reported by parents using the CBCL and adolescents using the YSR[a]

	Mild IBD symptoms (n = 121)			Severe IBD symptoms (n = 35)			
CBCL	Not true	Sometimes true	Often true	Not true	Sometimes true	Often true	P Value
Q47: Nightmares	83 (70)	36 (30)	0 (0)	23 (66)	10 (29)	2 (6)	0.308
Q54: Overtired	66 (56)	49 (41)	4 (3)	7 (20)	21 (60)	7 (20)	< 0.001
Q76: Sleeps less	95 (79)	21 (18)	4 (3)	18 (51)	16 (46)	1 (3)	< 0.01
Q77: Sleeps more during day/night	96 (80)	21 (18)	3 (3)	20 (57)	12 (34)	3 (9)	< 0.01
Q100: Trouble sleeping	93 (79)	23 (20)	2 (2)	20 (59)	11 (32)	3 (9)	< 0.01
YSR							
Q47: Nightmares	72 (60)	48 (40)	1 (1)	16 (47)	16 (47)	2 (6)	0.093
Q54: Overtired	59 (49)	59 (49)	3 (3)	9 (27)	18 (55)	6 (18)	0.001
Q76: Sleeps less	90 (74)	28 (23)	3 (3)	21 (62)	12 (35)	1 (3)	0.192
Q77: Sleeps more during day/night	88 (73)	21 (17)	12 (10)	24 (71)	7 (21)	3 (9)	0.935
Q100: Trouble sleeping	101 (84)	16 (13)	3 (3)	20 (61)	10 (30)	3 (9)	0.003

Data are presented as number (%). Patients reported their severity of inflammatory bowel disease (IBD) using a visual-analog scale (VAS), with mild disease having a score of 1-3 (median, 1.0) and severe disease with a score of 4-7 (median, 5.0). P Values between patients with mild and severe symptoms of IBD were determined with a linear-by-linear test (χ^2 variation). CBCL refers to Child Behavior Checklist; YSR, Youth Self-Report; Q, question number.

Sleep and Daytime Tiredness in Patients

Adolescents in the group of patients were divided into 2 subgroups according to IBD symptoms self-reported on a VAS, with a score range of 1 to 7 (see Disease activity and Background data). In this study, 121 adolescents reported mild IBD symptoms and 35 adolescents reported severe IBD symptoms.

Parent reports

According to parent reports, 41% of adolescents with severe IBD symptoms and 22% of adolescents with mild IBD symptoms had trouble sleeping sometimes or often ($P < 0.01$) (Table 3). Parents of adolescents with severe IBD symptoms reported their index child sleeping significantly less than most adolescents ($P < 0.01$) and sleeping significantly more than most adolescents during the day/night, ($P < 0.01$) (Table 3). In addition, significantly more adolescents with severe IBD symptoms (80%) were sometimes or often overtired than their peers with mild IBD symptoms (44%) ($P < 0.001$).

Adolescent self-reports

According to self-reports (YSR), adolescents with severe IBD symptoms reported significantly more trouble sleeping ($P = 0.003$) than did adolescents with mild IBD symptoms (Table 3). In the group of adolescents with severe IBD symptoms, 73% described being overtired sometimes or often. More than half of adolescent (52%) with mild IBD symptoms reported overtiredness. The group difference was significant ($P = 0.001$) (Table 3).

Patients with severe symptoms of IBD scored higher than did patients with mild IBD symptoms on the total sum-scale of the SSR ($P = 0.032$) (Table 4). The difference between the patient groups on the Sleep Behavior subscale approached significance ($P = 0.064$), with patients with severe symptoms reporting more sleep problems during the night than patients with mild symptoms. On the Sleep Behavior subscale, adolescents with severe symptoms reported more problems than did adolescents with mild symptoms on the items "Do you wake up at night when your parents think you are sleeping?" ($Z = -2.560$, $P = 0.010$) and "Does pain wake you up at night?" ($Z = -2.934$, $P = 0.003$). For these Sleep Behavior subscale items, mean scores for adolescents with severe IBD symptoms were 1.44 (SD 0.660) and 1.30 (SD 0.467), and, for adolescents with mild IBD symptoms, were 1.18 (SD 0.425) and 1.10 (SD 0.301), respectively.

Patients with severe symptoms reported significantly more daytime sleepiness than did patients with mild symptoms (Daytime Sleepiness subscale, $P = 0.034$) (Table 4). A significant

difference emerged between patient groups on Daytime Sleepiness subscale items "Do you take naps during the day?" and "Do you feel rested after a night's sleep?" For the subscale of taking naps during the day, the mean score for adolescents with severe IBD symptoms was 1.50 (SD 0.615) and, for adolescents with mild IBD symptoms, was 1.28 (SD 0.488) (Z = -2.027, P = 0.043). The corresponding mean scores for feeling rested after a night's sleep were 2.00 (SD 0.791) and 1.53 (SD 0.595) (Z = -3.206, P = 0.001).

Almost half of adolescents (n = 15; 43%) with severe IBD symptoms reported that disease symptoms affect the quality of their sleep. This is significantly (P < 0.001) more than in the group of adolescents with mild IBD symptoms (n = 12; 10%).

In the whole group of adolescents with IBD, 17% (n = 27) reported that IBD symptoms affect the quality of their sleep. Of these, 21 patients stated that the quality of sleep was worsened because of intermittent sleep. The reasons for waking up at night were, for example, toilet visits (13 answers), stomach aches (4 answers), or nightmares and sweating (1 answer). Four patients specified that the reason for worsened quality of sleep was a difficulty in falling asleep at night. Three reported needing lots of sleep, and 1 mentioned that the quality of sleep was poor.

No significant differences were present in any of these questionnaires regarding the diagnosis (UC, CD, and ID) (data not shown).

Table 4—Mean scores for SSR subscales and total score in patients with self-reported mild and severe symptoms of IBD[a]

	Mild IBD symptoms (n = 121)		Severe IBD symptoms (n = 35)			
	Mean	SD	Mean	SD	Z	P
Bedtime	15.6	2.3	16.5	2.9	-1.483	0.138
Sleep behavior	9.1	1.4	9.9	2.2	-1.854	0.064
Daytime sleepiness	6.7	1.6	7.6	2.2	-2.121	0.034
Total score	36.4	4.3	38.8	5.8	-2.147	0.032

[a]Data are presented as mean and SD. Patients reported their severity of inflammatory bowel disease (IBD) using a visual-analog scale (VAS), with mild disease having a score of 1-3 (median, 1.0) and severe disease with a score of 4-7 (median, 5.0). SSR refers to Sleep Self-Report; the subscores include Bedtime, Sleep Behaviour, and Daytime Tiredness. The Mann-Whitney U-test was used to determine the z scores and the P values.

DISCUSSION

To the best of our knowledge, this is the first comprehensive report of sleep problems and daytime tiredness among adolescents with IBD. Our findings show that parents of adolescents with IBD report significantly more often trouble sleeping in their children than do the parents of control subjects. Likewise, according to parent report, adolescents with IBD more frequently have nightmares and are overtired than are control adolescents. Interestingly, the patients themselves did not report more sleep problems or daytime tiredness than controls. However, according to both parent and self-reports, patients with severe IBD symptoms more often had trouble sleeping than did patients with mild IBD symptoms. In line with this, adolescents with severe IBD symptoms were overtired according to parent and self-reports (CBCL, YSR) and had daytime sleepiness (SSR) more frequently than did adolescents with mild IBD symptoms. Patients with severe IBD symptoms reported more frequently than those with mild symptoms that the symptoms of their disease had an effect on their sleep—not in falling asleep, but in maintaining sleep (SSR).

We found no earlier studies of sleep in pediatric patients with IBD. However, our results are consistent with previous findings of sleep quality and daytime tiredness among young patients with other chronic inflammatory conditions, i.e., JRA. In a questionnaire-based study, sleep and its relationship to disease activity were assessed in patients with JRA (n = 25) with the CSHQ given to parents and the SSR given to children.[15] Similar to our results, parents reported more sleep trouble (total score) and daytime sleepiness in the patient group than in the control group.[15] For arthritis-related variables, total score in the SSR correlated highly with average pain reported by parents and measured with the VAS in the Varni Pediatric Pain Questionnaire.[15] Zamir et al.[16] studied sleep fragmentation in children with JRA (n = 16). In their study, sleep was evaluated with a self-report questionnaire and polysomnographic recordings. Patient and control groups did not differ in self-reports of sleep, but, on objective polysomnography, disturbed sleep in patients with JRA was recorded and confirmed, and this was associated with daytime sleepiness.[16] Passarelli et al.[13] noted that, although no difference existed in the frequency of sleep complaints between patients with active JRA (n = 21) and the control group, significant alterations occurred in polysomnographic recordings that suggested disturbed sleep in patients with JRA.

These findings indicate that children with chronic inflammatory conditions may fail to report sleep problems that are detected by an objective measure such as polysomnography. To obtain accurate information, it is important that both the parent and the adolescent are asked about sleep problems in these patients. For more objective information, actigraphy, polysomnography, or both actigraphy and polysomnography should be used. Ward et al.[12] investigated sleep parameters obtained by polysomnography and self-reported sleep in children with active (n = 35) and inactive (n = 35) JRA and found that sleep parameters were not altered significantly between these groups. Additionally, children with active JRA did not report more sleep complaints, as compared with children with inactive JRA.[12] In the present study, however, the severity of IBD symptoms was associated with more sleep complaints, as reported by both parents and adolescents themselves.

Sleep disturbances in adults with IBD have been assessed in 3 separate studies. Extraintestinal symptoms, including sleep disturbances, were evaluated in a questionnaire-based study (The Multisystem Inventory).[10] According to these findings, patients with IBD of "average disease severity" (n = 53) reported significantly higher scores of sleep disturbances than did healthy control subjects (n = 56). This study did not include women.[10] In another study on sleep disturbances in adults with IBD, 16 patients (inactive disease) and 7 healthy control subjects filled in questionnaires (e.g., Pittsburgh Sleep Quality Index) and underwent a single night of polysomnography.[8] In the objective sleep assessment, patients with IBD did not differ from healthy control subjects. Nevertheless, patients with IBD did report significantly

worse quality of sleep and scored higher on the Pittsburgh Sleep Quality Index global scale than did healthy control subjects.[8] Finally, Ranjbaran et al.[9] showed in their questionnaire study that adults with inactive IBD (n = 80) had significant sleep disturbances even though their disease was not active. Among patients with IBD, sleep was interrupted because of, for instance, abdominal pain, bathroom visits, or nightmares, and the frequency of sleep interruption was significantly higher among patients with IBD than among healthy control subjects. Subjective sleep quality measured by the Pittsburgh Sleep Quality Index was significantly lower in the patient group than in the control group.[9] All 3 of these studies also included a control group of patients with irritable bowel syndrome. Groups of patients with IBD and those with irritable bowel syndrome did not differ in demographic variables or in the results of sleep disturbances and daytime dysfunction.[8-10] In these studies with a limited number of adults, all patients had inactive IBD, as active inflammation was considered to be a potential confounding factor. The findings of these earlier adult studies and our results reveal that both adults and adolescents with IBD (especially adolescents with severe IBD symptoms) have worse sleep quality and more sleep disturbances than do control subjects.

Refreshing sleep is vital to health; in addition to being associated with enhanced daytime wakefulness, sleep is also associated with overall well-being. Conversely, sleep disturbances are associated with mental and somatic illnesses. Sleep disturbances are encountered in patients with various inflammatory conditions such as asthma, systemic lupus erythematosus, rheumatoid arthritis, and adults with IBD.[8,9,24-27] Sleep disturbances in these chronic inflammatory conditions may be caused by anti inflammatory medication, especially corticosteroids[28]; by disease-related inflammation; or by some other factors associated with the disease, such as psychological stress, pain, or depression. Sleep disturbances are generally thought to worsen the course of chronic inflammatory conditions, exacerbate disease symptoms, increase disease activity, and lower the quality of life.[27] Sleep and the immune system communicate bidirectionally.[29] The recent finding of an inverse correlation between sleep quality and IBD severity[8,9,27] inspired the study group to create an animal model of colonic inflammation to determine the effects of acute and chronic intermittent sleep deprivation on the severity of colonic inflammation. Interestingly, they reported that both acute and chronic intermittent sleep deprivation exacerbate colonic inflammation in mice.[30] Thus, sleep deprivation may be one of the environmental factors causing flare-ups in IBD. Further research is needed to evaluate whether treatment of sleep may have beneficial effects on inflammation.

The response rate in our study was only moderate; 55% of patients with IBD and 27% of control adolescents answered the questionnaires, as we recently discussed.[19] However, parent-adolescent pairs answered at a parallel rate, and the whole country was represented well. Further, the sample of patients was large, compared with earlier studies on sleep in chronic inflammatory diseases in children and adults,[8-13,15,16] and the control group was population-based and matched for age, sex, and place of residence. The item response rate was high, and questionnaires were filled in completely. The SSR questionnaire, originally intended for school-aged children from 7 to 12 years of age, was used here because we found no other standardized questionnaire that assessed self-reported sleep in children and adolescents up to 18 years of age. The SSR questionnaire includes questions that also appear relevant for adolescents older than 12 years, and no significant age-related difference in responses was observed. The parallel sleep question "I sleep more during the day/night" in the standardized CBCL and YSR questionnaires was unspecific for this study, as it does not make a distinction between sleeping more during the day and sleeping more during the night. Both the parents of patients with IBD and the adolescents with IBD themselves reported sleeping more during the day/night than did parents of control subjects and adolescents in the control group. We concluded that, even though patients according to this question seemed to sleep more (likely during the day), they still had sleep problems during the night and were tired during the day, especially patients with severe symptoms. However, the more exact sleep amount of the participants remained unknown because we did not ask the participants to keep a sleep diary, which would have provided more exact data on bedtimes and arising times. Further, patients were not asked about medications, such as corticosteroids. The severity classification of the IBD symptoms was based solely on the subjective self-report of the patients, not on any information on the needed medications. The effects of corticosteroids on sleep have been documented in adults with inflammatory diseases such as rheumatoid arthritis.[28] In the present study, no conclusions can be made about the factors (such as symptoms of the disease, corticosteroid treatment, depression) causing the sleep problems in the group of patients with IBD.

Our results emphasize the importance of evaluating sleep in young patients with IBD. Notably, adolescents with severe symptoms of IBD frequently have sleep problems and may, thus, get an insufficient amount of sleep, which, in turn, worsens their IBD symptoms. Furthermore, poor sleep may increase the risk of psychosocial symptoms or disturbances, such as depression, in these patients.[17] In adolescents with severe symptoms of IBD, sleep evaluation is important in characterizing the disease burden. Further investigations are warranted to determine the association between inflammation status and sleep quality in children and adolescents with IBD.

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