PSYCHOSOCIAL SYMPTOMS AND SLEEP IN ADOLESCENTS WITH PAEDIATRIC INFLAMMATORY BOWEL DISEASE

Teija Pirinen

ACADEMIC DISSERTATION
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To my family
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REFERENCES

ORIGINAL PUBLICATIONS
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This thesis is based on the following original articles, which are referred to in the text by their Roman numerals.

I

II

III

IV
Pirinen T, Kolho KL, Ashorn M, Aronen ET. Sleep Trouble and Psychosocial Symptoms in Adolescents with Inflammatory Bowel Disease. Submitted.

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# ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>AAI</td>
<td>Adult Attachment Interview</td>
</tr>
<tr>
<td>ADHD</td>
<td>Attention-deficit hyperactivity disorder</td>
</tr>
<tr>
<td>ADM</td>
<td>Assessment Data Manager</td>
</tr>
<tr>
<td>A-SADS</td>
<td>Adult Schedule for Affective Disorders and Schizophrenia</td>
</tr>
<tr>
<td>CAS</td>
<td>Child Assessment Schedule</td>
</tr>
<tr>
<td>CBCL</td>
<td>Child Behavior Checklist</td>
</tr>
<tr>
<td>CD</td>
<td>Crohn’s disease</td>
</tr>
<tr>
<td>CDI</td>
<td>The Children’s Depression Inventory</td>
</tr>
<tr>
<td>CF</td>
<td>Cystic Fibrosis</td>
</tr>
<tr>
<td>CSHQ</td>
<td>Children’s Sleep Habit Questionnaire</td>
</tr>
<tr>
<td>DSM</td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
</tr>
<tr>
<td>ENS</td>
<td>Enteric nervous system</td>
</tr>
<tr>
<td>GI</td>
<td>Gastrointestinal</td>
</tr>
<tr>
<td>HRQoL</td>
<td>Health-Related Quality of Life</td>
</tr>
<tr>
<td>IBD</td>
<td>Inflammatory bowel disease</td>
</tr>
<tr>
<td>IBS</td>
<td>Irritable bowel syndrome</td>
</tr>
<tr>
<td>IC</td>
<td>Indeterminate (unclassified) colitis</td>
</tr>
<tr>
<td>ICD</td>
<td>International Classification of Diseases</td>
</tr>
<tr>
<td>JIA</td>
<td>Juvenile idiopathic arthritis</td>
</tr>
<tr>
<td>K-SADS</td>
<td>Kiddie Schedule for Affective Disorders and Schizophrenia</td>
</tr>
<tr>
<td>PCDAI</td>
<td>The Paediatric Crohn Disease Activity Index</td>
</tr>
<tr>
<td>PSG</td>
<td>Polysomnography</td>
</tr>
<tr>
<td>PUCAI</td>
<td>The Paediatric Ulcerative Colitis Activity Index</td>
</tr>
<tr>
<td>SES</td>
<td>Socio-economic status</td>
</tr>
<tr>
<td>SPSS</td>
<td>Statistical Package for the Social Sciences</td>
</tr>
<tr>
<td>SSR</td>
<td>Sleep Self-Report</td>
</tr>
<tr>
<td>UC</td>
<td>Ulcerative colitis</td>
</tr>
<tr>
<td>YSR</td>
<td>Youth Self-Report</td>
</tr>
</tbody>
</table>
ABSTRACT

According to the literature, the risk for emotional symptoms, anxiety and social dysfunction is increased among youth with inflammatory bowel disease (IBD). Previous studies in this area are, however, sparse and in those that do exist, methodological problems occur. Frequency of sleep disturbances, daytime tiredness, and psychosocial symptoms related to sleeping difficulties in paediatric IBD are so far unstudied. The current study aimed to evaluate the frequency of psychosocial symptoms and sleep problems among Finnish adolescents with paediatric IBD compared to population-based controls. Both parents and adolescents themselves were used as a source of information.

The data was collected in spring 2007 as a postal questionnaire-based survey. Parents and adolescents received standardised questionnaires that measured adolescents’ psychosocial symptoms, competence, sleep, and daytime tiredness (Child Behavior Checklist, CBCL, for parent; Youth Self-Report, YSR, and Sleep Self-Report, SSR, for adolescents). The final study includes 160 (56%) adolescents with IBD and 236 (27%) controls with their parents. The groups of patients and controls were similar according to demographic and descriptive characteristics (gender, age, place of residence and socio-economic status), and represented the whole country well.

In the first study, parent and self-reported psychosocial symptoms and competence were evaluated among adolescents with IBD in comparison to the controls, and in the patients, according to severity of IBD symptoms. The main findings here were that the patients reported equally as much psychosocial problems in self-reports as the controls did, even though their parents reported significantly more emotional symptoms, somatic complaints, social problems, thought problems, and lower competence in their children compared to the parents of controls. The frequency of psychosocial problems correlated positively with the severity of IBD symptoms according to both respondents. This study suggests that self-rated questionnaires may not be efficient enough to measure psychosocial well-being of adolescents with IBD and, thus, complementary assessments should be applied. Furthermore, psychosocial evaluation especially among patients with severe IBD symptoms should be routinely applied in clinical visits. Parental evaluation is of great value and should be included in the psychosocial assessment of adolescents with IBD.

The second study assessed parent-adolescent agreement regarding emotional, behavioural and somatic symptoms in adolescents with IBD. In 5% of the cases, parents and adolescents agreed on the presence of a psychosocial problem, but
Abstract

...in 21% of the cases they disagreed. According to both respondents, no problems existed in 74% of the cases. Altogether, the parent-adolescent agreement rate was poor to low, being lowest on anxious/depressed mood and thought problems, and highest on social problems. The parents reported significantly more often somatic symptoms close to clinical range (subclinical) in their adolescents than the adolescents themselves did. These results indicate that in patients with paediatric IBD, parents and adolescents often disagree on patient’s psychosocial problems and somatic complaints. Clinically significant psychosocial and somatic problems would stay unrecognised in this patient group without asking about these symptoms from both the parents and the adolescents themselves.

The third study evaluated frequency of parent and self-reported sleep problems and daytime tiredness among adolescents with IBD in relation to the controls and, in the patient group, in relation to the severity of the disease. The results revealed that, according to the parental perception, adolescents with IBD are burdened with more frequent sleep disturbances and overtiredness than the controls. However, self-reported sleep problems and daytime tiredness were equally common in both groups. Parent and self-reported sleep problems and overtiredness associated positively with the self-reported severity of IBD symptoms. Thus, especially those adolescents with IBD who suffer from severe symptoms of the disease should be further assessed for sleep disturbances and daytime tiredness.

Finally, the fourth study examined parent and self-reported psychosocial symptoms and somatic complaints in sleep-troubled (n=32) versus non-sleep troubled adolescents with IBD (n=125). According to both respondents, the sleep-troubled patients had more frequent psychosocial problems (especially anxiety/depressed mood and aggressive behaviour) and somatic complaints (various aches and nausea) than their counterparts without sleep trouble. Additionally, SSR-measured sleep quality correlated significantly with parent and self-reported attention problems. These results indicate that in those adolescents with IBD who self-perceive sleeping difficulties, further assessment of psychosocial symptoms and proper evaluation of somatic symptoms is needed, as are the interventions to improve sleep quality among them.
INTRODUCTION

Colitis ulcerosa and Crohn’s disease are collectively known as inflammatory bowel disease (IBD). It has been estimated that in Scotland and Sweden the prevalence of paediatric IBD is around 22/100 000 (Armitage et al., 2001; Hildebrand et al., 1994). For an unidentified reason, the number of paediatric IBD cases is growing both in Finland and worldwide (Benchimol et al., 2011; Lehtinen et al., 2011; Turunen et al., 2006). In Finland, the incidence of IBD nearly doubled in 1987-2003 (Turunen et al., 2006), and it continues to rise at an average rate of 6-8% per year (Lehtinen et al., 2011). IBD often affects adolescents and young adults but its appearance at any age is possible (Loftus and Sandborn, 2002; Loftus, 2004). The etiology of IBD is unknown (Geier et al., 2007). Genotype seems to be the main predisposing factor for the disease. However, it accounts only for 10% in colitis ulcerosa and 25% in Crohn’s disease. There is no cure for IBD. The symptoms can, however, be treated and revealed.

Serious chronic somatic conditions, such as IBD, may markedly influence physical, psychological and social developmental processes and cause extra stress during adolescence, which in turn may increase vulnerability to psychosocial problems (Lavigne and Faier-Routman, 1992; Mackner and Crandall, 2007; Michaud et al., 2004; Suris et al., 2004; Taylor et al., 2008). The symptoms of IBD may be harsh (e.g. abdominal pain, diarrhoea, rectal bleeding, fatigue, growth failure, delayed sexual maturation, sleep disruptions), and the course of the disease is unpredictable. Previous studies show that IBD negatively affects mental health and psychosocial functioning, and may predispose the patients to psychiatric disorders (Burke et al., 1989; Burke et al., 1994b; Canning, 1994; Engstöm and Lindquist, 1991; Mackner et al., 2004). Furthermore, the disease may have a stressful impact on all family members and have a negative influence on family functioning (Engström, 1999). It has also been shown that families of chronically ill children use mental health services at a high rate (Gortmaker et al., 1990).

With the increasing incidence of paediatric IBD, it has become more important to understand the impact of the disease on the everyday life, social capability, and mental health of the adolescents with IBD. Paying attention to psychosocial issues in clinical practice is needed to achieve the best success with the treatment of paediatric patients and their families. For example, psychosocial factors may influence compliance to medication (Hommel et al., 2008). Recognising a further need for psychosocial support in this population is also needed. Psychosocial issues among adolescents with IBD have not previously been assessed in the Finnish population.
Introduction

There is increasing evidence of the importance of sleep on the health and overall well-being of growing children and adolescents. Sleep disturbances among adolescents in the normal population are common (Owens, 2008). Paediatric patients with various somatic or psychiatric conditions suffer from sleep problems even more frequently than their peers in the community (Bandla and Splaingard, 2004; Ivanenko and Gururaj, 2009; Owens, 2008). Many sleep disturbances in paediatric patients go unrecognised by health care providers (Glassroth, 2004; Mindell et al., 1994). Sleep troubles associate with emotional and behavioural problems, and may have an excessive impact on everyday life and performance at school and social surroundings (Dahl, 1996; Fallone et al., 2002; Lavigne et al., 1999; Owens et al., 2005; Sadeh et al., 2002). Adult studies indicate that sleep problems are more common among adult patients with IBD compared to healthy controls (Keefer et al., 2006; Ranjbaran et al., 2007a; Zimmerman, 2003). So far, studies evaluating the frequency of disturbed sleep, daytime tiredness, and psychosocial symptoms related to sleeping difficulties among adolescents with paediatric IBD are lacking. Thus, paying attention to the quality of sleep and the consequences of a poor night’s sleep among paediatric patients with IBD is of great value.

The present dissertation work investigated psychosocial symptoms and sleep problems among Finnish paediatric IBD patients compared to community-based controls. In the patient group, the frequency of psychosocial symptoms and sleep problems according to the severity of IBD symptoms were also investigated, as were the psychosocial and somatic symptoms that associate with trouble sleeping in this population. The current study collected data from both parents and adolescents, and thus the evaluation of parent-adolescent agreement regarding psychosocial symptoms and somatic complaints was included.
FINNISH SUMMARY

Tutkimuksen tavoitteena oli selvittää psykososiaalisten oireiden, uniongelmien ja päiväväsymyksen yleisyyttä kroonista tulehduksellista suolistosairautta (Inflammatory bowel disease, IBD)sairastavilla suomalaisnuorilla. Tutkimusaineisto kerättiin postitse standardoiduilla kyselylomakkeilla (Child Behavior Checklist, CBCL; Youth Self-Report, YSR; Sleep Self-Report, SSR), jotka mittaavat lasten ja nuorten psykososiaalisten oireiden ja kompetenssin sekä uniongelmien määrää. Kyselylomakkeisiin vastasivat sekä vanhemmat (CBCL) että nuoret itse (YSR, SSR). Potilasryhmässä vastaiksia palautui 160 (56%) nuorelta ja kontrolliryhmässä 236 (27%) nuorelta.

Potilaat raportoivat itseellään saman verran psykososiaalisia oireita, uniongelmia ja päiväväsymystä kuin kontrollinuoret. Vanhempien mukaan potilailla oli kuitenkin merkittävästi enemmän tunne-elämän oireita, somaattisia vaivoja, ongelmia sosiaalisessa elämässä ja ajatustoiminnassa sekä enemmän unihäiriöitä ja päiväväsymystä kuin kontrollilla. Samoin potilaiden kokonaiskompetenssissä oli heidän mukaansa kontrolloihin verrattuna alhaisempi.

Tämän tutkimuksen perusteella psykososiaalisten oireiden, unihäiriöiden ja päiväväsymyksen yhteyt syolostotaudin oireiden vaikeusasteeseen oli selvä. Potilasnuoret ja heidän vanhempansa raportoivat enemmän psyykososiaalisia oireita, unihäiriöitä ja päiväväsymystä suolistotaudin suhteen hankalasti oireilevillä potilailla kuin niillä, joiden tauti oli vähäoireinen.


Kliinisessä työssä tulisi kiinnittää huomiota psykykkeen ja sosiaaliseen hyvinvointiin ja yöeen laatuun erityisesti niillä kroonista tulehduksellista suolistosairautta sairastavilla nuorilla, jotka itse kokevat suolistotautinsa oireet hankaliksi. Kroonista tulehduksellista suolistosairautta sairastavan nuoren kokema uniongelma antaa aiheen selvittää hänen psykososiaalisia oireitaan tarkemmin.
15

**REVIEW OF THE LITERATURE**

1. **PAEDIATRIC INFLAMMATORY BOWEL DISEASE**

Inflammatory bowel disease (IBD) is a collective term for chronic relapsing autoimmune-type inflammatory conditions of the gastrointestinal (GI) tract known as Crohn’s disease and ulcerative colitis. Crohn’s disease and ulcerative colitis differ mainly according to the anatomical location of inflammation. Crohn’s disease potentially affects the whole GI tract, while ulcerative colitis is located only in the large intestine. Furthermore, in ulcerative colitis the intestinal inflammation is limited to the innermost layer of the intestinal wall, while in Crohn’s disease it may spread through the entire thickness of the intestinal wall. In about 10% of cases it is impossible to distinguish between Crohn’s disease and ulcerative colitis, and therefore the disease is called unclassified colitis (or indeterminate colitis, IC). At long-term follow-ups as the disease progresses, some of these cases can be classified as Crohn’s disease or ulcerative colitis (Hanauer, 2006).

1.1. **ETIOLOGY**

The main causes for IBD are yet to be fully understood. However, genetic (Binder, 1998; Satsangi et al., 1998), environmental (Bernstein et al., 1999; Lashner, 1995), and immune factors (Sartor, 1995; Shanahan and Anton, 1988) seem to play a role in the pathogenesis. The most commonly accepted hypothesis for the cause of IBD suggests that in affected patients, genetic predisposition to altered innate mucosal immune response against luminal antigen (pathogenic or normal enteric organism) causes abnormal mucosal inflammation in the GI tract (Baumgart and Carding, 2007; Nieuwenhuis and Escher, 2008). Over 30% of those who are diagnosed with IBD before they are 20 years of age have other family members with IBD, indicating a marked genetic influence on the onset of the disease (Farmer, 1989). However, genetics alone offer insufficient explanation for the disease. Several environmental factors, such as non-steroidal anti-inflammatory drugs (NSAIDs), antibiotics, viral
and bacterial infections, have been identified as being partly responsible for the development of IBD (Mayer, 2010).

1.2. EPIDEMIOLOGY

For unknown reasons, the incidence of paediatric IBD is rising in many Western countries (Armitage et al., 2001; Barton et al., 1989; Cosgrove et al., 1996; Lindberg et al., 2000) including Finland (Turunen et al., 2006). In Finland, the mean annual incidence of paediatric IBD nearly doubled during 1987-2003, and during that period of time the highest recorded incidence rate was 9.7/100 000 (Turunen et al., 2006). Similar high incidence rates have been reported in Wisconsin, USA (Kugathasan et al., 2003) while in other Western countries the rates remain lower, ranging between 4.0 to 7.0 cases per 100 000 (Armitage et al., 2001; Hassan et al., 2000; Lindberg et al., 2000). According to very recent findings, the incidence of the condition is increasing at a rate of 6-8% per year in Finland (Lehtinen et al., 2011). The increase in the incidence rate has been reported to be similar for boys and girls (Lehtinen et al., 2011). Approximately 15-25% of IBD patients are diagnosed before the age of 20 (Kim and Ferry, 2004; Oliva-Hemker and Fiocchi, 2002). The peak incidence period of paediatric IBD seems to be around 12-15 years of age (Langholz et al., 1997; Turunen et al., 2006).

The prevalence rates of the disease have also continued to increase worldwide as a result of the rising incidence rate, along with improved treatment and survival (Loftus and Sandborn, 2002). Currently the prevalence rates of the condition in the paediatric population vary greatly between 22-71/100 000 (Hildebrand et al., 1994; Kappelman et al., 2007). In Finland, according to Social Insurance Institution data, about 30 000 individuals in 2007 and over 35 000 individuals in 2010 were entitled to medical reimbursement because of IBD.

1.3. CLINICAL PRESENTATION

IBD is characterised by unpredictable exacerbations and remissions. In paediatric patients, the clinical presentation of IBD is often more severe compared to adult-onset disease (Langholz et al., 1997; Nieuwenhuis and Escher, 2008). This difference is explained by the distinct anatomic location of inflammation. In paediatric patients with Crohn’s disease, inflammation rarely manifests exclusively in the small intestine but rather affects the colon, causing symptoms of colitis and thus being difficult to distinguish from ulcerative colitis (Auvin et al., 2005; Kugathasan et al., 2003; Mamula et al., 2003; Turunen et al., 2006). There is also often upper GI tract
involvement in paediatric Crohn’s disease (Nieuwenhuis and Escher, 2008). In paediatric ulcerative colitis at the time of diagnosis, inflammation is spread wider and more frequently affects the whole colon than in adults (in about 61-80% of cases) (Griffiths, 2004; Turunen et al., 2006).

Figure 1 illustrates the prevalence of the most common symptoms of Crohn’s disease and ulcerative colitis (Figure 1). Generally, growth failure is the first sign of the disease in children with early-onset IBD (Stephens et al., 2001). Bone demineralisation caused by inadequate nutrition, long-term treatment with corticosteroids, and decreased physical activity is a significant problem in paediatric patients with Crohn’s disease (Sentongo et al., 2002). Additionally, symptoms of IBD may comprise extraintestinal complication such as delayed sexual maturity, anaemia, osteoporosis, synovitis/arthritis, skin problems and renal and hepatic manifestations (Mamula et al., 2003). Development of malignancies of the affected bowel (colon carcinoma) is possible though rare (Brackmann et al., 2009; Zisman and Rubin, 2008). The symptoms of IBD are potentially harsh and embarrassing and may have a marked influence on the everyday life of adolescents, causing psychosocial complications such as depression, social isolation and school absence (see the chapter entitled Psychosocial symptoms in paediatric inflammatory bowel disease).

![Figure 1. Percentiles of commonly presenting symptoms in children and adolescents at the time of diagnosis with paediatric Crohn’s disease (CD) and ulcerative colitis (UC) (adapted from Kugathasan et al., 2003). * Data obtained from Langholz et al., 1997. ** Data obtained from Dubinsky, 2008.](image-url)
1.4. THERAPEUTIC OPTIONS

There is no absolute cure for IBD. Therapeutic options in paediatric IBD are comparable to those available in adult-onset disease. Treatment focuses on controlling the inflammation, minimising symptoms, preventing complications, and ensuring as normal physical and psychological growth as possible. Suitable treatment depends on the severity of the disease, the location of inflammation and the existence of complications. Treatment options are medication, nutritional therapy and surgery. Psychosocial aspects of the disease are included in the proper care of paediatric IBD.

Table 1 summarises medication guidelines in paediatric patients with mild to moderate Crohn’s disease and ulcerative colitis. Additionally, total enteral nutrition plays an important role in the treatment of Crohn’s disease (see below). Medication of IBD may include 5-aminosalicylate compounds (mesalamine), glucocorticoids (corticosteroids), immunomodulators (azathioprine, methotrexate, 6-mercaptopurine), and biologic treatment (infliximab). Antibiotics that modulate the bacterial flora of the bowel (metronidazole, ciprofloxacin) are known to be effective, though investigations have failed to prove this successfully (Sartor and Muehlbauer, 2007). Medication includes glucocorticoids, mainly when inducing remission and the aim is to wean them off as soon as possible due to their undesirable side-effects such as emotional changes, sleep disturbance, moon face, weight gain, acne, diabetes, hypertension, growth retardation and osteoporosis (McDonough et al., 2008). Treatment with corticosteroids has been proven to impair memory, executive functions, mood and sleep in paediatric patients with IBD (Mrakotsky et al., 2005). Despite this, 45% of paediatric patients with ulcerative colitis (Hyams et al., 2006) and 31% with Crohn’s disease (Markowitz et al., 2006) are still dependent on corticosteroids one year after diagnosis. Of children with newly diagnosed IBD, about 80% had been treated with glucocorticoids within the first 30 days after diagnosis (Hyams et al., 2006). In the Finnish cohort, the majority of paediatric IBD patients (80%) had been on glucocorticoids at some point, and 76% of them received glucocorticoids as a first line treatment at the time of diagnosis (Turunen et al., 2009).

In Crohn’s disease, total enteral nutrition by either elemental or polymeric formulas can be used to calm down the inflammation and induce remission (Borrelli et al., 2006; Ruuska et al., 1994). In some studies, total enteral nutrition has proved to be even more effective compared to corticosteroids in improving the intestinal inflammation and maintaining clinical remission (Berni Canani et al., 2006; Ruuska et al., 1994). However, opposite findings also exist (Griffiths et al., 1995). Because total enteral nutrition has no undesirable side-effects, and it simultaneously corrects the chronic malnutrition and mineral deficiency, it should be considered as first line treatment in Crohn’s disease when possible (Ruuska et al., 1994).
Table 1. Medication for Crohn’s disease (CD) and ulcerative colitis (UC) in paediatric patients (Adapted from Kim and Ferry, 2004).

<table>
<thead>
<tr>
<th></th>
<th>CD</th>
<th>UC</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Active disease</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mesalamine</td>
<td>Oral or rectal for active disease</td>
<td>Same</td>
</tr>
<tr>
<td>Corticosteroids</td>
<td>For active disease</td>
<td>Same</td>
</tr>
<tr>
<td>Purine analogues (6-MP/AZA)</td>
<td>For corticosteroid resistance or dependence</td>
<td>Same</td>
</tr>
<tr>
<td>Methotrexate</td>
<td>For 6-MP/AZA resistance or intolerance (less commonly used)</td>
<td>Same (but less evidence of efficacy)</td>
</tr>
<tr>
<td>Anti-TNF-α antibody</td>
<td>For corticosteroid resistance, in fistulising disease, or to wean off corticosteroids</td>
<td>Use unclear but may be beneficial</td>
</tr>
<tr>
<td>Antibiotics (metronidazole/ciprofloxacin)</td>
<td>Beneficial</td>
<td>Not beneficial</td>
</tr>
<tr>
<td><strong>Maintenance therapy</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mesalamine, 6-MP/AZA, methotrexate, and anti-TNF-α in selected patients</td>
<td>Same (except methotrexate and anti-TNF-α)</td>
</tr>
</tbody>
</table>

6-MP, 6-mercaptopurine; AZA, azathioprine; TNF, tumour necrosis factor

Crohn’s disease cannot be cured by surgical resection and, thus, surgery is reserved for acute and chronic complications of the disease (such as abscess or fistulae formation or stenosis/strictures). Intestinal inflammation in ulcerative colitis can be cured with total colectomy, but extraintestinal symptoms may still appear and remain. In addition to acute abdominal situations, surgery in ulcerative colitis is indicated primarily when medical treatment fails to control the disease, if there is evidence of colonic dysplasia or colon carcinoma, if there is severe glucocorticoid-induced complications or prolonged dependence on them, or in longstanding disease (greater than 10 years). In Finland, one-third of all paediatric patients with Crohn’s disease and almost a quarter (24%) with ulcerative colitis undergo surgery at some point (Turunen et al., 2009).
2 PSYCHOSOCIAL SYMPTOMS IN PAEDIATRIC IBD PATIENTS

The term psychosocial is defined here to involve both mental well-being and social aspects of behaviour. Children and adolescents with inflammatory bowel disease are required to cope with the disease-related challenges in social surroundings as well as the symptoms and medication of the disease, whilst the inflammation per se may sway their internal mental well-being and affect their behaviour in an unfavourable manner. In this chapter, psychosocial symptoms referring to maladaptation, abnormal state of mental health, and ill behaviour in relation to the social surroundings among children and adolescents with paediatric IBD are reviewed.

2.1. PSYCHOSOCIALLY BURDENSOME CHARACTERISTICS OF THE DISEASE

Initially, IBD was classified as psychosomatic in origin (Alexander, 1965; Engel, 1969). Although the exact etiology of IBD remains unknown, increased knowledge of the major role of genetic and environmental factors on the pathogenesis of IBD have diminished the assumption that psychological factors could be the main cause of the disease. Many burdensome characteristics of the disease may, however, predispose paediatric IBD patients to psychosocial problems.

IBD symptoms are potentially embarrassing, and the disease course is unpredictable and uncertain. This may cause restrictions to social life and impair social functioning of these patients (Engström and Lindquist, 1991; Mackner and Crandall, 2006). Disease factors such as concerns related to clinical examinations, medication and surgery, fear of losing control of the symptoms, and scaring malignancies may cause severe psychological stress, which in turn have reported to increase the somatic symptoms of the disease, at least in adult studies (Bernstein et al., 2010). Emotional and behavioural symptoms may reflect difficulties to adapt to lifestyle changes, which are necessary in order to manage with the disease and its symptoms, and to possible changes in appearance induced by the disease or its treatment (e.g. growth failure, delayed puberty, weight loss, cushingoid features due to corticosteroids). Reportedly, patients with IBD are concerned with their body image (Karwowski et al., 2009; Maunder et al., 1999). Malabsorption results in growth failure and weight loss. It may also lead to a deficiency of certain nutrients.
that are essential for emotional well-being and neurocognitive functioning such as folic acid, B-vitamins and tryptophan (Evers et al., 2010; Obeid et al., 2007; Reynolds and Stramentinoli, 1983; Tolmunen et al., 2004).

Corticosteroid treatment, which is frequently used to treat IBD, is known to cause emotional lability, euphoria, sleep disturbances, depression, psychotic symptoms, and appearance-altering side-effects, such as acne, Cushing’s syndrome, growth retardation and delayed puberty (Drigan et al., 1992; Fardet et al., 2007; McDonough et al., 2008; Schäcke et al., 2002). In paediatric IBD, treatment with corticosteroids associates with increased symptoms of depression; those on steroids had more problems with memory and depression compared to those not on steroids (Mrakotsky et al., 2005; Szigethy et al., 2004).

Surgery is required when medication fails to control inflammation. More than a third of individuals with early-onset IBD will need surgical resection within 20 years of diagnosis in order to manage the disease (Langholz et al., 1997). This may be a huge and frightening step for children, adolescents and their families. However, there is evidence that if these patients are well prepared and receive appropriate aftercare, abdominal surgery does not impair the psychological adjustment, self-esteem or quality of life of these children (Lask et al., 1987); indeed, quality of life may even improve permanently (Lillehei et al., 2010; Tulchinsky et al., 2010).

2.2. PARENT AND SELF-REPORTED PSYCHOSOCIAL SYMPTOMS

Until now, psychosocial problems have been well studied among the adult population of IBD patients. Adults with IBD are more likely to have psychiatric diagnosis (most commonly depression or anxiety) than healthy adults (Graff et al., 2009; Mikocka-Walus et al., 2007). In recent years, knowledge of psychosocial symptoms among paediatric IBD patients has also greatly increased. Psychosocial symptoms in paediatric IBD have mainly been assessed in the United States (Burke et al., 1989; Burke et al., 1994b; Mackner and Crandall, 2005; Mackner and Crandall, 2006; Szajnberg et al., 1993; Szigethy et al., 2004; Wood et al., 1987) but also in Germany (Steinhausen and Kies, 1982), Sweden (Engström and Lindquist, 1991; Engström, 1992; Engström, 1999; Lindfred et al., 2008), Great Britain (Moody et al., 1999), Canada (Gold et al., 2000), and the Netherlands (De Boer et al., 2005) (Table 2). According to these studies, children and adolescents with IBD seem to be at greater risk of difficulties in emotional and behavioural functioning as well as social and family functioning compared to their peers in the normal population (Engström and Lindquist, 1991; Wood et al., 1987). When these psychosocial issues are compared to other groups of chronically ill children and adolescents, the findings
Review of the literature

Table 2. Review of studies concerning psychosocial symptoms among children and adolescents with paediatric IBD.

<table>
<thead>
<tr>
<th>IBD patients</th>
<th>Controls</th>
<th>Study question</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>age (y)</td>
</tr>
<tr>
<td>Steinhausen H. (1982)</td>
<td>17</td>
<td>mean 13.0</td>
</tr>
<tr>
<td>Wood B. (1987)</td>
<td>88</td>
<td>6-17</td>
</tr>
<tr>
<td>Burke P. (1989)</td>
<td>55</td>
<td>mean 12.1</td>
</tr>
<tr>
<td>Burke P. (1990)</td>
<td>13</td>
<td>mean 12.3</td>
</tr>
<tr>
<td>Engström I. (1991)</td>
<td>20</td>
<td>9-18</td>
</tr>
<tr>
<td>Engström I. (1992)</td>
<td>20</td>
<td>9-18</td>
</tr>
<tr>
<td>Szajnberg N. (1993)</td>
<td>15</td>
<td>mean 11.6</td>
</tr>
<tr>
<td>Burke P. (1994)</td>
<td>36</td>
<td>mean 12.0</td>
</tr>
<tr>
<td>Engström I. (1999)</td>
<td>20</td>
<td>9-18</td>
</tr>
<tr>
<td>Gold N. (2000)</td>
<td>36</td>
<td>8-18</td>
</tr>
<tr>
<td>Szigethy E. (2004)</td>
<td>102</td>
<td>11-17</td>
</tr>
<tr>
<td>De Boer M. (2005)</td>
<td>40</td>
<td>12-18</td>
</tr>
<tr>
<td>Mackner LM. (2005)</td>
<td>50</td>
<td>11-17</td>
</tr>
<tr>
<td>Mackner LM. (2006)</td>
<td>50</td>
<td>mean 14.4</td>
</tr>
<tr>
<td>Lindfled H. (2008)</td>
<td>71</td>
<td>10-16</td>
</tr>
</tbody>
</table>

I/Q= Interview and/or questionnaire based study; y= years; CBCL= Child Behavior Checklist; HPC= Harter’s Perceived Competence Scale for Children; K-SADS= Kiddie Schedule for Affective Disorders and Schizophrenia; CAS= Child Assessment Schedule; CDI= The Children’s Depression Inventory; FAD= Family Assessment Device; PCDAI= Paediatric Crohn Disease Activity Index; ITIA = I think I am; MCM= Million Clinical Multi-Axial Inventory; YSR= Youth Self-Report; K-SADS-PL= Schedule for Affective Disorders and Schizophrenia for School-Age Children – Present and Lifetime Version; K-SADS-E=Kiddie Schedule for Affective Disorders and Schizophrenia- Epidemiologic Version; PH= Piers-Harris Test of Self-Concept; A-SADS-L= Adult Schedule for Affective Disorders and Schizophrenia – Life-time Version; AAI= Adult Attachment Interview; FRI=Family Relationship Index Scale; FILE=Family Inventory of Life events; DUCATQOL=Dutch Children’s Quality of Life Questionnaire
Review of studies concerning psychosocial symptoms among children and adolescents with paediatric IBD.

<table>
<thead>
<tr>
<th>Methods and Respondents</th>
<th>Main results</th>
</tr>
</thead>
<tbody>
<tr>
<td>I: parent</td>
<td>More psychiatric (mainly emotional) disorders in IBD group than in controls (59% vs. 18%); No association between disease variables and psychopathology.</td>
</tr>
<tr>
<td>Q: parent (CBCL), child (HPC)</td>
<td>More psychological (mainly emotional) dysfunction in IBD group than in siblings; No correlation between CBCL scores and disease variables.</td>
</tr>
<tr>
<td>I: child (K-SADS)</td>
<td>Lifetime prevalence of depression was higher in IBD (25%) than in CF (12%); No group difference in current depressive or lifetime/current anxiety disorders.</td>
</tr>
<tr>
<td>I: parent (A-SADS-L), child (K-SADS-E) Q: parent (FRI, FILE)</td>
<td>The depressed children (n=3) had less severe symptoms of IBD than non-depressed counterparts (n=10), and they had not needed steroids.</td>
</tr>
<tr>
<td>I: child (CAS) Q: parent (CBCL)</td>
<td>More children with IBD had psychiatric diagnosis (60%) than controls (15%) (mainly depressive and anxiety). Higher Total, Internalising and Externalising CBCL scores and lower social competence scores in patients than in controls. No correlation to disease severity.</td>
</tr>
<tr>
<td>I: child (CAS) Q: parent (e.g. CBCL), child (e.g. CDI)</td>
<td>IBD patients had lower self-esteem, social competence, and general well-being, and higher CDI scores than healthy controls. Overall, more psychiatric disturbances in IBD group than in other disease groups. No difference on anxiety.</td>
</tr>
<tr>
<td>I: parent (A-SADS-L), child (K-SADS) Q: parent (e.g. MCMi, CBCL) Psychological tests: child</td>
<td>73% of children had DSM-III diagnosis (internalising). 78% of parents had DSM-III diagnosis (personality disorder). CBCL revealed more Internalising than Externalising problems in children. Psychological test revealed constriction, anxiety, denial and depression in children with IBD. Three children were suicidal. Thirteen mothers were insecurely attached to their children.</td>
</tr>
<tr>
<td>I: parent, child (CAS) Q: parent (e.g. CBCL), child (e.g. CDI)</td>
<td>IBD group had higher levels of maternal distress and greater family dysfunction than healthy controls. No significant differences between disease groups. Self-esteem was lowered in IBD. No correlation between severity of IBD and psychiatric symptoms.</td>
</tr>
<tr>
<td>Q: parent (CBCL), child (CDI, PH)</td>
<td>IBD patients were less depressed, had fewer behavioural problems, and higher self-esteem than FGI patients. In IBD group, 19% thought their illness as problem to them (vs. 65% in FGI group).</td>
</tr>
<tr>
<td>I: child (K-SADS-PL) Q: child (CDI)</td>
<td>25% had clinically significant CDI scores. Children with moderate/severe IBD symptoms had higher mean CDI scores than those with mild disease symptoms. Patients on steroids were more likely to have clinically significant CDI scores than those not on steroids.</td>
</tr>
<tr>
<td>Q: parent (e.g. CBCL), child (e.g. DUCATQOL)</td>
<td>IBD patients have worse HRQoL and more Internalising problems than healthy controls. Self-esteem predicts HRQoL.</td>
</tr>
<tr>
<td>Q: child (e.g. YSR, PH), gastroenterologist (PCDAI)</td>
<td>No group difference on any of the measures. 20% in IBD group had clinically significant behavioural/emotional symptoms. Severity of the disease did not correlate with psychosocial symptoms.</td>
</tr>
<tr>
<td>Q: parent (CBCL, FAD), gastroenterologist (PCDAI)</td>
<td>Adolescents with IBD had more anxious/depression and social impairment than controls. Severity of the disease did not correlate with psychosocial symptoms.</td>
</tr>
<tr>
<td>Q: child (ITIA)</td>
<td>Self-esteem was similar in both groups. Children with severe IBD symptoms and separated parents had higher risk for problems with self-esteem.</td>
</tr>
</tbody>
</table>
are inconsistent (Burke et al., 1989; Engström, 1992; Gold et al., 2000). Paediatric IBD patients seem to present less with depression than their peers with functional gastrointestinal complaints (Gold et al., 2000) but they seem to experience more psychosocial impairment than their counterparts with cystic fibrosis (Burke et al., 1989) or diabetes (Engström, 1992). Mackner LM et al. (2004) reviewed the existing studies in this field and stated that overall they are characterised by poor methodology (Mackner et al., 2004). Sample sizes are small, unspecified and unpublished questionnaires are used, and when standardised measures are used, T-scores are not necessarily reported (e.g. Engström and Lindquist, 1991; Engström, 1992) limiting evaluation of clinical significance and comparison to other parallel studies (Mackner et al., 2004). Furthermore, methods to define disease symptom severity vary greatly between earlier studies, and in many of them the disease severity has not been included at all (Table 2). Additionally, all the Swedish studies of Engström I (1991, 1992, 1999) seem to be based on the same sample of IBD children and controls (Engström and Lindquist, 1991; Engström, 1992; Engström, 1999).

2.2.1. BEHAVIOURAL AND EMOTIONAL FUNCTIONING IN PATIENTS WITH PAEDIATRIC IBD

Prevalence of psychiatric disorders have been assessed in a few studies based on structured (e.g. CAS) or semi-structured (e.g. K-SADS, AAI) interviews (Burke et al., 1989; Burke et al., 1994b; Engström, 1992; Szajnberg et al., 1993; Szigethy et al., 2004) (Table 2). Of these, only Burke P et al. (1989) and Szigethy E et al. (2004) describe interviewer training or reliability checks, which are essential for the reliable usage of these instruments. Engström I et al. (1991, 1992, 1999) utilised the structured interviews of the Child Assessment Schedule (CAS) and found that significantly more of the 20 children with IBD (60%) had a psychiatric disorder, particularly serious depressive and anxiety disorders, than controls with headaches (30%) or diabetes (20%), or healthy controls (15%) (Engström, 1992). Steinhausen H et al. (1982) used an unspecified interview and reported similar frequencies (59%) of psychiatric diagnosis among children with IBD (n=17) according to the International Classification of Diseases, Ninth Edition (ICD-9) (Steinhausen and Kies, 1982). The Kiddie Schedule for Affective Disorders and Schizophrenia (K-SADS) revealed that 73% (n=11) of children with IBD met the criteria for DSM-III psychiatric diagnosis, mainly internalising disorders (Szajnberg et al., 1993). More recently, Szigethy et al. (2004) used both questionnaire (Children’s Depression Inventory, CDI) and interview (K-SADS-PL) measures to investigate the prevalence of depressive symptoms among adolescents with IBD (n=102). One-quarter (n=25, 25%) of them had clinically significant depressive symptom scores on the CDI. Of these 25
adolescents, 19 participated in the interview and of those, 16 met the criteria for diagnosable major or minor depressive disorder (Szigethy et al., 2004). There was no control group included (Szigethy et al., 2004) (Table 2).

Burke P et al. (1989) used K-SADS in order to compare anxiety and depressive disorders between children with IBD (n=55) and children with cystic fibrosis (CF; n=52) (Burke et al., 1989). The lifetime prevalence of depressive disorder was higher among IBD (25%) than CF patients (12%) but there was no group difference in the current prevalence of depression (10% in IBD), or in the lifetime or current prevalence of anxiety disorders (11% and 4% in IBD, respectively) (Burke et al., 1989). A few years later Burke P et al. (1994) studied the same issue in a different sample of 36 newly diagnosed children with IBD, though this time without a control group, and found that 14% (n=5) of the sample met the criteria for major depression, 28% (n=10) had depressive symptoms, and 28% (n=10) met the criteria for anxiety disorder (Burke et al., 1994b) (Table 2). The study subjects did not have a history of depression before the onset of the disease and thus the results suggest that depressive symptoms and disorders arise after IBD diagnosis (Burke et al., 1994b).

Several studies used standardised questionnaires for parents (e.g. CBCL) and children (e.g. CDI) (Table 2). In four studies, the mean normative T-scores fell within the normal range (Gold et al., 2000; Mackner and Crandall, 2005; Mackner and Crandall, 2006; Wood et al., 1987). Wood B et al. (1987) found that average CBCL scores for total and internalising symptoms were significantly higher in children with IBD than their siblings, and 39% of CD and 29% of CU patients had clinically significant CBCL scores for total problems (respective values in siblings were 24% and 4%) (Wood et al., 1987). Gold N et al. (2000) found that children with IBD (n=36) had fewer symptoms of CBCL and CDI than children with functional gastrointestinal complaints (n=26) and therefore concludes that for paediatric IBD patients, achieving normal psychosocial adjustment is possible (Gold et al., 2000). Mackner LM et al. (2005) found no significant difference between IBD adolescents and their healthy peers on any of the self-assessments used (Mackner and Crandall, 2005). However, a subset of IBD adolescents (20%) reported clinically significant emotional/behavioural symptoms but the frequency did not differ from that in control adolescents (31%) (Mackner and Crandall, 2005). Most of the IBD adolescents were in remission or the disease symptoms were mild at the time of the study, and the disease was diagnosed at least one year earlier. According to parental reports on the CBCL, adolescents with IBD had more anxiety, depression, and social impairment than healthy control adolescents (Mackner and Crandall, 2006).

Three studies using the same sample of 20 children with IBD, and controls of healthy children and children with diabetes and headaches (n=20 in each control group) report that children with IBD had significantly higher total and internalising scores on the CBCL, and in self-report (e.g. CDI) they expressed significantly more depressive symptoms than the healthy children did (Engström and Lindquist,
No significant difference emerged between children with IBD and healthy children in self-reported anxiety symptoms, and only few significant differences were documented between the illness groups, for example anxiety levels was significantly higher in the headache group than in other comparison groups and IBD patients scored significantly higher in a lie scale than the other groups (Engström and Lindquist, 1991; Engström, 1992; Engström, 1999). Furthermore, IBD patients had significantly more parent-reported behavioural problems (Engström and Lindquist, 1991) and their self-esteem was lower compared to healthy controls (Engström, 1992).

### 2.2.2. Social and School Functioning in Patients with Paediatric IBD

A study assessing social and school life of children with IBD reports that 60% of IBD subjects (n=64) had prolonged absences from school with a mean of three months over the previous 12 months, 80% reported that their success in school was lowered due to the disease, and their social life including playing outside with friends, taking part in sports, and staying overnight at a friend’s house was reduced and restricted (Moody et al., 1999) (Table 3). According to the CBCL social competence scale, IBD patients had significantly lower social competence than their healthy peers (Engström and Lindquist, 1991; Engström, 1992) and they also had a lower score on this scale compared to controls with diabetes or headaches (Engström, 1992). However, in these studies T-scores were lacking, making evaluation of clinical significance impossible. According to Mackner LM et al. (2006), parents reported on the CBCL that children with IBD had significantly worse social competence than healthy children (Mackner and Crandall, 2006), but children themselves did not confirm this finding on the YSR (Mackner and Crandall, 2005) (Table 3). Gold et al. (2000) reported that the mean CBCL Social Competence T-score among children with IBD (n=36) was similar compared to controls with functional gastrointestinal complaints and fell within the normal range, indicating adequate social functioning in these children (Gold et al., 2000). One study of health-related quality of life (HRQoL) in eight paediatric conditions (obesity, eosinophilic gastrointestinal disorder, IBD, epilepsy, type 1 diabetes, sickle cell disease, post-renal transplantation and cystic fibrosis) reports that there were no significant group differences between the IBD group and the other disease groups in self-reported HRQoL, including the domains of physical, emotional, social, school and psychosocial (Ingerski et al., 2010). According to the parental report, HRQoL in the IBD group was either similar or significantly better in all previously mentioned domains, including social and school functioning than in the other illness groups (Ingerski et al., 2010) (Table 3).
Table 3. Review of studies concerning social and school functioning in paediatric patients with IBD.

<table>
<thead>
<tr>
<th></th>
<th>IBD patients</th>
<th>Controls</th>
<th>Methods</th>
<th>Main results</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>age (y)</td>
<td>n</td>
<td>q: parent (e.g. CBCL, The Frisk Well-Being Scale), Child (e.g. I Think I am)</td>
</tr>
<tr>
<td>Engström I. (1992)</td>
<td>20</td>
<td>9-18</td>
<td>20/each</td>
<td>According to the parents, children and adolescents with IBD were socially less competent than controls. They also had problems with school, peer relations and self-image. Self-reported social competence was similar in IBD patients than in the healthy controls, and better than those with headache or diabetes.</td>
</tr>
<tr>
<td>Moody G. (1999)</td>
<td>64</td>
<td>5-17</td>
<td>-</td>
<td>Q: parent, child</td>
</tr>
<tr>
<td>Gold N. (1999)</td>
<td>36</td>
<td>8-18</td>
<td>26</td>
<td>Parent-reported social competence (CBCL) was similar in the IBD and FGI groups. In all study subjects, T-scores were in the normal range indicating adequate social competence.</td>
</tr>
<tr>
<td>Mackner LM. (2005)</td>
<td>50</td>
<td>11-17</td>
<td>42</td>
<td>Q: child (e.g. YSR)</td>
</tr>
<tr>
<td>Mackner LM. (2006)</td>
<td>50</td>
<td>Mean 14.4</td>
<td>42</td>
<td>Social competence was significantly lower in adolescents with IBD than in healthy controls. Of the adolescents with IBD, 22% had clinically significant Social competence scores (vs. 2% in healthy controls). Those patients who were diagnosed in adolescence had more often clinically significant problems with social functioning than those who were diagnosed in childhood (35% vs. 5%).</td>
</tr>
<tr>
<td>Ingerski LM. (2010)</td>
<td>34</td>
<td>Mean 15.4</td>
<td>555</td>
<td>Q: parents and child (PedsQL)</td>
</tr>
</tbody>
</table>

I/Q= Interview and/or questionnaire based study; y= years; CBCL= Child Behavior Checklist; YSR= Youth Self-Report; CDI= the Child Depression Inventory; PH= Piers-Harris Test; PedsQL= The Paediatric Quality of Life Inventory; CF= Cystic fibrosis; EGiD= Eosinophilic gastrointestinal disorder; SCD= Sickle cell disease
2.2.3. FAMILY PSYCHIATRIC HISTORY AND FAMILY FUNCTIONING

Chronic illness of a child influences other family members and family functioning. Family functioning and psychosocial symptoms of the parents and siblings have also been studied in families with a child suffering from IBD. Conflicting results exist between families with a child with IBD and comparison families with healthy children. Engström I et al. (1999) found that mothers reported greater family dysfunction in families with a child with IBD than in control families with a healthy child or a child with diabetes (Engström, 1999). Mackner LM et al. (2006) in turn found no difference in family functioning between families with a child with IBD or a healthy child (Mackner and Crandall, 2006). In families with a child with IBD, family dysfunction significantly relates to increased severity of the disease, a greater number of symptoms of pain/fatigue, more bowel movements and a higher prevalence of emotional and behavioural symptoms (Burke et al., 1990;Tojek et al., 2002;Wood et al., 1989). Within IBD families, family-wide stress, communication styles, and agreement rate regarding the disease factors are related to the activity of the child’s IBD, and a patient’s individual stress relates to his/her overall coping with the disease (Gerson et al., 1998).

A study of 13 newly diagnosed paediatric IBD patients found that six of these patients’ mothers had a history of depression, and the mothers of all three depressed children had a history of depression (Burke et al., 1990). Furthermore, the mothers of depressed children reported a lack of cohesion and high conflict rates in their families (Burke et al., 1990;Burke et al., 1994a). Another study found that the prevalence of current (10%) and lifetime diagnosis (51%) of maternal depression assessed by A-SADS interview was similar in mothers of children with IBD than those of cystic fibrosis (Burke et al., 1994a). Engström I et al. (1999) found that mothers of children with IBD reported more emotional and behavioural symptoms relating to themselves than mothers of healthy children (Engström, 1999). Mothers of IBD children also suffered from higher parental distress than mothers of healthy children but, in this respect, the fathers did not differ from the comparison fathers (Engström, 1991).

2.3. RELATIONSHIP BETWEEN PSYCHOLOGICAL FACTORS AND DISEASE SEVERITY

Psychological factors including anxiety, depression and experienced stress seem to cause disease exacerbations in adult IBD patients (Graff et al., 2009;Maunder and Levenstein, 2008;Mawdsley and Rampton, 2006;Mawdsley et al., 2006). Symptoms of IBD are more severe in depressed adults with IBD than in their non-depressed counterparts (Graff et al., 2009). So far, the studies on the relationship between
psychological factors and disease (symptom) severity in paediatric IBD patients have reported inconsistent results (Burke et al., 1994b; Engström and Lindquist, 1991; Mackner and Crandall, 2005; Steinhausen and Kies, 1982; Szigethy et al., 2004; Wood et al., 1987).

Of the disease variables including duration of IBD, histological and radiological findings, frequency of relapses and growth retardation, only the last showed significant association with disturbed psychological functioning in adolescents with IBD (Steinhausen and Kies, 1982). In another study, psychological functioning did not relate to any of the disease variables that included disease activity, disease severity, duration of the disease, and growth failure (Wood et al., 1987). However, according to that study, an internalising psychological style (referring to the way in which psychological problems are expressed and solved) associated with greater disease activity, and self-perceived severity of IBD correlated negatively with self-rated physical and social competence (Wood et al., 1987). One study reports more depressive symptoms in those paediatric IBD patients who suffer from moderate/severe disease symptoms than those with inactive disease (Szigethy et al., 2004). Furthermore, in that study usage of steroids was associated with a clinically significant rate of emotional symptoms (Szigethy et al., 2004). Risk of impaired self-esteem is elevated in young people with severe IBD symptoms (Lindfred et al., 2008). Interestingly, depressed paediatric IBD patients have also reported to have less severe IBD symptoms than their non-depressed counterparts (Burke et al., 1990; Burke et al., 1994b). One study recognised a subgroup of children and adolescents with good mental health and psychosocial outcomes despite severe IBD symptoms (Engström, 1999). These children and adolescents had common characteristics such as good knowledge of the disease and a willingness to learn more about it, ability to name factors (commonly stressful factors) that could increase IBD symptoms, belief of being able to influence the disease course themselves to a certain extent, and an open and permissive climate in the family and a well-functioning social network (Engström, 1999). Interestingly, negative affectivity associates significantly with subjective perception of IBD disease severity rather than with objectively determined (laboratory values) severity of the disease (Ondersma et al., 1997).

In inflammatory bowel disease, the relationship between psychological symptoms and disease severity seems to be bidirectional. Somatic symptoms of the disease, treatment and other disease-related concerns may cause stress and increase the risk of depression and anxiety among these patients (see the previous chapter). Psychological factors, such as stress and emotional problems, have an impact on systemic and local immune functions (Daruna and Morgan, 1990) and may, in turn, worsen the somatic symptoms of the disease, which have been well demonstrated among adult IBD patients (Bernstein et al., 2010; Levenstein et al.,
Experienced stress may also decrease the threshold for the perception of pain leading to subjective perceptions of more severe disease (Gonlachanvit et al., 2005; Murray et al., 2004). In animal models of colitis, acute psychological stress can result in objectively measured initiation and reactivation of colitis (Collins et al., 1996; Gué et al., 1997). Thus, a vicious circle is created: the symptoms of IBD may cause psychosocial stress and stress, in turn, may worsen the symptoms of the disease. The brain-gut axis (Figure 2), which operates through hormones between the hypothalamus, pituitary gland, adrenal gland, and enteric nervous system (ENS), is hypothesised to form a linkage between psychological factors and the abdominal symptoms in IBD (Hisamatsu et al., 2007). Further introduction of this hypothetical physiological interaction between the functions of the bowel and the brain is unfortunately beyond the scope of this study.

**Figure 2.** Brain-gut axis. CRF, corticotrophin-releasing factor; ACTH, adrenocorticotropic hormone; ENS, enteric nervous system (adapted from Hisamatsu et al., 2007; Mawdsley and Rampton, 2005)
Evaluation of a child’s psychosocial and somatic symptoms generally relies on the information gathered from both the parents and the children/adolescents themselves through clinical interviews or questionnaire-based methods in addition to clinical observation performed by health care workers. Screening questionnaires are often used in clinical practice since they are time and cost-effective methods for receiving necessary information (Fombonne, 1991). Disagreement between the respondents is expected due to generational conflicts and different viewpoints, and does not necessarily imply that the information received from one or both respondents is incorrect. Disagreement exists even when the questionnaires are comparable and validated for parents and adolescents (Salbach-Andrae et al., 2009a; Sourander et al., 1999). A low correlation rate ($r=0.22$) on emotional and behavioural symptoms between child and parent informants has been shown in a meta-analysis (Achenbach et al., 1987), and has since been replicated in paediatric psychiatric patients and in the general population (Ferdinand et al., 2006; Kolko and Kazdin, 1993; Rothen et al., 2009; Salbach-Andrae et al., 2009a; Sourander et al., 1999). It is suggested that disagreement on psychosocial symptoms between adolescents and their parents predicts a risk of unwanted outcomes of the adolescents, such as drug and tobacco use, police contact, expulsion from school or being sacked from a job, unwanted pregnancy, intentional self-harm, need for professional help, referral to mental health services, and reports of suffering from behavioural and/or emotional difficulties (Ferdinand et al., 2004).

In clinical, mainly psychiatric, settings, the parents have a tendency to attribute more emotional and behavioural problems to adolescents than adolescents do to themselves (Kazdin et al., 1983; Phares and Danforth, 1994; Salbach-Andrae et al., 2009a; Thurber and Osborn, 1993). In non-psychiatric study populations the opposite occurs (Rothen et al., 2009; Seiffge-Krenke and Kollmar, 1998; Sourander et al., 1999; Stanger et al., 1993; Vassi et al., 2008; Verhulst and van der Ende, 1992; Waters et al., 2003). It is suggested that both in clinical and normal populations, a higher parent-adolescents agreement rate prevails with behavioural than emotional problems (Cantwell et al., 1997; Kolko and Kazdin, 1993; Salbach-Andrae et al., 2009a; Sourander et al., 1999) since the parents are more able to report such symptoms that are visible and can be “seen” (behavioural problems) compared to hidden emotions (Vassi et al., 2008). However, the opposite results also exist (Seiffge-Krenke and Kollmar, 1998; Verhulst and van der Ende, 1992). Mothers are
often more capable of sensing their child’s problems and, thus, according to the literature, greater agreement prevails between mother and child than father and child (Seiffge-Krenke and Kollmar, 1998; Vassi et al., 2008).

The degree of agreement can be considered to indirectly reflect the quality aspects of the parent-child relationship and mutual comprehension. Investigations have recognised several parent and child-associated factors that influence the degree of parent-adolescent agreement: child’s age (Berg-Nielsen et al., 2003; Verhulst and van der Ende, 1992) and gender (Sourander et al., 1999; Verhulst and van der Ende, 1992; Waters et al., 2003); parental psychological status and stress (Berg-Nielsen et al., 2003; Martin et al., 2004; Seiffge-Krenke and Kollmar, 1998; Treutler and Epkins, 2003); family connectedness (Duke et al., 2005); mother’s satisfaction with marriage (Seiffge-Krenke and Kollmar, 1998); child’s school performance (Waters et al., 2003); socio-economic status of the family (Treutler and Epkins, 2003); parents’ alcohol drinking (Duke et al., 2005), profession (Luoma et al., 2004; Treutler and Epkins, 2003), and education (Luoma et al., 2004). For example, parent-adolescent disagreement was more likely to occur if the adolescent had good academic performance, or was dissatisfied due to his/her self-image or life; if the parents had a low education level or were unaware of their child’s leisure activities; or if the mother was depressed (Vassi et al., 2008). The direction of influence of the above-mentioned factors may be conflicting. For instance, some studies suggest that the older age of the child associates with a higher degree of agreement between parent and child (Berg-Nielsen et al., 2003), while others suggest the opposite (Achenbach et al., 1987; Verhulst and van der Ende, 1992).

The existing studies used various statistical methods to measure degree of agreement, thus, the results are not necessarily comparable (e.g. Pearson’s correlation coefficient (Sourander et al., 1999), intra-class coefficient (Salbach-Andrae et al., 2009a), and kappa (Martin et al., 2004)). Earlier, this issue has been studied mainly in normal and psychiatric populations. Studies assessing agreement on psychosocial symptoms between adolescents with chronic somatic disease and their parents are so far greatly lacking.
4 SLEEP PROBLEMS AND DAYTIME TIREDNESS IN PAEDIATRIC IBD

Sleep problems are common and often chronic among adolescents (Roberts et al., 2008a). In the community, up to 25% of children and adolescents suffer from disturbed sleep (Liu et al., 2005; Owens, 2008) and approximately 10% have significant problems with daytime tiredness (Owens et al., 2000). Among patients with paediatric somatic disease or psychiatric disorder, sleep problems are even more common (Bandla and Splaingard, 2004; Ivanenko et al., 2004b; Ivanenko et al., 2006; Ivanenko and Gururaj, 2009; Owens, 2008). In the community, children tend to identify and report more sleep disturbances themselves than their parents do (Owens et al., 2000).

In children and adolescents, sleep problems can be broadly defined and may include both primarily medical and biologically-based problems (e.g. obstructive sleep apnoea and parasomnias) and more behaviour-based disorders such as bedtime resistance (Ivanenko and Gururaj, 2009; Owens, 2008). Sleep trouble can be present in various forms such as difficulty falling asleep, difficulty maintaining asleep, poor sleep quality, waking up too early, or increased daytime tiredness. Sleep disturbances can be measured either by objective (polysomnography, actigraphy) or subjective (questionnaire, interview) methods or, in paediatric patients they can be rated by parents.

Comprehensive studies on the frequency of sleep disturbances and associating psychosocial symptoms in young patients with IBD are so far lacking. Only one preliminary study concerning sleep disturbances among adolescents with IBD (n=41) in Israel, published as an abstract, exists (Nachmias et al., 2006). In that study, a Mini-Sleep Questionnaire was utilised to detect sleep disturbances and daytime tiredness among adolescents with IBD. Half of the patients (n=22, 54%) had disturbed sleep. Morning fatigue on waking (76%), sleep interruption (54%) and chronic unexplained fatigue (39%) were the most common types of sleep disturbances (Nachmias et al., 2006). Sleep disturbance did not correlate with disease characteristics of IBD (disease type, activity, medical treatment), or age and gender of the patients. No precise information was given about the method of collecting data on sleep or disease activity, and a control group was lacking. Presumably, the questionnaire was self-completed but actually the respondent is not clearly stated in the abstract text (Nachmias et al., 2006).

The following paragraphs review studies concerning sleep disturbances among adult patients with IBD, and introduce the relationship between sleep disturbances,
and somatic health problems and inflammation status. Studies concerning sleep in paediatric patients who suffer from another chronic inflammatory condition, juvenile idiopathic arthritis (JIA), are also reviewed here. At the end of this chapter, the researcher introduces psychosocial symptoms that associate with sleep disturbances in the paediatric population.

4.1. SLEEP PROBLEMS IN ADULT PATIENTS WITH IBD

Three studies have investigated quality of sleep and/or daytime tiredness in adult IBD patients (Keefer et al., 2006; Ranjbaran et al., 2007a; Zimmerman, 2003). The first of them focused on extraintestinal symptoms, including sleep disturbances, in adult IBD patients (n=55) compared to patients with irritable bowel syndrome (IBS) (n=53) and healthy controls (n=56) (Zimmerman, 2003). That study included only males. The extraintestinal symptoms were assessed using a validated, self-reported questionnaire grading the intensity of various somatic symptoms on a 5-point scale (the Multisystem Inventory). The results revealed that both IBD (p=0.004) and IBS patients (p=0.041) suffered from sleep disturbances significantly more often than the controls, and that diarrhoea predicted sleep disturbances in IBD patients (Zimmerman, 2003).

The first comprehensive study on sleep disturbances in IBD examined sleep problems in adult patients with inactive IBD (n=16) by several questionnaires and one-night polysomnography (PSG), and compared the results with those of IBS patients (n=9) and healthy controls (n=7) (Keefer et al., 2006). Patients with IBD did not significantly differ from patients with IBS with respect to subjectively and objectively measured sleep parameters. However, the perceived sleep quality of both patient groups was lower than in the control group. Furthermore, the three groups did not differ with respect to daytime dysfunction or daytime tiredness (Keefer et al., 2006). As many as 64% (n=9) of the IBD patients stated that poor sleep led to intestinal symptoms and, 43% (n=5) described GI symptoms leading to poor sleep (Keefer et al., 2006). That study assessed quality of life in addition to sleep variables, and found that the quality of life and sleep were impaired in IBD patients although their disease was in remission (Keefer et al., 2006). The study was limited by small sample size.

Another questionnaire-based study of sleep disturbances among adult patients with inactive IBD (n=80) as compared to patients with IBS (n=24) and controls (n=15) replicates the earlier findings (Ranjbaran et al., 2007a). The study showed that the IBD subjects suffer more frequently from prolonged sleep latency, fragmented sleep, decreased daytime energy, and increased tiredness, that they use sleeping pills at a higher rate, and that their overall sleep quality is impaired compared to
healthy controls (Ranjbaran et al., 2007a). The IBD and IBS groups were similar in respect of abnormal sleep patterns. Of the IBD patients, 71% complained of interrupted sleep and night-time awakenings more than once or twice per week, while the figure was only 40% in controls (p=0.02). Patients with IBD had many reasons for sleep interruption: abdominal pain, need to use the bathroom, breathing difficulty, snoring, feeling too cold or too hot, and nightmares (Ranjbaran et al., 2007a). In IBD, 23% reported waking up due to anxiety and concerns about their disease (Ranjbaran et al., 2007a).

4.2. SLEEP PROBLEMS IN RELATION TO SEVERITY OF INFLAMMATORY DISEASE AND SOMATIC HEALTH PROBLEMS

4.2.1 SLEEP, IMMUNE SYSTEM, AND SEVERITY OF INFLAMMATION

Several studies show bidirectional associations between sleep and the immune system (Palma et al., 2007; Rogers et al., 2001). Activation of the immune system modulates the sleep-wake cycle and changes the sleep architecture (Born et al., 1997; Dingess et al., 1994; Lange et al., 2010). It is suggested that immuno-endocrine factors, e.g. circulating inflammatory cytokines and hormones related to hypothalamic-pituitary-adrenal (HPA) axis, mediate these changes (Ranjbaran et al., 2007b). Conversely, sleep deprivation, which is considered a stressor, may affect the immune system function, altering and reinforcing the inflammation process (Ranjbaran et al., 2007b) (Figure 2). It is unclear whether sleep problems in various chronic inflammatory conditions such as asthma (Janson et al., 1996), systemic lupus erythematosus (Gudbjörnsson and Hetta, 2001), rheumatoid arthritis (Bourguignon et al., 2003), and in IBD (Keef er et al., 2006; Ranjbaran et al., 2007a) are primarily the results of the disease-associated symptoms (pain, stress, depression), medical treatment (corticosteroid), or disease-related immune changes (Ranjbaran et al., 2007b).

A poor night’s sleep may exacerbate disease symptoms of chronic inflammatory conditions, such as IBD, and this effect is presumably intermediated by the changes that sleep deprivation causes on immune functioning (Ranjbaran et al., 2007b). In adults with IBD, sleep quality is inversely correlated with IBD activity (Ranjbaran et al., 2007a). Before disease activation, IBD patients often experience a significant stress (Levenstein et al., 2000; Mawdsley and Rampton, 2006). Thus, it is hypothesised that sleep deprivation could serve as one form of physiological
stress that could cause disease flare-ups (Ranjbaran et al., 2007b; Tang et al., 2009) (Figure 2). This has been investigated in a study using animal models. In that study, sleep deprivation was unable to cause bowel inflammation per se but could, indeed, cause worsening in inflammation status in a previously inflamed bowel (Tang et al., 2009). Furthermore, sleep patterns have been noticed to relate with colonic movement patterns (Furukawa et al., 1994; Narducci et al., 1987; Roarty et al., 1998). During slow-wave sleep, the propagating activity of the colon is eliminated and the bowel rests. Arousals and awakenings cause immediate stimulation of the colon as the propagating activity of the colon increases. Thus, changes to sleep patterns due to activation of the immune system and frequent arousals during sleep may cause less slow-wave sleep, thus giving less time for the colon to recover. This may further increase IBD symptoms (Furukawa et al., 1994; Keefer et al., 2006; Narducci et al., 1987; Roarty et al., 1998).

A questionnaire-based study of adult patients with IBD (n=80) reports that sleep quality correlated with IBD disease severity (Ranjbaran et al., 2007a). In that study, 66% of IBD patients assessed their sleep as poor during disease flare-ups, 49% believed that their inflammatory disease and GI symptoms could be affected by disturbed sleep, and 27% of the IBD patients thought that chronic sleep deprivation could cause disease flare-ups (Ranjbaran et al., 2007a). Such studies in paediatric IBD are so far lacking. In juvenile idiopathic arthritis (JIA), which is another paediatric chronic inflammatory condition, sleep has been shown to be more frequently disrupted and disturbed in those with active disease compared to healthy controls (Bloom et al., 2002; Passarelli et al., 2006). However, surprisingly the self-reported and PSG measured sleep quality was similar in the groups of active and inactive JIA (Ward et al., 2008). Here, studies concerning sleep in paediatric JIA patients are reviewed more closely as an example of paediatric inflammatory condition, since studies on sleep in paediatric IBD are so far lacking.

4.2.1.1. Sleep in juvenile idiopathic arthritis (JIA)

JIA is an autoimmune inflammatory disease among children. Similar to IBD, the disease course in JIA is unpredictable, with fluctuating periods of active and inactive phases. Children with JIA experience joint inflammation and swelling, morning stiffness and limited mobility, pain and tenderness, and they fatigue easily. In JIA, sleep quality and/or daytime tiredness have been explored in four studies (Bloom et al., 2002; Passarelli et al., 2006; Ward et al., 2008; Zamir et al., 1998).

Zamir G et al (1998) was the first to assess sleep patterns in children with JIA (n=16; age 12 ± 4 years) in a study, which also included controls (n=9; age 11 ± 3 years) (Zamir et al., 1998). Subjects completed a questionnaire, which assessed subjective
perception about sleep hygiene and sleep quality, and also asked for personal details and disease history. Additionally, sleep was monitored by an objective method (PSG). The groups did not differ according to self-reported sleep quality but the patients reported more daytime tiredness (longer afternoon naps) than the controls. PSG revealed significant differences in objectively measured sleep in these two groups. Sleep in JIA patients was fragmented as they had 90% more arousals and awakenings than controls. Furthermore, the median length of uninterrupted deep sleep in stages 2 and 3 and rapid eye movement (REM) sleep was shorter, whilst state shifts from deep to lighter sleep stages were more frequent in patients with JIA than in controls. Group difference was non-significant for sleep latency, total sleep time, sleep efficiency, or time spent in any sleep stage (Zamir et al., 1998). Thus, the main findings here were that in JIA, children have increased daytime tiredness and their night’s sleep is more fragmented compared to controls (Zamir et al., 1998).

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 JIA to assess sleep and its relation to pain, dysfunction, and disease activity, and the results were compared to those of 45 healthy age and gender-matched subjects (Bloom et al., 2002). Parents of JIA patients reported significantly higher total scores on the CSHQ (p<0.001) and on the subscales assessing night-waking, parasomnias, sleep-related anxiety, sleep-disordered breathing, and morning waking/daytime tiredness than parents of healthy controls. The total CSHQ scores or CSHQ subscale scores did not correlate with any disease variables. However, the total SSR score correlated with the presence of pain but not with other arthritis-related variables. The authors did not provide any other data on SSR scores. A complete report on the total and subscale scores on SSR in patients compared to controls are lacking (Bloom et al., 2002).

Also, Passarelli CM et al. (2006) used subjective questionnaire-based methods and objective PSG to investigate sleep in 21 patients with active JIA and 20 healthy controls (Passarelli et al., 2006). This study reports that pain and daytime functional impairment of adolescents with active JIA (n=21) are related to sleep fragmentation (Passarelli et al., 2006). Patients had more frequent leg movements and arousals and higher alpha-activity in non-REM sleep in PSG recordings compared to controls. However, self-reported sleep complaints did not differ between the groups (Passarelli et al., 2006). In contrast to the earlier studies (Bloom et al., 2002; Zamir et al., 1998), this study failed to find significant group difference in daytime tiredness between JIA patients and controls (Passarelli et al., 2006).

Ward TM et al. (2008) compared objectively (PSG) and subjectively measured (self-reported questionnaires) sleep, JIA symptoms (pain, fatigue), and anxiety between children with active (n=35) and inactive JIA (n=35) (Ward et al., 2008). There was no difference in PSG sleep variables between these groups but patients
with active JIA reported more pain and fatigue (p<0.02 for both) compared to those with inactive JIA. Of the children with active JIA, 54% and with inactive JIA 28% reported trouble sleeping, and 41% and 22%, respectively, reported waking up at night. However, there was no group difference in how rested they felt themselves in the morning as only approximately 10% in both groups reported not feeling rested in the morning (Ward et al., 2008).

4.2.2. IMPAIRED SLEEP AMONG THOSE WITH SOMATIC HEALTH PROBLEMS

Stomach ache is a crucial symptom of active IBD. Pain in several forms (headache, abdominal pain, limb pain, back pain), have been reported to associate with sleep disturbances (Long et al., 2008; Roth-Isigkeit et al., 2005). Among school-aged patients with chronic pain frequency of parent-reported sleep troubles were above the clinical cut-off point in 53% of the cases (Long et al., 2008). Chronic pain associates with higher frequency of arousals at bedtime and lower sleep quality (Palermo et al., 2011). Irritating gastrointestinal (GI) symptoms can also disturb sleep (Lewin and Dahl, 1999). Children with IBS (in which symptoms are somewhat similar to IBD without GI inflammation) have been reported to have significantly more sleep disturbances, emotional problems and anxiety than healthy controls (Iovino et al., 2009). Furthermore, compared to healthy controls, children with functional abdominal pain report more symptoms of behavioural sleep disorders and increased nightmares and daytime tiredness (Huntley et al., 2007). Sleep of healthy adolescents (n=20) and those with chronic pain (n=20) was studied by self-reports and actigraphy (Palermo et al., 2007). In that study, adolescents with chronic pain demonstrated similar total sleep time than their healthy peers, but they reported significantly poorer sleep quality and increased insomnia. In actigraphy recordings, lower sleep efficiency and more arousals were present among those with chronic pain than in the control group. Pain, depressive symptoms, and worry at bedtime predicted subjectively reported impaired sleep quality (Palermo et al., 2007). In children with JIA, pain but no other JIA-related symptoms positively correlated with self-reports of sleep disturbances (Bloom et al., 2002).

4.2.3. SOMATIC SYMPTOMS IN SLEEP-TRoubLED INDIVIDUALS

Sleep-troubled individuals suffer from several somatic complaints and diseases more often than those whose sleep is not disturbed (Taylor et al., 2007). Long-term sleep disturbances increased the risk of somatic health problems in a large study assessing health and function of adolescents (n=3134) suffering from chronic
insomnia (Roberts et al., 2008b). Sleep trouble associates with somatic symptoms like fatigue, less energy, symptoms of headache, stomach ache, backache, and worse perceived health (Gau, 2000; Liu et al., 2007; Tynjälä et al., 1993; Vignau et al., 1997). Somatic complaints and pain often coexist with sleep trouble (Lewin and Dahl, 1999; Stein et al., 2001). For example, in a large study of school-aged children (n=472), all five sleep factors (parasomnia, enuresis, tiredness, noisy sleep and insomnia) were significantly associated with emotional and behavioural problems but also with somatic complaints and attention problems according to parents’ reporting (CBCL) (Stein et al., 2001). In a Finnish study, significant correlations were found between sleep time measured by actigraph and teacher-reported somatic symptoms among healthy 7 to 12-year-old children (n=49) (Aronen et al., 2000). Insufficient quantity and quality of sleep may lower the threshold for pain by causing psychosocial changes, which weaken coping skills necessary for effective pain management (Lewin and Dahl, 1999).

4.2.4. CONCLUSION

Association between disturbed sleep and somatic symptoms (e.g. in various inflammatory conditions) may be reciprocal. For example, pain may cause sleep disturbances, and disturbed sleep can either cause an increase in somatic symptoms through stress and changes in immune functions, or by lowering threshold for pain and thus resulting in more severe subjective experience of pain (Figure 3).

Figure 3. Association between sleep trouble, disease symptoms, and inflammation process.
4.3. SLEEP PROBLEMS AND ASSOCIATING PSYCHOSOCIAL SYMPTOMS IN PAEDIATRIC POPULATION

Adequate sleep in adolescence is important for healthy development and proper daytime functioning. Evidently, associations exist between disturbances in the quantity and quality of sleep and various psychosocial symptoms in children and adolescents from normal and clinical, mainly psychiatric, populations. So far, these associations have not been investigated in adolescents with paediatric IBD.

In children and adolescents, poor quality and an inadequate amount of sleep have a negative impact on cognitive functioning and development, mood regulation, academic and social performance, behaviour, and overall quality of life (Dahl, 1996; Fallone et al., 2002; Lavigne et al., 1999; Owens et al., 2005; Sadeh et al., 2002; Smaldone et al., 2007). The association between subjective or parent-reported sleep trouble and emotional problems (e.g. anxiety, depressive symptoms, and depression) is unarguable and seems to become stronger as children mature into adolescence and adulthood (Alfano et al., 2009; Gregory and O’Connor, 2002; Johnson et al., 2000; Roberts et al., 2002). Half of the adolescents with lifetime diagnosis of insomnia report one or more comorbid psychiatric disorders (mood, anxiety, behavioural, and/or substance use disorders) (Johnson et al., 2000), and half of children with persistent sleep disturbances referred to a paediatric sleep medicine centre (n=46) had another psychiatric diagnosis (most commonly attention-deficit hyperactivity disorder (ADHD), anxiety, or mood disorder) (Ivanenko et al., 2004a). In depressed children and adolescents, sleep trouble associates with severe depression (Liu et al., 2007).

Sleep disturbances and insufficient sleep in healthy children are typically associated with behavioural problems such as irritability, decreased attention, distractibility, impulsivity, hyperactivity, excessive daytime tiredness, chronic fatigue, decrements in daytime alertness and performance, school absence and increased risk of injury (Aronen et al., 2000; Ferber, 1996; Owens et al., 2005). Objectively measured quantity of sleep (actigraphy) associates with behavioural problems at school in a non-clinical sample of school-aged children (Aronen et al., 2000). Furthermore, primary sleep problems can even be misdiagnosed as ADHD in children (Dahl, 1996). Recently, insomnia was correlated with tobacco and alcohol use, perceived economic status and school performance in a non-clinical sample of Greek adolescent high-school students (n=2195) (Siomos et al., 2010).

Existing longitudinal studies reveal that sleep problems in adolescence predict emotional and behavioural problems (e.g. substance use disorder) in adulthood in population-based surveys (Fichter et al., 2009). On the other hand, those adults who have a history of poor sleep and insomnia are more likely to develop depression than those without such history (Breslau et al., 1996; Ford and Kamerow, 1989).
Prospective studies on sleep difficulties among the general paediatric population suggest that sleep problems early in life predict development of depression and anxiety in later years (Gregory and O’Connor, 2002). Inadequate sleep in adolescents also predicted lower self-esteem in addition to emotional problems (Fredriksen et al., 2004) and, according to another study, somatic health problems, interpersonal problems, psychological problems and problems with daily activities (Roberts et al., 2008b). Association between sleep trouble and emotional symptoms seems to be bidirectional (Dahl and Lewin, 2002). Depressive symptoms also seem to predict sleep disturbances (Patten et al., 2000).
AIMS OF THE STUDY

The aim of this study was to determine the psychosocial burden experienced by Finnish adolescents with paediatric inflammatory bowel disease (IBD), and among them to evaluate the frequency of sleep problems and daytime tiredness in comparison with population-based matched controls. In this study, the information was gathered from both the parents and the adolescents, and, thus, the degree of parent-adolescent agreement regarding psychosocial symptoms and somatic complaints was also evaluated.

The main objectives of this thesis were:
1) To evaluate parent and self-reported emotional and behavioural symptoms and competence in adolescents with IBD in relation to their population-based controls, and to evaluate these symptoms in the patient group according to disease symptom severity (Study I).
2) To investigate the degree of parent-adolescent agreement regarding emotional, behavioural, and somatic symptoms in adolescents with IBD (Study II).
3) To assess parent and self-reported sleep problems and daytime tiredness in adolescents with IBD in relation to their population-based controls, and in patients, to assess these problems according to the severity of IBD symptoms (Study III).
4) To evaluate how sleep trouble associates with psychosocial symptoms and somatic complaints among adolescents with IBD according to parent and self-reports (Study IV).
STUDY DESIGN, SUBJECTS AND METHODOLOGY

1. STUDY DESIGN

This study applies cross-sectional study design and includes adolescents with IBD and their population-based controls. All the studies of this thesis (I, II, III and IV) are based on the data, which was collected as a postal questionnaire-based survey in spring 2007. Reports were obtained from both parent and adolescent informants. Geographically this study covered the whole Finland (Figure 4). Three separate questionnaires were used to assess psychosocial symptoms and sleep in study subjects: CBCL to be completed by a parent, and YSR and SSR to be completed by an adolescent. Additionally, a background enquiry of the disease was sent to the adolescents with IBD. Both parental and adolescent questionnaires were posted to adolescent’s address. Parents and adolescents returned the completed questionnaires separately in envelopes provided. The cost of postage was prepaid.

2. STUDY SUBJECTS

2.1. PATIENTS WITH IBD

Contact information of 300 patients aged 10 to 18, who were diagnosed during 1994-2006 with paediatric IBD according to the files of the Social Insurance Institution, was accessed from the database of the Population Register Centre. Postal addresses were available for 287 such patients. The questionnaires were sent to these 287 patients and their parents in spring 2007. One reminder was sent to 175 patients who had not replied within two months. Two patients with recent diagnosis (less than 1 year) were excluded. The final study group includes 160 patients (56%) and their parents. Parental CBCL questionnaires were mainly completed by mothers.
Study design, subjects and methodology

(91%), fathers completed the remainder (9%). The mean age of the patients at onset of the disease was 10 years (SD= 3.3, range 1–15 years) (see patients’ disease characteristics in Table 4). Only the parent-adolescent dyads, who returned both the parental and self-reports, were included in the agreement analyses (n=156) (II). Study IV includes only the patients who answered in the YSR item assessing sleep trouble (n=157).

Table 4. Disease characteristics of the adolescents (n=160) in the patient group.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Number of adolescents with diagnosis of IBD, UC, CD, and IC, and gender distribution</th>
<th>Duration of IBD in years</th>
<th>Self-reported severity of IBD symptoms on a scale from 1 (asymptomatic) to 7 (extremely severe)</th>
</tr>
</thead>
<tbody>
<tr>
<td>IBD</td>
<td>n=160</td>
<td>mean (SD)</td>
<td>mean (SD)</td>
</tr>
<tr>
<td>UC</td>
<td>83 (52%) - Boys 33 (40%)</td>
<td>5.1 (3.5)</td>
<td>2.1 (1.4)</td>
</tr>
<tr>
<td>CD</td>
<td>53 (33%) - Boys 36 (68%)</td>
<td>5.4 (3.2)</td>
<td>2.5 (1.5)</td>
</tr>
<tr>
<td>IC</td>
<td>19 (12%) - Boys 11 (58%)</td>
<td>4.7 (3.4)</td>
<td>2.7 (1.9)</td>
</tr>
</tbody>
</table>

Inflammatory bowel disease (IBD); ulcerative colitis (UC); Crohn’s disease (CD); intermediate colitis (IC)

2.2. POPULATION-BASED CONTROLS

The postal address for three controls matched for age, gender, and place of residence per each adolescent with IBD were randomly selected from the database of the Population Register Centre (n=861) (Figure 4, Table 5). Controls are included in studies I and III.

Study questionnaires were sent to these 861 controls and their parents. One reminder was sent to the control adolescents and their parents if none of the three matched controls of a patient returned questionnaires. The final control group includes 236 (27%) adolescents and their parents. Biological mothers completed the vast majority (90%) of the CBCL questionnaires.

As analysed by demographic and descriptive characteristics (age, gender, place of residence and socio-economic status) the groups of patients and controls did not differ significantly and represented the whole country well (Figure 4, Table 5). The non-respondents in the patient and control groups did not differ from respondents according to age, gender, or place of residence (SES data not available).
**Socio-economic status (SES)**

SES was based on parent and adolescent reports on the level of education of both parents’. The higher socio-economic class of the parents was considered as the socio-economic class of the family. SES was classified according to Helsinki City socio-economic statistics (Bruun, 1954; Järvenpää, 1964).

Table 5. Demographic data on patients (n=160) with inflammatory bowel disease and controls (n=236).

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Controls</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age Mean (SD)</strong></td>
<td>15.4 (2.2)</td>
<td>15.2 (2.2)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Boys</td>
<td>85 (53%)</td>
<td>115 (49%)</td>
</tr>
<tr>
<td><strong>Social-economic status (SES)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Class I</td>
<td>35 (22%)</td>
<td>72 (30%)</td>
</tr>
<tr>
<td>- Class II</td>
<td>66 (41%)</td>
<td>85 (36%)</td>
</tr>
<tr>
<td>- Class III</td>
<td>52 (33%)</td>
<td>70 (29%)</td>
</tr>
<tr>
<td>- Class IV</td>
<td>7 (4%)</td>
<td>11 (5%)</td>
</tr>
</tbody>
</table>
Study design, subjects and methodology

Figure 4 illustrates the reference hospitals for the adolescents with inflammatory bowel disease (n=160) and their population-based controls (n=236) (adapted from Väistö et al., 2010).
3. METHODOLOGY

3.1. BACKGROUND DATA AND DISEASE SEVERITY

The participating patients received a background enquiry, in which they were asked to report the severity of IBD symptoms during the preceding week, age at onset of the disease, and the sub-diagnosis of the disease (UC, CD, IC to double-check that the responder had IBD). The severity of IBD symptoms was reported in a numerical visual analogy scale (VAS) shown visually as a line from 1 (asymptomatic) to 7 (extremely severe). In studies I and III, IBD patients were divided into two groups according to the self-reported severity of IBD symptoms: patients with mild IBD symptoms (VAS scores 1-3; n=121) and patients with severe IBD symptoms (VAS scores 4-7; n=35). Comparable numerical VAS scoring from 1 to 7 has been used in earlier studies about quality of life in Finnish IBD patients (Pakarinen et al., 2009; Turunen et al., 2009).

3.2. QUESTIONNAIRES ASSESSING PSYCHOSOCIAL SYMPTOMS AND COMPETENCE

3.2.1. CHILD BEHAVIOR CHECKLIST (CBCL)

Parent-rated psychosocial symptoms and competence of the adolescents were assessed using the standardised CBCL questionnaire for which comprehensive reliability and validity evidence is available (Achenbach and Rescorla, 2001). The questionnaire is designated for parents of 6-18-years old children. The questionnaire was translated into Finnish by the Child Psychiatric Clinic of Helsinki University Hospital in 2002. The questionnaire consists of 113 problem items rated according to three response alternatives (0 = not true; 1 = somewhat or sometimes true; 2 = very true or often true). These problem items generate eight narrow-band syndrome scales of the CBCL, which in turn comprise broad-band scales of Emotional (Internalising) and Behavioural (Externalising) Symptoms. These two broad-band scales, together with narrow-band syndrome scales of Social Problems, Thought Problems, and Attention Problems comprise the Total Symptoms scale (Table 6).
The competence section of the CBCL includes seven items assessing adaptive behaviour and competence. These competence items inquire about specific activities and hobbies, amount of involvement in activities and relationships, and academic performance (Achenbach and Rescorla, 2001). The competence section includes three subscales called Activities, Social and School, which together comprise the scale of Total Competence (Table 6).

Single problem items that are included in the narrow-band syndrome scale of Somatic Complaints (nightmares, dizziness, tiredness, aches, headaches, nausea, eye problems, skin problems, stomach aches, vomiting, and in the CBCL constipation) were utilised in studies I and IV.

3.2.2. YOUTH SELF-REPORT (YSR)

The adolescents completed the standardised YSR questionnaire, which evaluates self-reported psychosocial symptoms and competence of 11 to 18-year-old children and adolescents (Achenbach and Rescorla, 2001). Items and scales in this questionnaire are similar and comparable to those in the CBCL (Table 6). However, there are a few exceptions: items about educational services and school grade repetition are not included in the YSR. Thus, School Competence is not scored for YSR but raw data for academic performance is included (Achenbach and Rescorla, 2001). To define somatic symptoms, there is a question about constipation in the CBCL but not in the YSR. Like CBCL, YSR is a reliable and valid questionnaire (Achenbach and Rescorla, 2001). Here, the Finnish translation of the questionnaire was applied. A few patients were Swedish-speaking, and thus received a Swedish version of the questionnaire.

3.2.3. CLINICAL AND SUBCLINICAL CUT-OFF POINTS IN THE CBCL AND YSR

The Achenbach system generates T-scores to all broad-band scales, narrow-band syndrome scales, and competence scales. T-scores are reported to make the evaluation of clinical significance of psychiatric symptoms and competence easier and to enable comparison with other parallel studies (Achenbach and Rescorla, 2001). Table 7 introduces the subclinical and clinical cut-off points for the different scales.
Table 6. Hierarchy of the psychosocial symptoms in the questionnaires of Child Behavior Checklist (CBCL) and Youth Self-Report (YSR), and items included in the CBCL narrow-band scales. A lighter grey background indicates broad-band scales and darker grey narrow-band scales.

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<td>Anxious/Depressed</td>
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<td>Social Behaviour</td>
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<td>35. Worthless</td>
<td>60. SexPartsM</td>
<td>41. Impulsive</td>
<td>67. RunAway</td>
<td>23. DishSchool</td>
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<td>50. Fearful</td>
<td>70. SeesThings</td>
<td>78. Stares</td>
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<tr>
<td>91. TalkSuicide</td>
<td>84. StrangeBehv</td>
<td>82. StealsOut</td>
<td>90. Swears</td>
<td>72. Fights</td>
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<td>112. Worries</td>
<td>85. StrangeIdeas</td>
<td>90. Swears</td>
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<td>92. SleepWalk</td>
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<td>99. Tobacco</td>
<td>68. Screams</td>
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<td>Total Symptoms</td>
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</tbody>
</table>
Study design, subjects and methodology

Table 7. Subclinical and clinical cut-off points for the Child Behavior Checklist (CBCL) and Youth Self-Report (YSR) scale scores.

<table>
<thead>
<tr>
<th>Psychosocial Problems</th>
<th>Subclinical</th>
<th>Clinical</th>
</tr>
</thead>
<tbody>
<tr>
<td>Broad-band scales of Total, Internalising, and Externalising Symptoms</td>
<td>$60 \leq T\text{-score} \leq 63$</td>
<td>$T\text{-score} &gt; 63$</td>
</tr>
<tr>
<td>Narrow-band syndrome scales</td>
<td>$65 \leq T\text{-score} \leq 70$</td>
<td>$T\text{-score} &gt; 70$</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Competence</th>
<th>Subclinical</th>
<th>Clinical</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Competence</td>
<td>$37 \leq T\text{-score} \leq 40$</td>
<td>$T\text{-score} &lt; 37$</td>
</tr>
<tr>
<td>Subscales of Activities, Social Competence, and School</td>
<td>$30 \leq T\text{-score} \leq 35$</td>
<td>$T\text{-score} &lt; 30$</td>
</tr>
</tbody>
</table>

3.3. QUESTIONNAIRES ASSESSING SLEEP TROUBLE AND DAYTIME TIREDNESS

3.3.1. SLEEP SELF-REPORT (SSR)

Besides YSR, adolescents were asked to complete a structured SSR questionnaire for a more detailed report of their sleep habits (Owens et al., 2000). The SSR questionnaire is a standardised subjective retrospective measure of sleep habits for school-aged children (Owens et al., 2000), and it was translated into Finnish in 2004. The questionnaire is divided into two sections. The first section includes three 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 three subscales to describe Bedtime (12 items), Sleep Behaviour (seven items), and Daytime Tiredness (four items) (Table 8). Response options for these items 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 three-point scale, and for each subscale sum-scores are formulated. Six items are scored inversely due to inverse question design. The minimum and maximum sum-scores consequently are from 12 to 36 for Bedtime, from 7 to 21 for Sleep Behaviour, and from 4 to 12 for Daytime Tiredness. A higher score indicates more sleep problems.
In addition, we included two extra sleep-related questions for adolescents with IBD: “Do IBD symptoms affect the quality of your sleep?” and an open question: “If yes, how?” Adolescents were advised to answer these questions according to their sleep habits over the preceding six-month period.

Of the SSR, 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 significantly differ between the groups of patients and controls (p=0.332).

In study IV, sleep quality scales of the SSR (Bedtime, Sleep Behaviour) were utilised to analyse correlations between sleep quality and psychosocial issues.

**Table 8.** Items included in the subscales of Bedtime, Sleep Behaviour, and Daytime Sleepiness in the questionnaire of Sleep Self-Report (SSR).

<table>
<thead>
<tr>
<th>Sleep Self-Report (SSR)</th>
<th>Sleep Behaviour</th>
<th>Daytime Sleepiness</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bedtime</strong></td>
<td></td>
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</tr>
<tr>
<td>- Do you go to bed at the same time every night on school nights?</td>
<td>- Do you think you sleep too little?</td>
<td>- Do you have trouble waking up in the morning?</td>
</tr>
<tr>
<td>- Do you fall asleep in the same bed every night?</td>
<td>- Do you think you sleep too much?</td>
<td>- Do you feel sleepy during the day?</td>
</tr>
<tr>
<td>- Do you fall asleep alone?</td>
<td>- Do you wake up at night when your parents think you are asleep?</td>
<td>- Do you take naps during the day?</td>
</tr>
<tr>
<td>- Do you fall asleep in your parents’, brother’s or sister’s bed?</td>
<td>- Do you have trouble falling back to sleep if you wake up during the night?</td>
<td>- Do you feel rested after a night’s sleep?</td>
</tr>
<tr>
<td>- Do you fall asleep in about 20 minutes?</td>
<td>- Do you have nightmares?</td>
<td></td>
</tr>
<tr>
<td>- Do you fight with your parents about going to bed?</td>
<td>- Does pain wake you up at night?</td>
<td></td>
</tr>
<tr>
<td>- Is it hard for you to go to bed?</td>
<td>- Do you sometimes go to someone’s bed during the night?</td>
<td></td>
</tr>
<tr>
<td>- Are you ready for bed at your usual bedtime?</td>
<td>- Do you feel sleepy during the day?</td>
<td></td>
</tr>
<tr>
<td>- Do you have a special item (doll, blanket, etc.) that you take to bed?</td>
<td>- Do you take naps during the day?</td>
<td></td>
</tr>
<tr>
<td>- Are you afraid of the dark?</td>
<td>- Do you feel rested after a night’s sleep?</td>
<td></td>
</tr>
<tr>
<td>- Are you afraid of sleeping alone?</td>
<td>- Do you sometimes go to someone’s bed during the night?</td>
<td></td>
</tr>
<tr>
<td>- Do you stay up late when your parents think you are asleep?</td>
<td>- Do you feel sleepy during the day?</td>
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</tbody>
</table>
3.3.2. SLEEP ITEMS IN THE CBCL

The five problem items dealing with sleep and tiredness in the CBCL questionnaire were utilised in the current study in order to measure parent-rated sleep and daytime tiredness in adolescent patients and controls (III) (Table 9).

3.3.3. SLEEP ITEMS IN THE YSR

In addition to the SSR, five problem items dealing with sleep and tiredness in the YSR were used to measure adolescent self-rated sleep and tiredness in the study III (Table 9). For the fourth study (IV), the patient group was subdivided into the groups of sleep-troubled (20%, n=32) and non-sleep-troubled (80%, n=125) according to their own reports on the sleep trouble item of the YSR (“I have trouble sleeping”) in order to evaluate psychosocial and somatic symptoms that associate with sleeping difficulties.

Table 9. List of sleep-related items in the Child Behavior Checklist (CBCL), and comparable items in the Youth Self-Report (YSR).

<table>
<thead>
<tr>
<th>CBCL</th>
<th>YSR</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Nightmares (Item 47)</td>
<td>- I have nightmares (Item 47)</td>
</tr>
<tr>
<td>- Overtired without good reason (Item 54)</td>
<td>- I feel overtired without good reason (Item 54)</td>
</tr>
<tr>
<td>- Sleeps less than most kids (Item 76)</td>
<td>- I sleep less than most kids (Item 76)</td>
</tr>
<tr>
<td>- Sleeps more than most kids during day and/or night (Item 77)</td>
<td>- I sleep more than most kids during day and/or night (Item 77)</td>
</tr>
<tr>
<td>- Trouble sleeping (Item 100)</td>
<td>- I have trouble sleeping (Item 100)</td>
</tr>
</tbody>
</table>

3.4. STATISTICAL ANALYSIS

Statistical analyses were performed using SPSS 15.0-17.0 software for Windows. CBCL and YSR items were scored using ADM (version 6.5) scoring software (Achenbach 1999-2006).

Mean group differences for broad-band scale scores of the CBCL/YSR were statistically tested with t-test for independent samples. For narrow-band scale scores of the CBCL/YSR and sum-scores of the SSR subscales, mean group differences were tested with the non-parametric Mann-Whitney U-test. Cross-tabulation and non-parametric Chi-Square tests were used to analyse and statistically test the parent and self-reported frequencies with which the IBD and control adolescents scored over the subclinical/clinical cut-off points on the broad-band and narrow-band scales of the CBCL/YSR. Additionally, the Linear-by-Linear test (a Chi-Square variation) was used for trend-analyses of single somatic and sleep-related items in the CBCL/
YSR, and ANOVA-test for variance was used to analyse mean group differences for broad-band scales of CBCL/YSR scores among IBD adolescents with various types of IBD (UC, CD and IC) and for various locations of residence (Helsinki, Kuopio, Tampere, Turku and Oulu). For correlation analyses we used the two-tailed Pearson correlation. In agreement analyses, Cohen’s kappa (κ) served to measure agreement between parent and adolescent reports on dichotomised variables (e.g. broad-band and narrow-band T-scores of CBCL/YSR in the normal range versus those in the subclinical/clinical range). Kappa-values were categorised as poor (≤ 0.20), low (0.20 – 0.40), moderate (0.40 – 0.60), and nearly perfect (> 0.80) (Landis and Koch, 1977). Statistical significance was set at p ≤ 0.05.

3.5. ETHICS

The Ethics Committee for Gynaecology and Obstetrics, Paediatrics and Psychiatry of the Hospital District of Helsinki and Uusimaa approved the study protocol. Answering the questionnaires was optional and did not have any influence on clinical examinations and treatment of the patients.
RESULTS

1. PSYCHOSOCIAL SYMPTOMS AND COMPETENCE AMONG ADOLESCENTS WITH IBD (I)

1.1. COMPARED TO POPULATION-BASED CONTROLS

Parents in the patient group reported in their children significantly higher mean T-scores in the CBCL scales of Total Symptoms, Emotional Symptoms, Social Problems, Thought Problems, and nearly significantly higher mean T-scores for Attention Problems (p=0.059) than the parents of population-based controls (Table 10). Furthermore, adolescents with IBD scored significantly higher mean T-scores for all narrow-band syndrome scales included in the broad-band scale of Emotional Symptoms than the controls according to the parents (Table 10). Group difference in the scale of Behavioural Symptoms was non-significant. Total Competence was significantly lower among the adolescents with IBD than the controls. However, the group differences in the subscales of Activities, Social, and School Competence were non-significant according to parent-reports (Table 10). The number of adolescents scoring over the clinical cut-off point for Emotional Symptoms was significantly higher in the group of patients (n=35, 22%) than controls (n=16, 7%; p<0.001) according to the parents’ reports.

There was no significant group difference in the YSR scales indicating self-reported psychosocial symptoms and competence between adolescents with IBD and their population-based controls. In both groups, all mean T-scores were below the subclinical cut-off points. Adolescents with IBD also reported a similar amount of single somatic symptoms than the controls.
Table 10. Mean T-scores for the Child Behavior Checklist scales as reported by the parents in the patient and control groups (adapted from Väistö et al., 2010).

<table>
<thead>
<tr>
<th>Table 10.</th>
<th>IBD Patients</th>
<th>Controls</th>
<th>p</th>
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<tbody>
<tr>
<td></td>
<td>Mean T-Score (SD)</td>
<td>Mean T-Score (SD)</td>
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<tr>
<td>Total Symptoms</td>
<td>50 (15)</td>
<td>46 (12)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Emotional Symptoms</td>
<td>56 (6.4)</td>
<td>49 (4.9)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>- Anxious/Depressed</td>
<td>53 (2.6)</td>
<td>52 (2.1)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>- Withdrawn/Depressed</td>
<td>57 (2.8)</td>
<td>54 (2.1)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>- Somatic Complaints</td>
<td>63 (3.2)</td>
<td>57 (1.9)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Behavioural Symptoms</td>
<td>48 (5.1)</td>
<td>47 (4.4)</td>
<td>ns</td>
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<tr>
<td>- Rule-breaking behaviour</td>
<td>53 (2.1)</td>
<td>53 (2.3)</td>
<td>ns</td>
</tr>
<tr>
<td>- Aggressive behaviour</td>
<td>53 (3.7)</td>
<td>52 (3.0)</td>
<td>ns</td>
</tr>
<tr>
<td>Other Syndrome Scales</td>
<td>52 (1.6)</td>
<td>52 (1.4)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>- Social Problems</td>
<td>54 (1.5)</td>
<td>53 (1.6)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>- Thought Problems</td>
<td>53 (2.8)</td>
<td>53 (2.5)</td>
<td>ns</td>
</tr>
<tr>
<td>Total Competence</td>
<td>46 (4.6)</td>
<td>48 (4.0)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>- Activities</td>
<td>45 (2.6)</td>
<td>47 (2.5)</td>
<td>ns</td>
</tr>
<tr>
<td>- Social</td>
<td>47 (2.4)</td>
<td>49 (2.2)</td>
<td>ns</td>
</tr>
<tr>
<td>- School</td>
<td>49 (0.9)</td>
<td>50 (0.8)</td>
<td>ns</td>
</tr>
</tbody>
</table>

ns= non-significant; IBD= Inflammatory Bowel Disease

1.2. ACCORDING TO SEVERITY OF IBD SYMPTOMS

The patients were divided into two subgroups according to the self-reported severity of IBD symptoms (see the background enquiry). Most of the patients (n=121) reported having mild IBD symptoms (IBD symptom severity ranging from 1 to 3). Thirty-five patients suffered from severe IBD symptoms (IBD symptom severity ranging from 4 to 7). Table 11 illustrates in bold those CBCL and YSR broad-band and narrow-band scales for which the parents and the adolescents themselves reported significantly higher (p<0.05) mean T-scores among those with severe IBD symptoms compared to those with mild IBD symptoms.
Results

Table 11. The patients with severe IBD symptoms scored significantly (p<0.05) higher mean T-scores compared to those with mild IBD symptoms in those scales which are illustrated in bold here according to the parents (CBCL, Child Behavior Checklist) and the adolescents themselves (YSR, Youth Self-Report).

<table>
<thead>
<tr>
<th>CBCL</th>
<th>YSR</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Symptoms</strong></td>
<td><strong>Total Symptoms</strong></td>
</tr>
<tr>
<td>Emotional Symptoms</td>
<td>Emotional Symptoms</td>
</tr>
<tr>
<td>- Anxious/Depressed mood</td>
<td>- Anxious/Depressed mood</td>
</tr>
<tr>
<td>- Withdrawn/Depressed mood</td>
<td>- Withdrawn/Depressed mood</td>
</tr>
<tr>
<td>- Somatic Complaints</td>
<td>- Somatic Complaints</td>
</tr>
<tr>
<td>Behavioural Symptoms</td>
<td>Behavioural Symptoms</td>
</tr>
<tr>
<td>- Rule-breaking behaviour</td>
<td>- Rule-breaking behaviour</td>
</tr>
<tr>
<td>- Aggressive behaviour</td>
<td>- Aggressive behaviour</td>
</tr>
</tbody>
</table>

According to self-reports, gender associated significantly with emotional symptoms so that girls reported more emotional symptoms (p<0.05), anxious/depression (p<0.01), and somatic complaints (p<0.01) than boys. Boys in turn reported lower total competence compared to girls (p<0.05). Furthermore, academic performance was significantly better in girls than in boys (p=0.001). Gender difference in total symptoms and behavioural symptoms was non-significant.

Subtypes of IBD (UC, CD, and IC), duration of the disease, SES, or place of residence did not significantly associate with the psychosocial symptoms reported by either parents or adolescents themselves.
2. PARENT-ADOLESCENT AGREEMENT ON PSYCHOSOCIAL SYMPTOMS AND SOMATIC COMPLAINTS IN PAEDIATRIC IBD (II)

4.1. DEGREE OF AGREEMENT

In paediatric IBD, agreement on psychosocial symptoms between parents and adolescents was altogether poor to low (κ-values ranged from 0.00 to 0.38), and it was closer regarding emotional (κ = 0.34) than behavioural symptoms (κ = 0.15). The agreement rate was very poor on the syndrome scales of Anxious/Depressed mood (κ = 0.02) and Aggressive Behaviour (κ = 0.12); whilst it was poorest in the syndrome scale of Thought Problems (κ = 0.00). On the syndrome scales of Somatic Complaints and Attention Problems the degree of agreement was low (κ = 0.22, κ = 0.28, respectively) and on Social Problems it was close to moderate (κ = 0.38).

4.2. FREQUENCY WITH WHICH THE PATIENTS SCORED IN THE SUBCLINICAL/CLINICAL RANGE ACCORDING TO PARENT AND SELF-REPORTS

Parent and adolescent-reported frequencies with which adolescents scored over the subclinical limit were mostly similar in all CBCL/YSR broad-band and syndrome scales. Only in the scale of Somatic Complaints, the parents reported significantly higher frequency with which the adolescents scored over the subclinical cut-off point than the adolescents themselves did (CBCL 44%, n = 68; YSR 14%, n = 21; p < 0.001). In the broad-band scale of Behavioural Symptoms (p = 0.069) and in the syndrome scale of Social Problems (p = 0.064) the difference was nearly significant. In both of these scales, adolescents reported scores over the subclinical limit more often than their parents did.

Figure 5 illustrates the frequencies with which patients scored over the subclinical cut-off point (T-score ≥ 60) in the broad-band scales of the CBCL and YSR questionnaires according to parental and adolescent reports (“Both”), parental or adolescent reports (“Parent alone”; “Adolescent alone”), and neither parental nor adolescent reports (“Neither”) (Figure 5). In 5% of the cases, parents and adolescents agreed that the adolescent had significant psychosocial problems and in 74% of the cases they agreed that the problems were lacking. Disagreement existed in 21% of the cases (Figure 5a).
Results

Figure 5. Frequency with which the adolescent patients with inflammatory bowel disease score over the subclinical limit (T-score ≥ 60) in the Emotional, Behavioural, and Total Symptom scales of the Child Behavior Checklist and Youth Self-Report according to parent and/or adolescent reports (“Both”, “Parent only”, “adolescent only”) and neither parent nor adolescent reports (“Neither”) (adapted from Pirinen et al., 2012).
3. SLEEP PROBLEMS AND DAYTIME TIREDNESS AMONG ADOLESCENTS WITH IBD (III)

3.1. COMPARED TO POPULATION-BASED CONTROLS

According to the CBCL items, significantly more adolescents with IBD (25%, n=40) than controls (13%, n=29, p<0.01) had trouble sleeping sometimes or often. Furthermore, parents of IBD patients reported overtiredness (p<0.001), nightmares (p<0.01), and more sleeping during the day and/or night (p<0.001) in their child significantly more often than the parents of controls did.

According to the sleep-related items in the YSR, no significant difference was evident in frequency of trouble sleeping or overtiredness between adolescents with IBD and controls. In the patient group, 32 (20%) reported having trouble sleeping sometimes or often and respective figures for controls were 54 (23%, p=0.366).

In the SSR questionnaire item “Do you think you have trouble sleeping?” 11% of patients (n=16) and 13% of controls (n=31) reported having sleep trouble (p=0.429). No difference emerged between the patients and controls in the SSR subscale scores (Bedtime, Sleep Behaviour, Daytime Sleepiness) or the total sum-scale scores of the SSR (all p’s>0.27).

3.2. ACCORDING TO SEVERITY OF IBD SYMPTOMS

Parents reported that significantly more patients with severe IBD symptoms (41%, n=14) had trouble sleeping sometimes or often than patients with mild IBD symptoms (22%, n=25; p<0.01). In addition, significantly more adolescents with severe IBD symptoms (80%, n=28) were sometimes or often overtired than their counterparts with mild IBD symptoms (44%, n=53; p<0.001). No significant differences were present in CBCL scores regarding the diagnosis (CU, CD, and IC).

According to the sleep-related items in the YSR, 39% (n=13) of adolescents with severe IBD symptoms and 16% (n=19) of adolescents with mild IBD symptoms reported trouble sleeping sometimes or often. The group difference was significant (p=0.003). Of the adolescents suffering from severe IBD symptoms, 73% (n=24) described being overtired sometimes or often. The number was also high among adolescents with mild IBD symptoms since every second one of them (52%, n=62) reported overtiredness. The group difference was, however, significant (p=0.001).

On the total sum-scale of SSR, patients with severe IBD symptoms had higher mean scores than patients with mild IBD symptoms (p=0.032), indicating that the former had altogether more sleep problems. On the Sleep Behaviour subscale,
patients with severe IBD symptoms reported more sleep problems than patients with mild IBD symptoms, and the group difference approached significance (p=0.064). On the Sleep Behaviour subscale, adolescents with severe symptoms reported more problems than adolescents with mild symptoms on the items “Do you wake up at night when your parents think you are asleep?” (p=0.010) and “Does pain wake you up at night?” (p=0.003).

Patients with severe symptoms reported significantly more daytime sleepiness than patients with mild symptoms (Daytime Sleepiness subscale of the SSR, p=0.034). A significant difference was evident 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?”, where adolescents with severe IBD symptoms reported significantly higher mean scores than adolescents with mild IBD symptoms (p=0.043 and p=0.001, respectively). The group difference in the SSR subscale of Bedtime was non-significant.

In the entire patient group, 17% (n=27) reported that IBD symptoms affect the quality of their sleep. Significantly more adolescents with severe IBD symptoms (n=15; 43%) reported that disease symptoms affect the quality of their sleep than adolescents with mild IBD symptoms (n=12; 10%; p<0.001). No significant differences were present in the YSR or SSR regarding the diagnosis (CU, CD, and IC).
4. PSYCHOSOCIAL SYMPTOMS AND SOMATIC COMPLAINTS THAT ASSOCIATE WITH SLEEPING DIFFICULTIES IN ADOLESCENTS WITH IBD (IV)

4.1. RELATION BETWEEN SLEEP TROUBLE AND PSYCHOSOCIAL SYMPTOMS

According to the parental reports, sleep-troubled adolescents scored significantly higher mean T-scores for total problems (p=0.008), anxiety/depression (p=0.023), somatic complaints (p<0.001), and aggressive behaviour (p=0.006) than adolescents not reporting sleep trouble. In the CBCL scale of Attention Problems, the group difference was non-significant.

The adolescent patients reported similar associations between sleep trouble and psychosocial symptoms than their parents did. In self-reports, sleep-troubled patients scored significantly higher mean T-scores for total problems (p=0.001), anxiety/depression (p=0.002), somatic complaints (p<0.001), and aggressive behaviour (p=0.002) than adolescents with no sleep trouble. Additionally, adolescents with self-reported sleep trouble reported higher mean T-score for attention problems than adolescents without sleep trouble, although the difference was only close-to-significant (p=0.083).

4.2. CORRELATION BETWEEN SLEEP QUALITY AND PSYCHOSOCIAL SYMPTOMS

The SSR scales indicating sleep quality (Bedtime, Sleep Behaviour) correlated significantly (all p’s <0.05) with the CBCL and YSR broad-band scales of Emotional and Behavioural symptoms and narrow-band syndrome scale of Attention Problems.

4.3. RELATIONSHIP BETWEEN SLEEP TROUBLE AND SINGLE SOMATIC SYMPTOMS

Of the single somatic symptoms, sleep trouble associated significantly with various aches and nausea in adolescents with IBD according to both parental and self-reports (Table 12).
### Results

**Table 12.** Single Somatic Symptoms among Sleep-Troubled and Non-Sleep-Troubled Adolescents with Inflammatory Bowel Disease (Scale 0= Does not Apply, 1= Applies Somewhat, 2= Applies Well or Often) as reported by the Parents (Child Behavior Checklist, CBCL) and adolescents (Youth Self-Report, YSR).

<table>
<thead>
<tr>
<th></th>
<th>YES n (%)</th>
<th>NO n (%)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CBCL</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nightmares</td>
<td>14 (44)</td>
<td>16 (50)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Dizzy</td>
<td>21 (66)</td>
<td>11 (34)</td>
<td>0.009</td>
</tr>
<tr>
<td>Tired</td>
<td>9 (28)</td>
<td>17 (53)</td>
<td>0.001</td>
</tr>
<tr>
<td>Aches</td>
<td>9 (28)</td>
<td>21 (66)</td>
<td>0.004</td>
</tr>
<tr>
<td>Headaches</td>
<td>13 (41)</td>
<td>16 (50)</td>
<td>0.097</td>
</tr>
<tr>
<td>Nausea</td>
<td>18 (56)</td>
<td>11 (34)</td>
<td>0.009</td>
</tr>
<tr>
<td>Eye problems</td>
<td>30 (94)</td>
<td>1 (3)</td>
<td>0.607</td>
</tr>
<tr>
<td>Skin problems</td>
<td>15 (47)</td>
<td>11 (34)</td>
<td>0.129</td>
</tr>
<tr>
<td>Stomach aches</td>
<td>5 (16)</td>
<td>16 (50)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Vomiting</td>
<td>25 (78)</td>
<td>6 (19)</td>
<td>0.084</td>
</tr>
<tr>
<td>Constipation</td>
<td>25 (78)</td>
<td>6 (19)</td>
<td>0.085</td>
</tr>
<tr>
<td><strong>YSR</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nightmares</td>
<td>12 (38)</td>
<td>18 (56)</td>
<td>0.007</td>
</tr>
<tr>
<td>Dizzy</td>
<td>21 (66)</td>
<td>11 (34)</td>
<td>0.226</td>
</tr>
<tr>
<td>Tired</td>
<td>5 (16)</td>
<td>22 (69)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Aches</td>
<td>17 (53)</td>
<td>13 (41)</td>
<td>0.025</td>
</tr>
<tr>
<td>Headaches</td>
<td>11 (34)</td>
<td>19 (59)</td>
<td>0.013</td>
</tr>
<tr>
<td>Nausea</td>
<td>19 (59)</td>
<td>12 (38)</td>
<td>0.002</td>
</tr>
<tr>
<td>Eye problems</td>
<td>26 (81)</td>
<td>5 (16)</td>
<td>0.299</td>
</tr>
<tr>
<td>Skin problems</td>
<td>14 (44)</td>
<td>12 (38)</td>
<td>0.062</td>
</tr>
<tr>
<td>Stomach aches</td>
<td>11 (34)</td>
<td>16 (50)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Vomiting</td>
<td>27 (84)</td>
<td>5 (16)</td>
<td>0.083</td>
</tr>
</tbody>
</table>

Linear-by-Linear test (a Chi-Square variation) for statistical significance. Statistically significant differences are indicated in bold.
DISCUSSION

1. PSYCHOSOCIAL SYMPTOMS IN ADOLESCENTS WITH IBD (I)

This study supports the preliminary findings, which report that adolescents with IBD are at higher risk for parent-rated emotional and social dysfunction, and lower competence compared to healthy controls (Engström and Lindquist, 1991; Mackner and Crandall, 2006). Moreover, in line with earlier studies (Mackner and Crandall, 2005), the current study reports that adolescents with IBD and the control adolescents suffer from similar frequencies of self-rated psychosocial symptoms, referring either to patients’ positive adaptation to the disease or alternatively to the denial of psychosocial symptoms and the disease’s negative impact on everyday life.

Here, as reported by the parents, 22% of the patients suffered from a clinical amount of emotional symptoms, which was significantly more than in the control group (7%). Even higher rates of psychopathology in paediatric IBD patients, mainly diagnoses of depression and anxiety, have been reported earlier in interview-based studies (60-73%) (Engström, 1992; Szajnberg et al., 1993) and similar rates in a questionnaire-based study (25%) (Szigethy et al., 2004).

Parental opinion of the child’s mental well-being is of great importance as it complements self-reports and offers another point of view to the child’s psychosocial problems. However, parental concerns related to the child’s illness (Akobeng et al., 1999a) may cause the parental reports to be overestimating. Parents of chronically ill children may also observe their children more sensitively than parents of healthy children, which may partly contribute to the differences found in the parent-reported frequencies of psychosocial symptoms between adolescents with IBD and their controls.

Interestingly, in the current study the adolescents with IBD reported similar frequencies of psychosocial and somatic symptoms on themselves to the controls. This result is in line with another previous report using the same YSR questionnaire (Mackner and Crandall, 2005). Lack of group difference in the self-reported frequency of psychosocial symptoms may either indicate denial and underestimation of psychosocial problems or, on average, good psychosocial well-being among these patients. As a coping strategy, chronically ill adolescents may take an indifferent
attitude towards their symptoms (Akobeng et al., 1999b). Previously, a tendency to deny symptoms have been characterised in the paediatric IBD population in two interview-based studies (Engström, 1992; Szajnberg et al., 1993). Engström I (1999) describes that the interviews were challenging to carry out because children and adolescents with IBD were reluctant to discuss, used short one-word sentences to reply and gave concrete, emotionally thin answers (Engström, 1999). Furthermore, healthy children seem to have tendency to report more psychopathology in themselves than their parents do (Sweeting and West, 1998; Weissman et al., 1987) and the situation may be opposite in children which chronic somatic condition. These factors may partly explain the lack of group difference between the self-reports of patients and controls in the current study. Self-administered questionnaires may not be efficient enough to assess mental and social well-being of the adolescents with IBD and, thus, complementary measurements should be applied.

Due to cross-sectional study design, conclusions of causal connections between the onset of IBD and impaired psychological functioning, as reported by the parents, are impossible. Earlier studies indicate that depressive symptoms and disorders develop after IBD diagnosis; on the other hand, anxiety may precede the diagnosis in these patients (Burke et al., 1994b). Most existing studies in this field used earlier psychopathology in patients as exclusion criteria.

This study reports that self-rated IBD symptom severity and psychosocial dysfunction are positively associated in paediatric IBD patients in Finland, as reported by the parents and the patients themselves. However, it is impossible to tell whether worsening of IBD symptoms caused impaired psychosocial functioning or whether psychiatric factors influenced on the worsening of IBD symptoms. In the light of the literature, both causal ways are possible (see the chapter entitled Relationship between psychological factors and disease severity). In previous studies, disease severity has been noted to be one of the major predictor of fatigue and depression in adolescents with IBD (Szeghy et al., 2004). Depression may also predispose these adolescents to disease flare-ups. Several studies suggest that psychological stress may worsen the symptoms of IBD (Bernstein et al., 2006; Maunder, 2005; Mawdsley and Rampton, 2005). Contrary to our results, Mackner LM (2005) found no association between YSR emotional symptoms and disease factors, which may be explained by the different evaluation of the severity of IBD symptoms (subjective symptoms, physical examination, and laboratory tests) (Mackner and Crandall, 2005); in the current study the evaluation of disease symptom severity was based solely on subjective report. The results here do not permit the drawing of any conclusions about the possible psychosocial etiology of IBD.

Treatment of paediatric IBD aims to decrease the number of relapses of the disease and lengthen remission. Additionally, improving quality of life and
psychosocial functioning of these children/adolescents are also important goals. Evaluation of the psychosocial symptoms should be included in all clinical visits. Especially those adolescents who report severe IBD symptoms may suffer from significant psychological stress and impairment, and they should be evaluated for emotional and social problems more carefully and proper support and treatment should be offered. Few studies exist on how to help IBD adolescents who suffer from depressive and anxiety symptoms and restricted social functioning. IBD adults with psychosocial stress benefited from IBD-focused psychological counselling, which improved psychological well-being and lessened IBD-related somatic symptoms and disease severity (Wahed et al., 2010). A review article suggests that antidepressants (paroxetine, bupropion, and phenelzine) are effective for treating both psychological and somatic symptoms in adults with IBD (Mikocka-Walus et al., 2006). Subjective need for psychological interventions have been documented to be more frequent in adult patients with IBD than those with rheumatoid arthritis, as 31% in the former and 13% in the latter group expressed a need for this kind of therapy (Miehsler et al., 2008). In IBD, the need for psychological support given by the physician was associated with worries and concerns related to the disease, and the need for psychotherapy associated with worries and concerns about IBD, anxiety, impaired social functioning, and short disease duration (Miehsler et al., 2008). In paediatric IBD, cognitive-behavioural therapy has been proven to be effective in emotional symptoms (Keller et al., 2004; Szigethy et al., 2007; Szigethy et al., 2009). Mood improvement was independent from the improvements in the IBD symptomatology (Szigethy et al., 2009). Organising peer support could be one way of improving psychosocial well-being in paediatric patients with IBD. For instance, attending IBD summer camp has been noted to improve these patients’ (n=61, age range 9-16 years) HRQoL and social functioning, to increase their understanding of the disease, and to lower distress related to the treatment interventions (Shepanski et al., 2005).
Objective evaluation of psychosocial problems and mental well-being of an individual paediatric patient is challenging during short clinical visits. Using different sources of information often complement the whole picture of patient’s psychosocial symptomatology. Thus, the evaluation is often based on clinical interviews with the patient and/or the parent or on questionnaires completed by either or both respondents. In addition, reports from teachers or other adults who know the patient well can be utilised in the evaluation process. Agreement analyses aim to clarify how similarly the different respondents evaluate various symptoms on an individual patient. The current study investigated the degree of parent-adolescent agreement on psychosocial and somatic symptoms in paediatric IBD using standardised CBCL/YSR questionnaires. This issue is of great importance in order to make individually-designed treatment plans for paediatric patients with IBD.

The degree of parent-adolescent agreement was here altogether poor to low on the presence of psychosocial and somatic problems in the adolescents with IBD. Among them, 10% of significant psychosocial symptoms would have remained unrecognised if only the adolescents or the parents were asked. Earlier, similarly low agreement rates have been reported among paediatric psychiatric and normal populations (Achenbach et al., 1987; Ferdinand et al., 2006; Kolko and Kazdin, 1993; Rothen et al., 2009; Salbach-Andrae et al., 2009a; Sourander et al., 1999). Comparable studies that investigate agreement on psychosocial and somatic symptoms between parents and adolescents among somatically ill paediatric patients are few. In asthma, a low agreement rate was reported on the presence of anxiety and depression ($\kappa = 0.18$) (Rockhill et al., 2007). Similarly, an interview-based study revealed poor to low degree of parent-adolescent agreement ($\kappa = 0.08-0.29$) among chronically ill children (cancer, cystic fibrosis, IBD, and insulin-dependent diabetes) (Canning, 1994).

The current study reports higher agreement rate between adolescents with IBD and their parents regarding Emotional ($\kappa = 0.34$) than Behavioural Symptoms ($\kappa = 0.15$) which is opposite to earlier studies carried out among both in the community and clinical populations (Kolko and Kazdin, 1993; Salbach-Andrae et al., 2009a; Salbach-Andrae et al., 2009b; Yeh and Weisz, 2001). In the CBCL/YSR questionnaires, the broad-band scale of Emotional Symptoms includes the scale of Somatic Complaints, where the $\kappa$-value was highest of the three syndrome scales.
included in the Emotional Problems, and may thus partly explain this result. Mutual conversation on somatic symptoms between parents and adolescents is presumably easier than on symptoms related to mental well-being, depression and anxiety. Notably, agreement in the syndrome scale of Anxious/Depression was extremely poor (κ=0.02), and thus a conclusion that in IBD parents and adolescents agree more on emotional than behavioural problems is problematic.

On average in the whole patient group, parents and adolescents reported similar frequencies with which the patients scored over the subclinical limit on most of the broad-band and syndrome scales. This is in line with an earlier study which assessed psychiatric disorders in children with chronic conditions, including some children with IBD (n = 11). In that study, parents and children in the IBD group reported similar frequencies of emotional (18%) and behavioural (9%) disorders in these patients, whereas in other chronic illness groups, parents reported more frequent psychiatric disorders in their children than the children themselves did (Canning, 1994). In the current study, parents reported significantly more often symptoms in the subclinical/clinical range in the scale of Somatic Complaints than the adolescents themselves did, which may reflect parental stress and concerns about the child’s disease. The adolescents, in turn, scored themselves more often in the subclinical/clinical range on the scales of Behavioural Symptoms and Social Problems than their parents did, possibly indicating that the parents of adolescents with IBD may be unknowing of the behavioural and social concerns that their children have. Even if frequencies of patients scoring in the subclinical/clinical range in the CBCL/YSR scales were mostly similar, the parents and adolescents seemed to disagree on who the individual patients are that suffer from psychosocial symptoms on the subclinical-clinical range.

Even though utilising different sources of information can complement the whole picture of a patient’s psychosocial well-being, inconsistent reports may be problematic in the clinician’s point of view. In clinical settings, knowing the factors that may contribute to the parent-adolescent agreement regarding adolescent’s emotional and behavioural issues would help clinicians to interpret gained information correctly. These possible factors include e.g. a child’s age and gender (Berg-Nielsen et al., 2003; Verhulst and van der Ende, 1992) and parental psychosocial well-being or lack of it (Martin et al., 2004). Furthermore, parental psychosocial symptomatology has been shown to contribute to parental evaluation of the child (Treuuter and Epkins, 2003). Here, parental psychosocial problems and problems in the families stayed undefined and unanalysed, and in the analyses the effect of age and gender of the patient on the degree of agreement remained undetermined. Furthermore, the agreement rate between mother and adolescent and father and adolescent, which has been earlier documented to vary (Seiffge-Krenke and Kollmar, 1998; Vassi et al., 2008), was not studied separately in the current study.
3. SLEEP TROUBLE AND ITS RELATION TO PSYCHOSOCIAL AND SOMATIC SYMPTOMS IN ADOLESCENTS WITH IBD (III, IV)

So far, only one earlier study handling sleeping problems in paediatric IBD patients published as an abstract exists (Nachmias et al., 2006). The current study assessed the frequency of parent and self-reported sleep problems and daytime tiredness among adolescents with IBD by five sleep-related items in the CBCL and YSR questionnaires and by the standardised Sleep Self-Report (SSR). Importantly, parental reports complement self-reports here and offer another point of view on sleeping difficulties among young patients with IBD. However, a lack of objective measurements of sleep such as polysomnography (PSG) or actigraphy can be considered a weakness of the current study. On the other hand, subjective self-reports of sleep have proven to correlate with objective measures of sleep difficulties in paediatric populations (Gaina et al., 2004; Iwasaki et al., 2010).

3.1. PREVALENCE OF SLEEP TROUBLE AND DAYTIME TIREDNESS IN ADOLESCENTS WITH IBD COMPARED TO HEALTHY CONTROLS

Comparable to the findings in the study assessing psychosocial symptoms in adolescents with IBD (I), no significant group difference emerged in the frequency of self-reported sleep problems, sleep quality, and daytime tiredness (YSR, SSR) between adolescents with IBD and their population-based controls. These results are inconsistent to what has earlier been reported in adult IBD patients (Keefer et al., 2006; Zimmerman, 2003) or in JIA patients (Bloom et al., 2002; Zamir et al., 1998). Subjective sleep quality reported on the Pittsburgh Sleep Quality Index (PSQI) was poorer among adult patients with inactive IBD compared to their healthy controls (Keefer et al., 2006). However, no group differences emerged according to daytime dysfunction between these two groups (Keefer et al., 2006). Furthermore, JIA patients reported themselves suffering from daytime tiredness significantly more often than their healthy controls (Bloom et al., 2002; Zamir et al., 1998). In one study JIA patients, however, reported a similar frequency of sleeping problems than the controls (Passarelli et al., 2006).

Although no significant group difference emerged here in self-reports between patients and controls, parents in the patient group did report significantly more
sleep problems and daytime tiredness (CBCL) in their children than the parents of controls. Similarly in JIA, parents have reported more sleep-related problems and daytime tiredness in their children with JIA than the parents of healthy controls (Bloom et al., 2002).

In the current study, about 20% of the adolescents in both groups reported suffering from sleeping problems sometimes or often (YSR), which is in line with previous epidemiological studies concerning prevalence of sleep problems in the child and adolescent population (Holmberg and Hellberg, 2008; Owens et al., 2000; Paavonen et al., 2000). However, this frequency is lower compared to the previous report of sleep problems among adolescents with IBD (54%) (Nachmias et al., 2006). Interestingly, in the current study, parents of the controls reported much lower prevalence of sleep problems in their children (13%) compared to the self-reports (23%), while the parents in the patient group recognised sleep problems in their children at a similar rate (25%) as what is earlier shown to be the prevalence of such problems in children/adolescents. This may suggest that in control group the parents are unaware of their child’s sleeping difficulties.

Approximately 10-30% of adolescents are reported to suffer from excessive daytime tiredness according to parent and adolescent reports (Holmberg and Hellberg, 2008; Owens et al., 2000). However, in the current study the frequency of self-reported daytime tiredness seemed to be much higher in both patient and control groups, as 57% of the patients and 56% of the controls reported suffering from overtiredness sometimes or often. The inconsistency between the results of these studies may be explained by methodological differences. Owens et al (2000) used teacher’s reports to rate frequency of daytime sleepiness among school-aged children (Teacher’s Daytime Sleepiness Questionnaire) (Owens et al., 2000) but here the frequency was self-rated. Of adult patients with inactive IBD, 79% needed to take naps during the day, referring to decreased daytime energy and increased daytime tiredness among them (vs. 50% of the controls) (Ranjbaran et al., 2007a). In this study, parents in the patients group reported comparable frequency of overtiredness in their children than the patients (52%) but the parents of controls reported much lower frequency (31%) compared to their children.

3.2. FREQUENCY OF SLEEP PROBLEMS AND DAYTIME TIREDNESS ACCORDING TO IBD SYMPTOM SEVERITY

In the patient group, both respondents reported significantly more sleep problems and overtiredness (CBCL, YSR) in those with severe IBD symptoms compared to those with mild IBD symptoms. This was also evident in the SSR subscale of Daytime Sleepiness, where those with severe symptoms scored significantly higher
than those with mild IBD symptoms. Here, nearly half (43%) of the patients with severe IBD symptoms report that the disease and its symptoms affect the quality of their sleep. Similarly, 43% of adult IBD patients have earlier reported that GI symptoms have an impact on their sleep (Keefer et al., 2006), and in another study 66% of adult IBD patients thought their sleep was poor in active states of the disease (Ranjbaran et al., 2007a). Comparable to the psychosocial symptoms (I), frequencies of sleep problems or daytime tiredness did not differ between patients with different subtypes of the disease (UC, CD, IC).

Patients with severe IBD symptoms seem to suffer from more frequent sleep interruptions than those with mild IBD symptoms, and one reason for frequently interrupted sleep may be the several somatic symptoms of the disease (SSR item “Does pain wake you up at night?” and the extra question “Do IBD symptoms affect the quality of your sleep?” in study III). Frequent sleep interruptions have been mentioned earlier by adult IBD patients (Ranjbaran et al., 2007a), and they have been objectively documented in paediatric patients with JIA (Passarelli et al., 2006; Zamir et al., 1998). Furthermore, chronic pain has been objectively documented to associate with frequent arousals during sleep (Palermo et al., 2007; Palermo et al., 2011). Frequent sleep interruptions may explain the daytime tiredness, which was noticed here to be more common in young IBD patients with a severe disease course than those with mild IBD symptoms (III). Another possible explanatory factor here would be anaemia due to rectal bleeding or malnutrition (iron deficiency, B12 –vitamin deficiency) (Mamula et al., 2003).

In study IV, somatic symptoms (reported in CBCL and YSR questionnaires), especially various aches, associated with sleep trouble among the whole patient group. Those who have severe IBD symptoms presumably have more sleep-disturbing aches and, thus, the group difference between those with severe vs. mild IBD symptoms was significant in the SSR item “Does pain wake you up at night?” Also, emotional symptoms which were found to be more common in adolescents with severe IBD symptoms than those with mild IBD symptoms (I) may affect their night’s sleep, causing sleep disturbances (Johnson et al., 2000; Patten et al., 2000). In earlier studies, adult patients with IBD have listed reasons for their sleep interruptions: abdominal pain, need to use bathroom, breathing difficulty, snoring, feeling too cold or too hot, and nightmares (Ranjbaran et al., 2007a). In this study, nightmares were equally common in those with mild and severe IBD symptoms. Significantly more patients with severe IBD symptoms took naps during the day compared to those with mild IBD symptoms. Daytime tiredness negatively affects social life, free time activity and performance in school (Fallone et al., 2002; Vignatelli et al., 2004). Thus, in clinical work sleep problems and daytime tiredness should be assessed carefully, especially in those with severe IBD symptoms, and interventions to improve sleep quality among them should be applied. The current study was
unable to classify and diagnose the prevailing sleep disorder (Ivanenko and Gururaj, 2009) more specifically. That issue in patients with paediatric IBD should be assessed in future studies.

3.3. PSYCHOSOCIAL SYMPTOMS THAT ASSOCIATE WITH SLEEP TROUBLE IN ADOLESCENTS WITH IBD

Adolescents and their parents reported very similar associations between sleep trouble and psychosocial symptoms on the young IBD patients. The similarity of the reports increases the reliability of these findings. According to both respondents, sleep trouble associated significantly with anxiety/depressed mood, aggressive behaviour, and somatic complaints (especially various aches). Sleep-troubled patients also scored more frequently above the subclinical limit on the YSR scale of Anxiety/Depressed mood than their counterparts without sleep trouble, indicating a significant number of emotional problems among the sleep-troubled individuals in this population. Earlier community-based studies have revealed comparable associations between sleep trouble and emotional symptoms (Alfano et al., 2009; Roberts et al., 2002). Also in young patients with JIA, a significant relationship between sleep trouble and anxiety has been documented (Ward et al., 2008).

In normative populations, significant associations have been revealed between sleep problems (e.g. objectively measured sleep amount and quality of sleep), and attention problems and working memory (Aronen et al., 2000; Dahl, 1996; Steenari et al., 2003; Stein et al., 2001). In line with this, parent and self-reported attention problems correlated significantly with SSR-measured sleep quality (SSR subscales on Bedtime and Sleep Behaviour). However, these associations were not evident when the single YSR sleep problem item was utilised to classify patients into those with sleep trouble and those without. This difference might be caused because of a more profound assessment of sleep in the SSR.

Sleeping problems associate with various behavioural problems in children and adolescents (Aronen et al., 2000; Ferber, 1996; Owens et al., 2005), including problems with aggression and emotional control (Aronen et al., 2000; Dahl, 1996; Lavigne et al., 1999; Stein et al., 2001). Similarly, in this study, sleep-troubled patients had more parent and self-reported behavioural problems and problems with aggression. Sleeping difficulties are known to impact negatively on social performance and academic competence (Dahl, 1996; Smaldone et al., 2007). The associations of these aspects of behaviour were not included in the current study but they might be an interesting topic for future analyses.
As mentioned earlier, sleep trouble associated significantly with mean T-scores on the CBCL/YSR scales of Somatic Complaints. In addition, the frequency of patients scoring over the subclinical limit on the scale of Somatic Complaints was significantly higher among sleep-troubled than non-sleep troubled adolescents with IBD according to both respondents. Therefore, in this study, single somatic symptoms included in the scale of Somatic Complaints were analysed more closely between these two groups. Results revealed that among young IBD patients, sleep trouble associated mainly with various parent and self-reported aches, which is in line with what is earlier documented concerning the associations between aches/pain and sleep (Lewin and Dahl, 1999; Palermo et al., 2007; Palermo et al., 2011; Stein et al., 2001). Pain and sleep are interrelated: pain has a negative impact on the initiation and maintenance of sleep (Lewin and Dahl, 1999). Insufficient sleep, in turn, has been shown to increase the perception of pain (Moldofsky and Scarisbrick, 1976) and to impair coping skills necessary for effective pain management (Lewin and Dahl, 1999). Children with somatic complaints tend to report more sleep problems than those without these complaints (Bruusgaard et al., 2000). Furthermore, sleeping difficulties may cause reporting more comorbid somatic complaints (e.g. chronic pain and gastrointestinal problems) (Taylor et al., 2007).

According to the current cross-sectional study it is impossible to tell whether somatic symptoms, including abdominal pain, which is one of the leading somatic symptoms in IBD, led to trouble sleeping or whether deficient sleep induced more aches in adolescents with IBD. In the future, longitudinal studies should be administered to clarify causal connections between sleeping problems and IBD-related somatic complaints.
4. METHODOLOGICAL CONSIDERATIONS

The methodological strengths of the current study are: the use of standardised and validated questionnaires to measure psychosocial symptoms and sleep, gathering the information from both parent and adolescent respondents, large sample size and sample distribution across Finland of the patient group, and inclusion of population-based controls matched for age, gender, and place of residence.

4.1. QUESTIONNAIRES

The Child Behavior Checklist (CBCL) and Youth Self-Report (YSR) are popular screening instruments used to identify children and adolescents with impaired psychosocial functioning for further evaluation and intervention. They are used both in clinical and research settings. CBCL/YSR questionnaires are not diagnostic. However, many studies have reported moderate to high levels of associations between CBCL/YSR scores and diagnoses derived from structural psychiatric interviews (Ferdinand, 2008; Hofstra et al., 2001; Krol et al., 2006; Petty et al., 2008; van Lang et al., 2007). The questionnaires have been used in studies including various paediatric populations, as well as paediatric IBD patients (Brown et al., 1991; Brown et al., 1992; Canning et al., 1992; Daltroy et al., 1992; Wood et al., 1987).

Use of the CBCL/YSR with children and adolescents with chronic somatic illnesses has been criticised because the narrow-band syndrome scale of Somatic Complaints is included into the broad-band scale of Emotional Symptoms, which may potentially cause overestimation of emotional symptoms and elevation in the total symptom scores (Perrin et al., 1991). However, it is also argued that in physically ill adolescents, it is nevertheless essential to include somatic items in the assessment of emotional symptoms, because exclusion would cause failure to find the individuals suffering from marked depressive symptoms (Szigethy et al., 2009). Comprehensive reliability and validity checks are available for the CBCL/YSR questionnaires internationally (Achenbach and Rescorla, 2001). The Finnish translations, however, have not yet been systematically validated in the Finnish population. One possible response bias concerning the posted questionnaires is that the parent and adolescent respondents have discussed the questionnaires at home.

Assessment of sleep difficulties was based on validated and standardised Sleep Self-Report (SSR) (III, IV). SSR measures self-rated sleep problems in three subscales: Bedtime, Sleep Behaviour, and Daytime Sleepiness. Comparable parent-assessment of sleep (Children’s Sleep Habits Questionnaire, CSHQ) was not included.
in this study. However, the five sleep items in the CBCL were utilised to obtain parental perception of their child’s sleep and daytime tiredness.

In study IV, only one YSR item was used to divide the patient group into sleep-troubled and non-sleep-troubled in order to assess somatic and psychosocial symptoms in these two subgroups. The item is not standardised and refers only to self-perceived trouble sleeping. However, sleep trouble showed similar associations to psychosocial symptoms here to earlier studies, where sleep trouble has been objectively rated (Aronen et al., 2000; Ward et al., 2008). Additionally, in this study the adolescents and their parents reported similar associations between sleep trouble and psychosocial symptoms, which adds to the reliability of the gained results (IV). Furthermore, it can be argued that sleep trouble is mainly a subjective symptom and should therefore be subjectively rated. Earlier, similar method to determine sleep trouble has been used in a study which assessed the relationship between sleep trouble and anxiety/depression in children aged 6-11 years using CBCL and the Teacher Report Form (TRF) (Johnson et al., 2000). In that study, a child’s trouble sleeping was rated by the parent in the CBCL in a comparable manner as we did here (Johnson et al., 2000). In adolescents with chronic pain, subjectively, but not objectively, rated poor sleep quality has associated significantly with depressive symptoms and worry at bedtime (Palermo et al., 2007). The single question “Do you have trouble sleeping?” is applicable in clinical visits, and as the results here imply, those adolescents with IBD who admit to suffering from trouble sleeping should be further evaluated for psychosocial symptoms. However, in the future an objective measure of sleep disturbance (actigraphy/PSG) might be used when measuring connections between sleep trouble, and psychosocial and somatic symptoms in adolescents with IBD.

4.2. PARTICIPANTS

Although the response rate was only moderate, as only 56% of the patients replied, the number of patients included (n=160) was fairly high. The response rate was comparable to other Finnish questionnaire-based studies (Haapamäki et al., 2010). In earlier respective studies assessing psychosocial symptoms in paediatric IBD, the number of patients has been smaller, comprising less than 50 on average. Additionally, the patient group represented the whole Finland well. Here the item response rate was high, parents and adolescents answered at a parallel rate, and the questionnaires were properly completed. About the non-respondents can only be stated that they did not differ from respondents according to age, sex and place of residence, but the SES and severity of their disease are unknown. It might be either that their somatic and psychic health was so good that they did not consider
it necessary to answer or either their condition was so bad that they did not have
the strength to make the effort to answer this questionnaire. As in earlier studies,
there was no difference in reported psychosocial functioning between adolescents
with UC or CD (Engström, 1992; Gold et al., 2000), and therefore they were analysed
here as one IBD group. In addition, in agreement analysis the IBD group was
analysed as one, although at least one earlier study suggests that there is a better
parent-adolescent agreement rate in UC than in CD and that patients with CD
report psychosocial symptoms at a higher rate compared to their parents (Wood
et al., 1987). Study subjects were mostly white Scandinavians with homogeneous
ethnic composition. Thus, results may not be generalised worldwide.

The postal addresses of the patients, who were entitled to reimbursement for IBD-
related medical costs according to Social Insurance Institution, were traced from the
database of the Population Register Centre. The background inquiry asked about
specific IBD diagnosis (CD, UC, IC) for double-checking that these patients really
had IBD. The controls might have had some chronic somatic condition but these
cases were not excluded. Possible confounding factors, e.g. family history of sleep
disturbances or psychosocial issues, parental mental health, current stressors at the
time of the study, family functioning in patients and controls were not evaluated.
This would have been interesting, since family factors are known to associate with
the frequency of behavioural problems in Finnish adolescents (Hurtig et al., 2005).
The same applies to study IV, where it would have been interesting to see whether
there were differences between groups of sleep-troubled and not-sleep troubled
adolescents, according to other factors that might have explained the prevalence
of psychosocial symptoms. It is known that family factors e.g. communication in
the family (Burke et al., 1990; Tojek et al., 2002; Wood et al., 1989) and parental
mental health (Burke et al., 1994b) influence on the psychosocial functions of young
people with IBD, and these factors were not asked in the questionnaires. Moreover,
another possible influencing factor – medication of the patients – was not included
in the current study. For example, corticosteroids have a negative impact on sleep
(Mrakotsky et al., 2005). Importantly, medication should be included in future
studies on this field.

4.3. MEASURING THE SEVERITY OF IBD

Self-perceived disease severity has earlier been reported to correlate with objectively
measured inflammatory status in IBD (Wood et al., 1987). Earlier studies on the
relationship between severity of IBD and psychosocial symptoms have revealed
inconsistent results (Table 2). In the current study the association was clear, but it
may be biased by the method used to rate the disease severity. Depressed children
and adolescents may consider the disease symptoms more severe than their non-depressed counterparts, even if their objectively-rated disease severity is similar. Subjectively-rated IBD symptom severity has been reported to correlate with affective symptoms better than objectively-rated IBD symptom severity (Ondersma et al., 1997). After all, this study allows for the important conclusion that those children and adolescents who subjectively consider that they are suffering from severe IBD symptoms should be further evaluated for psychosocial (I) and sleep problems (III) in order to find those cases that need and would benefit from treatment, including psychological counselling.

In the current study, disease severity was self-rated on a scale from 1 (asymptomatic) to 7 (extremely severe). The method used to determine IBD symptom severity has varied between earlier studies assessing psychosocial symptoms in patients with paediatric IBD, which impairs comparison between the achieved results. Earlier studies in this field have applied both objective evaluations of the disease severity (laboratory values, physician examination) and patient-reported disease symptoms (e.g. pain, number of stools, blood in stools) (Burke et al., 1989; Burke et al., 1990; Burke et al., 1994b; Wood et al., 1987). However, many of them have not included any kind of assessment of severity of the disease (Table 2). Because good validated non-invasive methods to rate IBD symptom severity exist (e.g. the Paediatric Ulcerative Colitis Activity Index, PUCAI (Turner et al., 2007; Turner et al., 2009); and the Paediatric Crohn Disease Activity Index, PCDAI (Leach et al., 2010)) it is recommended to apply those instruments in future studies in order to make the comparison between results about the association of the severity of IBD and psychosocial symptoms easier. For example, PUCAI scores are formulated by patient-reported symptoms, which include abdominal pain, rectal bleeding, stool consistency, number of stools per 24 hour period, nocturnal stools that cause awakening, and patients’ activity levels (Turner et al., 2007). The PUCAI score is normally rated by a physician but could also reliably be rated by patients themselves (Lee et al., 2011). Thus, it could be used in future questionnaire-based studies, as well.
CONCLUDING REMARKS AND FUTURE PROSPECTS

This study is the first one concerning psychosocial symptoms and sleep in paediatric IBD patients performed in Finland. It included more patient subjects than any earlier comparable study in this field. Additionally, a population-based control group matched for age, gender and place of residence was included. Furthermore, the data was collected from both the parents and the adolescents with widely used standardised measures.

The main results of the present study suggest that in Finland, adolescents with IBD more often have emotional (depression, anxiety) and social problems, their sleep quality is more frequently impaired, and they are less competent than their healthy peers in the community. Emotional problems and sleep problems are present, especially if the adolescent rates his/her IBD symptoms as severe. Moreover, psychosocial symptoms, especially anxiety and depression, aggressive behaviour and difficulties related to attention, are likely to be present among patients who experience sleep disturbances in addition to those who report severe IBD symptoms. Surprisingly, the self-reported psychosocial symptoms including emotional, behavioural, and somatic symptoms, and sleep problems in the patient group did not differ from those in the control group.

In the future, studies concerning psychosocial problems in adolescents with IBD should develop new ways to ask the adolescents about their symptoms, as it seems that it is difficult for them to report on their symptoms using questionnaires (Väistö et al., 2010) or in clinical interviews (Engström, 1992; Szajnberg et al., 1993). It may be necessary to create a trusting relationship with the adolescents before they can reveal more of their symptoms. Parents should be used as another source of information. It may also be possible to gain valuable information on psychosocial well-being of the patients from the teachers. Objective evaluation of the disease symptom severity, such as clinical examination and laboratory tests, should be included in future studies, in addition to a subjective one in order to draw conclusions about the relationships between inflammation processes and psychosocial problems among this paediatric population. Furthermore, it is recommended to collect data on medication used to control the inflammation and disease symptoms in study subjects, as they have earlier been reported to influence psychosocial symptoms and sleep parameters. To get a deeper understanding of the sleep quality in this population and in order to be able to specify the type of prevailing sleep disorder, objective evaluation of sleep (actigraphy/PSG) is recommended. Furthermore, objectively measured inflammation status and objective sleep recordings would clarify the causal relations between disease severity and inflammation, and sleeping difficulties.
CONCLUSIONS

The main results and conclusions can be summarised as follows:

(I) According to the parents but not the adolescents themselves, adolescents with IBD have more depressive symptoms and somatic complaints, impaired social functioning, and lower total competence than their peers in the community. Positive association emerged between self-perceived severity of IBD symptoms and parent and self-reported psychosocial symptoms. Other methods besides questionnaires should be applied when assessing the psychosocial well-being of IBD adolescents, as the questionnaires alone might be insufficient.

(II) Parent-adolescents agreement rate was poor to low in patients. Significant psychosocial and somatic symptoms would remain unnoticed if only the parent or the adolescent, instead of both, were asked. On average, parents report three times more serious somatic symptoms than the adolescents themselves, which possibly reflects parental stress as a result of the disease. They also may be unaware of behavioural and social concerns of their children, as the patients reported more serious behavioural and social problems themselves than the parents did.

(III) Patients with severe IBD symptoms have trouble sleeping and overtiredness more often than patients with mild IBD symptoms or controls, according to both the adolescents and their parents. In adolescents with severe IBD symptoms, evaluation of sleep is important when estimating the disease burden. Further studies are needed to clarify the association between inflammation status and sleep quality in paediatric IBD.

(IV) Parents and adolescents reported similar associations between sleep trouble and psychosocial symptoms in paediatric IBD. Trouble sleeping associated with anxious/depressed mood, aggressive behaviour, and somatic complaints including various aches. Furthermore, self-perceived poor sleep quality correlated significantly with parent and self-reported attention problems. Evaluations of sleep problems in clinical visits and interventions to improve sleep quality are important in this population.
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