The social position of adolescents and young adults with chronic digestive disorders

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The social position of adolescents and young adults with chronic digestive disorders

De sociaal-maatschappelijke positie van jongeren met een chronische spijsverteringsaandoening

(met een samenvatting in het Nederlands)

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Contents

1 General introduction

Background and aims

The period of growing up and reaching adulthood is a time of many biological, psychological and social changes. Adolescence is an important phase in life as many choices are made that direct future life. Coping with a chronic disease can add another dimension to adolescents' lifes [1]. Reviews on the effects of chronic disease in children and adolescents show that most studies are conducted in populations with more prevalent chronic diseases, such as asthma or diabetes [1,2]. Relatively little is known about the effects of a chronic digestive disorder on the social position of young patients. Available studies in young populations usually involve patients with one specific disorder such as inflammatory bowel disease (IBD), often within non-controlled designs [3-8].

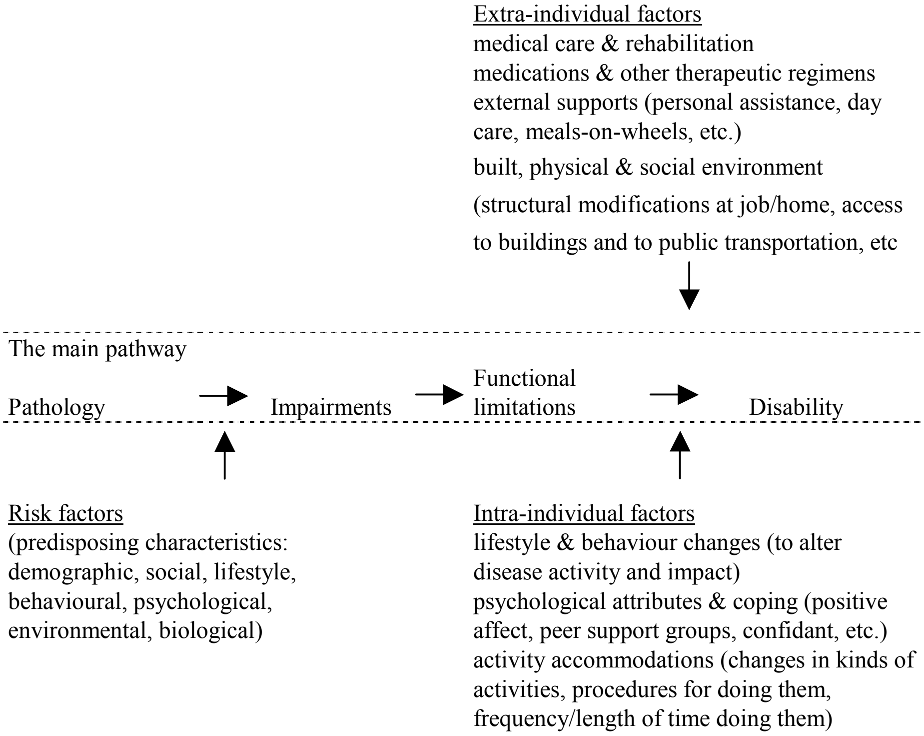
Scientific knowledge of the effects of chronic digestive disorders on the social position is usually aimed at adult patients [9-13]. In general, these studies show that difficulties are experienced in particular in labour participation, financial matters, social contacts and relationships. Adult patients with chronic digestive disorders seem to emphasize social restrictions more than physical restrictions. There are indications, however, that the social position of younger patients also is adversely affected by a chronic digestive disorder. According to Rabbett, et al. [4] and Akobeng, et al. [6], young patients with IBD are at risk to experience difficulties in sports, such as swimming and running, school absenteeism, long distance (school) trips and staying overnight at friends' houses, due to (worries about) a lack of toilet facilities close by or embarrassment concerning the frequent use of it, or just plain lack of energy. On the other hand, compared to reference scores of healthy children, Loonen et al. [8] did not find any differences with regard to the social functioning of children with IBD, such as playing with other children, making friends or being restricted in social activities.

It can be concluded that, so far, social position issues in adolescents and young adults with a chronic digestive disorder have hardly been subject of research within a controlled design. Therefore, central to this study is the impact of being diagnosed with a chronic digestive disorder, i.e. IBD, chronic liver diseases, congenital digestive disorders, coeliac disease or food allergy, on the social position of adolescents and young adults. Two main objectives can be distinguished. The first objective is to gain insight in the social position of adolescents and young adults with a chronic digestive disorder compared to the social position of population controls. The second objective of this thesis is to investigate whether the type of disease and disease burden characteristics imply risk factors for possible difficulties in the social position. Furthermore, it is aimed to investigate whether generic coping strategies, that is, coping with stress and problems in different, not specifically disease dependent situations, are important factors in experiencing difficulties in the social position. Further insight into the consequences of having a chronic digestive disorder for the social position of adolescents and young adults, and more knowledge on the impact of disease burden and coping strategies, provide a basis for preventive interventions aiming to support young patients to develop with a maximum of equal possibilities in society.

Conceptual framework

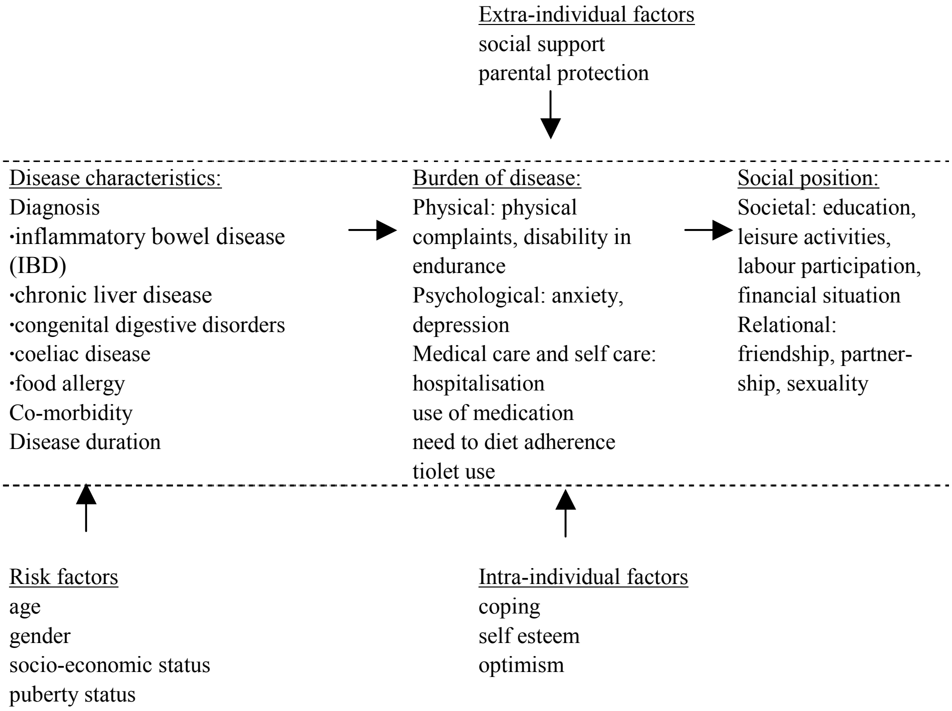
The present study is performed within a conceptual framework based on the Disablement Process model of Verbrugge and Jette [14]. This disablement model is a socio-medical model of disability, especially useful for epidemiological and clinical research. It is built on the International Classification of Impairments, Disabilities and Handicaps (ICIDH), a taxonomy developed by the World Health Organization [15] on the one hand, and on the 'Nagi Scheme' [16-18] on the other hand. Whereas the ICIDH provides comparability in national statistics, and therefore has become of important political value, the Nagi Scheme originates from a sociological point of view. It must be noted that recently, the ICIDH has been updated into the International Classification of Functioning, Disability and Health (ICF) [19], it is still a standard taxonomy, but with acknowledgment of the former criticism on the limited scientific applicability. The ICF now provides, among other aims, a scientific basis for understanding and studying human functioning, both outcomes and determinants. In both schemes, that of the WHO and of Nagi, the central focus is on the relationship between disease and various kinds of functional outcomes. The disablement model of Verbrugge and Jette has refined this pathway by putting more attention on predisposing characteristics and introduced factors, such as social environment, coping and lifestyle. Figure 1 shows this main pathway with the introduced factors.

Fig. 1 The Disablement Process model of Verbrugge & Jette, 1994



The term pathology refers to biochemical and physiological abnormalities that are detected and medically labelled as a disease, injury or congenital/developmental condition. Impairments are dysfunctions and significant structural abnormalities in specific body systems, such as musculoskeletal, cardiovascular and neurological. Functional limitations in this model are considered restrictions in performing basic physical and mental actions used in daily life, e.g. reach, climb stairs and read. Disability is defined as the experienced difficulty doing activities in any domain of life due to a health or physical problem, e.g. job, personal care, hobbies and socializing with friends and kin [14]. Based on this model, the following conceptual framework was developed (Figure 2):

Fig. 2 Conceptual framework of this thesis



Social position can be considered a rather distal outcome measure, referring to participation in several daily life domains, as listed in Figure 2. It refers to the disability concept in the disablement model of Verbrugge and Jette, i.e. experienced difficulties in undertaking daily activities. Burden of disease involves more direct consequences or manifestations and inconveniences due to a disease. In comparison with the model of Verbrugge and Jette, burden of disease has to do with both impairments and functional limitations, with the emphasis on functional limitations. A conceptual difference with the disablement model concerns medical care and self care. In the model of Verbrugge and Jette, these aspects are considered extra-individual factors: external care to help a patient. In the conceptual frame of this thesis, however, they are interpreted from the patients' point of view, that is, medical care and self care are considered as adaptive tasks patients have to deal with. It is hypothesized that negative associations exist between burden of disease measures and social position aspects. Furthermore, the factors that are supposed to influence the central pathway in Figure 2, are, apart from socio-demographic characteristics, social support and parental protection, i.e. extra-individual factors, and self esteem, optimism and coping, i.e. intra-individual factors.

Apart from the impact of disease burden, coping is taken into account as coping can be considered a key concept in explaining the impact of stressors on health and well-being [20]. In most studies on coping with stressful events and daily hassles the transactional model of Lazarus & Folkman [21] is used as a frame of reference [2]. Central to this model is the appraisal of external or internal demands; people who are confronted with a stressor (e.g. a chronic disease) evaluate this stressor and the availability of coping resources. Such individual appraisal determines the ability to adapt. The most widely cited and adopted definition of coping is the one derived from the model of Lazarus and Folkman: constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. According to Compas et al. [22], scientific literature provides evidence that coping is of importance in the psychological adjustment of adolescents exposed to stressors. In general, problem-focussed and active coping have been found to be associated with better adjustment, whereas emotion-focussed coping and passive coping have been found to be related to poorer adjustment [22-25]. It will be investigated whether similar relationships exist with regard to the social outcomes mentioned above in young patients with chronic digestive disorders. Relationships concerning the other intra-individual factors (as self-esteem and optimism) and extra-individual factors (social support and parental protection), will not be addressed in this thesis.

Chronic digestive disorders

This thesis deals with various types of chronic digestive disorders, i.e. inflammatory bowel diseases IBD, chronic liver diseases, congenital digestive disorders, coeliac disease and food allergy. Crohn's disease and colitis ulcerosa are well known *inflammatory bowel diseases*. They manifest dependent on the extension and seriousness of the inflammation, and, in case of Crohn's disease, on the localisation in the digestive system. Complaints and symptoms can consist of blood and mucus in the defecation, diarrhea, pain (e.g. bowel spasms), fever, and an increased defecation urge [26]. As a consequence, a patient may prefer to stay at home or close to home, which makes it more difficult to live a socially normal life. During an active period of the disease, i.e. an inflammation, fever, malnutrition and loss of weight are major symptoms. Treatment involves three main parts: improvement of the nutritional state, medication intake (i.e. prednisone) and surgical operation, sometimes resulting in a temporary or permanent stoma. Chronic liver diseases rather refer to the stage of a liver disease, than to specific diseases. Chronic liver diseases can be viral, i.e. hepatitis B, C or D, or non viral, i.e. auto immune hepatitis or hereditary in nature such as Wilson's disease. Viral liver disease can be active, often accompanied by a liver inflammation, or can be latently present. In both cases, the disease is transmittable. During a later stage of a liver disease, liver cirrhosis (development of strands of connective tissue in the liver) can occur which leads to an insufficiently functioning of the liver. Complaints that can accompany chronic liver diseases are fatigue and lack of energy, pain in the liver region or joint pains, itching, and a yellow colouring skin. Treatment involves improvement of the nutritional state, medication therapy, and, in a far advanced stage, liver transplantation may follow [26]. *Congenital disorders of the digestive system* usually consist of a malformation of the oesophagus, bile duet system, small and large intestine, or the rectum. For example, in case of an anorectal malformation, the rectum is absent or hardly developed. Also, Hirschsprung disease is an example of a congenital digestive disorder, caused by a nerve disorder in the lower part of the large intestine. This results in serious constipation as the affected part is not able to show normal bowel movement. In case of malformations, surgical corrections have to be carried out almost always, most often already at a young age. Sometimes a temporary or permanent stoma is necessary. In case of Hirschsprung disease, the affected part of the intestine has to be removed. In many cases a small part of the affected intestine has to remain to avoid the construction of a definitive stoma. This means that defecation problems can develop, so that medication therapy (clysmata, laxatives) is necessary to stimulate normal bowel movement. *Coeliac disease* is a disease of the small intestine caused by a permanent intolerance or allergy for gluten, a protein present in wheat meal products. When untreated, complaints consist of chronic diarrhea with malabsorbtion, anaemia, a swelled belly, loss of weight and a growing disorder. Treatment involves a gluten free diet, that means for instance no (usual) bread, candy, pasta products or beer. Sometimes medication, such as corticosteroids, is indicated [26,27]. Food allergy is a syndrome of allergic reactions to certain foods, such as eggs, fish, nuts, chocolate, fruit or milk. Allergic reactions vary from mild symptoms, caused by a broad range of food products, to very serious reactions caused by only one or a few products. These reactions can consist of headache, asthmatic complaints, eczema, diarrhea, vomit, oedema of mouth area (oral allergic syndrome) or in the worse case anaphylactic shock. Treatment involves a diet in which the allergic reaction causing food product is completely left out [26].

Exact data on the prevalence of chronic diseases in the Netherlands do not exist [28,29], but estimated figures indicate that the prevalence in the age group 15-24 years of IBD is 0.06% [30], chronic liver disease 0.9% [26], congenital digestive disorders 0.01% to 0.1% [11,26,30,31], coeliac disease 0.07% [27] and food allergy and food intolerance 0.3 to 7.5% in children and 2% in adults [32].

Research questions

Within the conceptual framework and elaborating on previous research, the following main research questions are formulated:

1. Do various chronic digestive disorders, i.e. IBD, chronic liver diseases, congenital digestive disorders, coeliac disease and food allergy, have a negative impact on the social position of adolescents and young adults? Which specific aspects of the social position are negatively affected by a chronic digestive disorder?
2. How can the burden of a chronic digestive disorder in adolescents and young adults be described, in terms of daily manifestations, compared to population controls?
3. Does burden of disease constitutes a risk factor for school performance and leisure activities of adolescents and young adults with chronic digestive disorders?

4. Does burden of disease constitutes a risk factor for the labour market position of young adult patients with chronic digestive disorders?
5. Do coping strategies differ between several diagnostic groups and population controls? Do they differ between various age groups?
6. Does the use of coping strategies contribute to the school performance and leisure activities of adolescents and young adults with chronic digestive disorders?

Study population

Data were obtained from 758 adolescents and young adults with chronic digestive disorders, classified into five disease categories: IBD (n= 305), chronic liver diseases (n=94), congenital disorders (n=137), food allergy (n=98) and coeliac disease (n=124). These patients were recruited via 25 medical specialists in 11 academic and specialized hospitals (see Appendix 1). To be eligible for inclusion, the following criteria were used: the diagnosis had to be stated by a certified medical specialist, patients had to be registered with this diagnosis for at least six months, age from 12 to 25, being non-institutionalized, being aware of diagnosis, not being terminally ill, being mentally capable to participate, and mastering the Dutch language sufficiently. The International Classification of Diseases, 10th revision (ICD-10) [33], was used in classifying patients into one of the five diagnostic categories. Extra patients with coeliac disease were recruited via a patient organization, using the same criteria (diagnosis had to be confirmed by at least one small-bowel biopsy). There was no selection on illness activity or severity of complaints and disability.

The study population also included a population-based control group. These controls were randomly recruited from the patient files of 173 general practitioners who were also the general practitioner of participating patients. In recruiting controls, the same criteria were used as for the recruitment of patients, except for being diagnosed within one of five diagnostic categories (see Appendix 2).

For the recruitment procedure, general practitioners were provided with a random set of three different letters of the alphabet on the basis of which they were requested to select three controls with surnames starting with the

indicated letters and fitting the specified criteria. In this way, a representative control group was selected since it can be assumed that (almost) every inhabitant in the Netherlands is registered with a general practitioner.
To increase the response rate, non-respondents were reminded of the study up to three times. The final total response in patients was 57.1%, varying from 48.7% in chronic liver disease patients to 67.2% in the IBD group. The response rate in controls was 54.7%. The study was approved by all participating hospitals' ethical committees. All participants gave written informed consent.

Measurements

Data were collected by a postal survey (1998-1999) among the participants (see Appendix 2). After registration (informed consent), a structured questionnaire was sent out to patients and controls. To prevent the youngest participants from filling in all questions on aspects relating to labour participation, financial situation and sexuality, a less extended version was developed, leaving out some questions on these subjects. The distinction between younger and older participants, patients as well as controls, was made on the basis of financial autonomy; respondents who were not financially self-supporting (a paid job, study funding or benefits as income source) received the more restricted questionnaire. Furthermore, as not all participating physicians gave their permission for the entire survey (including questions on coping strategies) among their patients, a separate questionnaire was developed containing supplementary items on coping strategies . To facilitate the overview Appendix 2 includes just one questionnaire covering the items used in this study.

Several *background characteristics* were measured, including gender, age, socio-economic status and puberty status. Socio-economic status was indicated by the highest education of one of the parents or carers, assessed on a seven-point scale from (1) no or only primary education to (7) a completed university training. Puberty status was operationalized by the following physical characteristics: having had the first menstruation in the case of female subjects, and having a breaking voice in combination with axillary hair in male subjects (dichotomous: yes versus no). Puberty status was taken into account because chronic disorders can be accompanied by growth failure and delayed puberty [28,34,35], a factor that could play a role in several aspects of social position.

Social position was assessed by 24 aspects, relating to education, leisure activities, friendship, labour participation, financial situation, partnership and sexuality. *Education* was assessed by the following aspects: school absenteeism due to illness (number of whole weeks during total school time), failing classes (dichotomized: at least once versus never), final educational level, educational level during school period (seven-point scale as socio-economic status) and having a side-line job (dichotomized: having/not having a paid job for less than 12 hours per week). *Leisure activities* were assessed by two scales derived from the Netherlands Health Interview Survey [36]: going out (3 items, Cronbach's alpha 0.63) and undertaking cultural activities (four items, Cronbach's alpha 0.63). The scale going out consisted of the following items: going to the cinema, going to a disco or house party, and visiting a pub. The scale undertaking cultural activities included visiting a library, play or concert, visiting a museum, and reading books. All items were scored on a four-point scale. In order to facilitate interpretation, the scale scores were transposed to the same four-point format as the separate items. *Friendship* was assessed by one scale derived from the national survey Youth and Sex [37] consisting of two items: having friends and undertaking activities with friends (Cronbach's alpha 0.64).As both items were scored on a five-point scale, the scale score was also transposed to that format. *Labour participation* was assessed by several aspects: having a paid job (dichotomized: having/not having a paid job of at least 12 hours per week), number of months to get the first job, needing re-education in order to get a job (yes versus no), number of working hours per week, having a permanent job (yes versus no) and having a job of at least educational level (yes versus no). The *financial situation* was assessed by two aspects: getting benefits as main income source (yes versus no) and meeting difficulties in establishing financial commitments (dichotomized: at least once versus never), such as taking out an insurance or mortgage or another kind of loan. *Partnership* was assessed by three aspects. First, having a partner (yes versus no), to be completed only by respondents aged 18 years or older in order to be comparative with national statistics [38]. Second, dating, derived from the national survey Youth and Sex [37] (dichotomized: having dated with someone at least once versus never). The third aspect concerns self-confidence in dating, a scale derived from the same questionnaire [37]. This scale consists of six items, in which each item was scored on a four-point-scale (Cronbach's alpha 0.70). Finally, *sexuality* was assessed by four aspects derived from the national survey Youth and Sex [37]: first, experience with sex (dichotomized: having made love to someone at least once versus never), second, experience with sex compared with friends, scored on a five-point scale, third, contentment with sex life, scored on a ten-point scale, and fourth, feeling restricted in making love (dichotomized: feeling restricted regularly versus never or sometimes).

Burden of disease was operationalized by a list of measures based on medical literature, information from the involved physicians and relevant patient organizations. On the basis of these information sources, a substantial list of complaints and disabilities was formulated. In selecting disease burden measures for the final set, the emphasis was laid on daily tasks and challenges. In this manner, a set of eight disease burden measures was composed: physical complaints, disability in endurance, anxiety, depression, hospitalisation, frequency of daily medication intake, the need to adhere to a diet and frequency of nocturnal toilet use.
Physical complaints were assessed by a set of 23 complaints, for example abdominal pain, diarrhea, skin rash, fatigue and flatulence. All items were scored on a 3-point scale from (0) no trouble to (2) much trouble during the last four weeks. *Disability in endurance* was assessed by a scale derived from the Children Quality Of Life questionnaire (TACQOL) [39], consisting of 3 items (Cronbach's alpha 0.86). *Anxiety* and *depression* were measured by the Hospital Anxiety and Depression Scale (HADS) [40,41], both consisting of 7 items, scored on a 4-point scale (Cronbach's alphas respectively 0.78 and 0.69). *Hospitalisation* was measured using a scale existing of two items: 'number of times hospital admission' and 'number of times undergoing surgery' (Cronbach's alpha 0.68). *Use of medication* was assessed by the number of times of medication intake per day. The *need to diet adherence* was measured on a 4-point scale, from (0) no diet at all ("I can eat and drink what I want") to (3) strict diet adherence ("I have to adhere to a real diet"). Finally, *toilet use* refers to urge to go to the toilet at night. This measure was assessed on a 5-point scale, ranging from (0) never to (4) always.

Coping was assessed by the Coping Inventory for Stressful Situations (CISS-21-item version) [42,43]. The CISS-21 is a theoretically derived, validated measurement instrument. It consists of 21 items measuring three generic coping strategies: emotion oriented coping (e.g. “Become very upset”), task oriented coping (e.g. “Work to understand the situation”) and avoidance coping (e.g. “Visit a friend”). Each scale consists of 7 items, randomly distributed within the form to control for order effects. Respondents were asked to rate each item on a five-point scale ranging from (1) “not at all” to (5) “very much”. Scale scores were transposed to the same format (five-point scale) as the item scores. As in this study a younger target group is involved than the CISS-21 primarily was developed for (as from the age of 16 years), it will be investigated whether this measurement instrument is also suitable for application to adolescents aged 12 years and older, that is, whether the theoretically assumed three-factor structure of the CISS-21 is being maintained when applied to adolescents.

Outline of this thesis

The first research question - whether having a chronic digestive disorder has a negative influence on the social position of adolescents and young adults - is described in chapter two. Chapter three deals with the impact of burden of disease on school and leisure activities of adolescents and young adults with various digestive disorders. In addition, a description of burden of disease in the several diagnostic groups in comparison with the control group is given. Chapter four aims to look further at labour participation. In this chapter the labour market position of adolescents and young adults with various chronic digestive disorders is described in comparison with healthy peers. Furthermore, it is investigated whether labour market participation is dependent on disease burden. In chapter five, because of application to a younger target group than where it originally was developed for, the factor structure of the Coping Inventory for Stressful Situations (CISS-21) is investigated. Subsequently, in chapter six, coping strategies are compared across adolescents and young adults with several chronic digestive disorders and healthy peers. This chapter also takes into account the impact of coping on school performance and leisure activities. Chapter seven discusses the results and limitations of this study and gives recommendations for patients and physicians and also for future research. Finally, a summary of this study is given in chapter eight.

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2 Social position of adolescents with chronic digestive disorders

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Abstract

Objective To investigate the consequences of having a chronic digestive disorder on the social position of adolescents.

Methods Five diagnostic groups, including inflammatory bowel disease (IBD), chronic liver diseases, congenital digestive disorders, coeliac disease and food allergy (total n=758, ages 12 to 25 years) were each compared with a population-based control group in a multicentre study using a cross-sectional design. Social position was assessed by a mailed questionnaire measuring 24 aspects, categorized as education, leisure activities, friendship, labour participation, financial situation, partnership and sexuality.

Results Eight aspects of social position were found to be affected negatively by one or more chronic digestive diseases: absence from school due to illness, going out, having a paid job, needing re-education in order to get a job, getting benefits as main income source, encountering bottlenecks in establishing financial commitments, having self-confidence in making a pass at someone, and restrictions in making love. Adolescents with chronic liver disease and IBD were found to experience more restrictions in social position. Adolescents with food allergy and congenital digestive disorders appear to experience some restrictions , but to a lesser degree, and adolescents with coeliac disease do not appear to have any problems regarding social position compared with controls.

Conclusion The social position of adolescents is affected negatively by having a chronic digestive disease, in particular chronic liver disease and IBD. Negative consequences occur in education, leisure activities, labour participation, financial situation, partnership and sexuality.

Keywords: inflammatory bowel disease, chronic liver disease, congenital digestive disorder, coeliac disease, food allergy, social position, adolescents

Introduction

Chronic digestive disorders are accompanied by complaints and circumstances, such as pain, fatigue, growth arrears, diet commitments, decreased physical condition, flatulency and incontinence, that can have negative social consequences. These negative consequences are especially important in adolescence as in this period choices are being made that are directive for future life.

Scientific knowledge of the social position of patients with chronic digestive disorders is limited and mostly involves adult patients in non-controlled designs [1-4]. In general, these studies show that difficulties are met in particular in the domain of labour participation, financial matters, social contacts and relationships. Adult patients with chronic digestive disorders seem to emphasize social restrictions more than physical restrictions.

Unlike previous studies, we wished to investigate the social position of adolescents between the ages of 12 and 25 years suffering from inflammatory bowel disease (IBD), chronic liver diseases, congenital digestive disorders, coeliac disease or food allergy in comparison with a control group. Exact data indicating the prevalence of these diseases in the Netherlands do not exist [5,6], but the estimated prevalence in the age group 15-24 years of IBD is 0.06% [7], chronic liver disease 0.9% [8], congenital digestive disorders 0.01% to 0.1% [1,7-9], coeliac disease 0.07% [10] and food allergy 0.3 to 7.5% in children and 2% in adults [11].

The aim of this study was to determine whether having a chronic digestive disorder has a negative influence on the social position of adolescents in general, and to identify the specific aspects of social position affected negatively by having various chronic digestive disorders.

Methods

Subjects

Five diagnostic groups, including IBD, chronic liver diseases, congenital digestive disorders, coeliac disease and food allergy, were each compared with a population-based control group in a multicentre study. Patients were recruited via 25 medical specialists in 11 academic and specialized hospitals using the following criteria: being diagnosed within one of five diagnostic categories stated by a certified medical specialist, illness duration of at least 6 months, age from 12-25 years, being non-institutionalized, being aware of diagnosis, not being terminally ill, being mentally capable to participate, and mastering the Dutch language sufficiently. In classifying patients, the translation of the International Classification of Diseases, 10th revision (ICD-10) [12] was used. Extra patients with coeliac disease were recruited through a patient organization using the same criteria (diagnosis had to be confirmed by at least one small-bowel biopsy). There was no selection on illness activity or severity of complaints and disability.

In The Netherlands, (almost) every inhabitant is registered with a general practitioner, so controls were recruited randomly from the patient files of 173 general practitioners of participating patients. In recruiting controls the same criteria were used as for the recruitment of patients (except for being diagnosed within one of five of the diagnostic categories). General practitioners were provided with a random set of three different letters of the alphabet on the basis of which they were requested to select three controls with surnames starting with the indicated letters and fitting the specified criteria.

In order to realize an adequate response, subjects were reminded about the study up to three times.

The study was approved by all participating hospitals' ethical committees. All subjects gave written informed consent.

Measurement

Data were collected by a survey among the subjects.

Background variables

Next to gender and age, socio-economic status and puberty were measured as background variables. Socioeconomic status was indicated by the highest education of one of the parents or carers assessed on a seven-point scale from 1= no or only primary education to 7 = completed university training. Puberty was assessed by the following physical characteristics: having had the first menstruation in the case of female subjects, and the presence of a heavy voice in combination with axillary hair in male subjects.

Social position

Social position was assessed by 24 aspects relating to education, leisure activities, friendship, labour participation, financial situation, partnership and sexuality.
Education was assessed by five aspects: (1) absence due to illness (number of whole weeks during total schooltime), (2) failing classes (dichotomized: at least once v. never), (3) final educational level, (4) educational level during school period (seven-point scale), and (5) having a side-line job (having/not having a paid job for < 12 h/week).

Leisure activities were assessed by two scales derived from the Netherlands Health Interview Survey [13]: (1) going out (3 items, Cronbach's alpha 0.63) and (2) undertaking cultural activities (four items, Cronbach's alpha 0.63). The scale 'going out' consisted of the following items: going to the cinema, going to a disco or house party, and visiting a pub; the scale 'undertaking cultural activities' was assessed by the following items: visiting a library, play or concert, visiting a museum, and reading books. All items were scored on a four-point scale. In order to facilitate interpretation, the scale scores were transposed to the same format (1-4).

Friendship was assessed by one scale derived from the national survey Youth and Sex [14] consisting of two items: having friends and undertaking activities with friends (Cronbach's alpha 0.64). As both items were scored on a five-point scale, the scale score was transposed to the same format to facilitate interpretation.

Labour participation was assessed by six aspects: (1) having a paid job (having/not having a paid job of at least 12 h/week), (2) number of months to get the first job, (3) needing re-education in order to get a job (yes/no), (4) number of working hours a week, (5) having a permanent job (yes/no), and (6) having a job of at least educational level (yes/no).

The financial situation was assessed by two aspects: (1) getting benefits as main income source (yes/no) and (2) meeting difficulties in establishing financial commitments (dichotomized: at least once v. never), such as in taking out an insurance or mortgage or another kind of loan.

Partnership was assessed by three aspects: (1) having a partner (yes/no), to be completed only by respondents aged ≥ 18 years in order to be comparative with national statistics [15]; (2) making a pass at someone, derived from the national survey Youth and Sex [14] (dichotomized: having made a pass at someone at least once v. never); and (3) self-confidence in making a pass at someone, derived from the same questionnaire [14], consisting of a six-item scale (Cronbach's alpha 0.70), in which each item was scored on a four-point-scale.

Sexuality was assessed by four aspects, all derived from the national survey Youth and Sx [14]: (1) experience with sex (dichotomized: having made love to someone at least once v. never), to be completed only by respondents being financially self-supporting so that younger respondents were prevented from filling in this question; (2) experience with sex compared with friends, scored on a five-point scale; (3) contentment with sex life, scored on a ten-point scale; and (4) feeling restricted in making love (dichotomized: feeling restricted regularly v. never or sometimes).

Statistical analysis

To describe the sample, analysis of variance (ANOVA) was applied, using Scheffé's (homogeneous groups) or Tamhane's T2 (non-homogeneous groups) procedure for comparing means and the Chi-squared test in comparing percentages (two-tailed significance level of 0.01).

In order to test differences with regard to aspects of social position between diagnostic groups and the control group, ANOVA (continuous variables) or the logistic regression procedure (dichotomous variables) was performed (one-tailed significance level of 0.01). Additionally, after the overall test had shown significance, the simple contrast method was used to compare each diagnostic group with the control group (reference category). The simple contrast method allows for comparing each category of the predictor variable (except the reference category) with the reference category in one analysis. In these procedures, age, gender and socioeconomic status were added as covariates (in logistic regression procedure in a separate block) to control for their effects. These three background variables appeared to differ significantly between groups (see Description of the sample below), while being associated with most of the outcome measures.

Results

Description of the sample

The sample consisted of 758 patients, suffering from IBD (n=305), or a chronic liver disease (n=94), or a congenital digestive disorder (n=137), or coeliac disease (n=124) or food allergy (n=98). The mean response was 57.1%, varying from 48.7% in adolescents with chronic liver diseases to 67.2% in adolescents with IBD. The sample also included 306 controls with a response rate of 54.7%.

Table 1 summerizes the characteristics of each diagnostic and control group. The mean age varied from 17.5 years to 20.0 years in the different groups, the IBD-group being significantly older than the control group. Among the diagnostic groups, no significant differences were found. The percentage of female subjects varied from 47% to 69%. No significant differences were found between diagnostic groups and the control group; differences were only found among three diagnostic groups. The mean score on socioeconomic status varied from 3.9 to 4.8. None of the diagnostic groups differed significantly from the control group; differences existed only among diagnostic groups. The percentage of participants that had not reached puberty varied from 9% to 19%, showing no significant differences between the diagnostic groups and control group or between the diagnostic groups.

Representativeness of the control group

In order to verify the representativeness of the control group, three aspects were compared with available national statistics of the Dutch population between the ages of 12 and 25 years. National statistics on educational level [15] indicate that 4.8% had no education or primary school, 74.7% had secundary education and 20.5% had higher education. In our control group, these figures are, respectively, 0.9%, 72.7% and 26.9%. With respect to failing classes, 32.5% of the controls who failed at least once (Table 2) seems a high percentage. However, available national statitistics on this aspect [15] indicate that in three different grades of secundary schools, 23%, 42% and 31% fail classes. These percentages include pupils and students who fail a second time, but they do not cover the total school period as in our study. A third aspect which was suitable for comparison with national statistics involves partnership. National data on relationships [13] point out that 63% of the female population between the ages of 18 and 25 years report having a partner; in our control group, 61% of the females in the same age group reported having a partner. On the basis of these data, the control group was considered representative for the general population.

Table 1 Characteristics of patients and controls

	I Inflammatory bowel disease n=305	II Chronic liver disease n=94	III Congenital digestive disorders n=137	IV Coeliac disease n=124	V Food allergy n=98	Control group n=306	
Age (Mean,SD)	20.0(3.7)*	19.4 (4.0)	18.1 (3.8)	17.5 (3.7)	18.5 (3.8)	18.5 (3.9)	F(5)=11.13, p=.000
Gender (% women)	54.8	56.4	46.7$^{\#}$ IV,V	64.5$^{\#}$ III	69.4$^{\#}$ III	54.9	Chi^{2}(5)=15.88, p=.007
Socio-economic status (Mean, SD)	4.2 (1.7)$^{\#}$ IV	3.9 (2.0) $^{\#}$IV	4.3 (1.7)	4.8 (1.6)$^{\#}$ I, II	4.7 (1.6)	4.5 (1.6)	F(5)=4.65, p=.000
Puberty (% reached)	86.6	86.7	81.3	88.6	90.8	87.8	Chi^{2}(5)=5.54, ns

*p≤ .01 in comparison with control group $^{\#}$ p≤ .01 in comparison with indicated diagnostic group

Social position

Tables 2 and 3 display the mean scores and percentages on the outcome measures for each diagnostic group and the control group.

Education

One of the five aspects of education, number of weeks absence due to illness, was found to be affected by three chronic digestive diseases: adolescents with IBD, chronic liver disease and food allergy show a significantly higher number of weeks absence during their school period compared with controls (Table 2).

Leisure activities

One of two aspects, going out, was found to be affected by two chronic digestive diseases: adolescents with IBD and chronic liver disease report going out significantly less often in comparison with controls (Table 2). This means that they go less often to the cinema, discos or house parties, and pubs.

Friendship

The results in Table 2 show that none of the diagnostic groups differed significantly from the control group on this aspect.

Labour participation

Two out of six aspects of labour participation were found to be affected by one or more chronic digestive diseases: having a paid job and needing re-education (Table 3). Adolescents with IBD and chronic liver disease appear to have a paid job significantly less often than controls. Furthermore, adolescents with chronic liver disease report significantly more often the need for re-education in order to get a job compared with controls.

Financial situation

Both aspects of financial situation were found to be affected by having an chronic digestive disorder (Table 3). First, compared with controls, adolescents with IBD appear to be significantly more dependent on benefits as a main income source. Second, adolescents with chronic liver disease meet difficulties significantly more often in establishing financial commitments, such as being refused insurance, having to pay a higher insurance premium, or being refused a mortgage or other kind of loan.

Partnership

One out of three partnership aspects, self-confidence in making a pass at someone, was found to be affected by two chronic digestive diseases: chronic liver disease and food allergy. Both aspects were assessed in respondents not having a partner. Table 3 shows that adolescents with chronic liver disease and food allergy have significantly less self-confidence in making a pass at someone.

Sexual functioning

One out of the four sexual functioning aspects, regularly feeling restricted in making love, appeared to be affected by having a chronic digestive disease: compared with controls, significantly more adolescents with congenital digestive disorders feel restrictions in making love, i.e. feeling ashamed (Table 3).

Table 2 Social position of patients and controls

	Inflammatory bowel disease	Chronic liver disease	Congenital digestive disorders	Coeliac disease	Food allergy	Control group	
EDUCATION							
number of weeks absence due to illness (Mean, SD)	13.4 (21.0)*	7.5 (13.8)*	4.7 (12.0)	4.4 (13.2)	7.5 (19.9)*	1.6 (6.0)	F(5)=15.82, p=.000
failing classes (%)	42.4	40.0	34.8	24.4	32.7	32.5	ns
final educational level, range 1-7 (Mean, SD)[1]	3.6 (1.4)	2.9 (1.4)	3.4 (1.6)	3.9 (1.5)	4.1 (1.7)	3.9 (1.5)	F(5)=2.97, p=.007
educational level during schoolperiod, range 1-7 (Mean, SD)[2]	4.7 (1.5)	4.6 (1.7)	4.4 (1.6)	4.7 (1.3)	5.1 (1.2)	4.6 (1.4)	ns
having a sideline job (%)[3]	5.2	1.7	3.4	5.1	2.9	11.5	Chi^2(5)=13.83, p=.009
LEISURE ACTIVITIES							
going out, range 1-4 (Mean, SD)[4]	2.1 (0.7)*	1.9 (0.7)*	2.0 (0.7)	2.0 (0.7)	2.0 (0.6)	2.1 (0.7)	F(5)=3.16, p=.004
undertaking cultural activities, range 1-4 (Mean, SD)[4]	1.7 (0.5)	1.7 (0.5)	1.7 (0.5)	1.7 (0.5)	1.8 (0.5)	1.7 (0.5)	ns
FRIENDSHIP							
friendship, range 1-5 (Mean, SD)[5]	3.6 (1.0)	3.6 (0.9)	3.5 (1.0)	3.7 (0.8)	3.6 (0..9)	3.7 (0.8)	ns

* $p \leq .01$ in comparison with control group (after controlling for differences in age, gender and socioeconomic status)

[1] 1 = no education or primary school to 7=university, to be completed by respondents who had finished their education (n = 234)

[2] 1 = no education or primary school to 7=university, to be completed by respondents attending school/college at the time of this study (n = 784)

[3] to be completed by respondents attending school/college exclusive of those having a job of ≥12 h/week (they were considered as 'working'; a job of < 12 h/week was considered to be a sideline job) (n = 695)

[4] 1 = almost never to 4 = very often

[5] 1 = no friends and never undertaking activities with friends to 5 = more than 10 friends and undertaking activities with friends almost every day

Table 3 Social position of patients and controls

	Inflammatory bowel disease	Chronic liver disease	Congenital digestive disorders	Coeliac disease	Food allergy	Control group	
LABOUR PARTICIPATION							
having a paid job (%)[1]	68.0*	67.6*	72.0	71.9	63.4	77.5	Chi^2(5)=17.62, p=.002
number of months to get the first job (Mean, SD) [2]	2.6 (4.9)	4.8 (15.0)	2.1 (4.5)	1.1 (2.6)	1.7 (2.4)	2.8 (9.6)	ns
needing re-education (%)[1]	13.2	22.2*	13.9	12.5	0.0	4.4	Wald(1)=5.99, p=.007
number of working hours/week (Mean, SD)[2]	34.3 (7.2)	34.2 (7.2)	35.2 (6.5)	35.4 (6.9)	34.0 (5.6)	36.1 (5.2)	ns
having permanent job (%)[2]	78.4	76.0	72.2	82.6	69.2	82.6	ns
having job of at least education level (%)[2]	81.7	88.5	91.4	95.7	88.5	81.1	ns
FINANCIAL SITUATION							
getting benefits as main income source (%)[3]	13.6*	10.8	7.0	2.0	4.5	3.9	Chi^2(5)=3.62, p=.009
bottlenecks in establishing financial commitments(%)[4]	25.6	43.5*	25.0	22.2	11.8	15.9	Wald(1)=6.65, p=.005
PARTNERSHIP							
having a partner (%)[5]	49.1	42.2	40.8	56.7	55.4	53.3	ns
making a pass at someone (%)[6]	61.2	52.0	54.8	56.0	52.6	65.0	ns
self-confidence in making a pass at someone, range 1-4 (Mean, SD)[7]	2.2 (0.6)	2.1 (0.7)*	2.3 (0.5)	2.1 (0.6)	2.1 (0.6)*	2.3 (0.5)	F(5)=2.81, p=.008

Table 3 *continued*

	Inflammatory bowel disease	Chronic liver disease	Congenital digestive disorders	Coeliac disease	Food allergy	Control group	
SEXUALITY							
experience with sex (%)[3]	75.8	72.7	69.5	76.5	73.9	78.0	ns
experience compared with friends, range 1-5 (Mean, SD)[8]	2.7 (0.9)	2.7 (1.0)	2.7 (0.9)	2.8 (0.9)	2.8 (1.0)	2.8 (0.9)	ns
contentment with sex life, range 1-10 (Mean, SD)[9]	6.9 (2.5)	6.8 (2.3)	6.5 (2.3)	7.5 (2.0)	7.2 (2.4)	6.9 (2.2)	ns
regularly feeling restricted in making love (%)[10]	13.1	10.7	18.9*	0.0	19.4	4.5	Wald(1)=5.48, p=.010

* $p \leq .01$ in comparison with control group (after controlling for differences in age, gender and socioeconomic status)

[1] to be completed by respondents who had finished education (n = 234)

[2] to be completed by respondents with a paid job (≥12 working hours/ week) (n = 303)

[3] to be completed by respondents being financial independent, e.g. paid job, financial study support or benefits (n = 535)

[4] to be completed by respondents having made at least one financial commitment (n = 227)

[5] to be completed by respondents aged ≥18 years (n = 651)

[6] to be completed by respondents aged ≥15 years not having a partner (n = 498)

[7] 1 = no self-confidence to 4 = much self-confidence, to be completed by respondents aged ≥15 years not having a partner (n = 498)

[8] 1 = much less experience to 5 = much more experience, to be completed by all respondents (n = 1064)

[9] 1 = very discontented to 10 = very contented, to be completed by respondents who have had experience with sex (n = 403)

[10] to be completed by respondents who have had experience with sex (n = 403)

Discussion

In this study five diagnostic groups were each compared with a population-based control group with respect to social position. Results indicate that several aspects of social position of adolescents are affected negatively by having a chronic liver disease or IBD. These aspects include a higher absence from school due to illness, going out less often, getting a paid job less often, needing re-education more often in order to get a job, being dependent more often on benefits as a main income source, meeting difficulties in establishing financial commitments more often, and having less self-confidence in making a pass at someone. Thus, suffering from a chronic liver disease or IBD can have a serious impact on the social position of adolescents in daily life, now and in the future.

Chronic liver diseases can be considered as disorders that are accompanied by physical barriers, such as pain, fatigue and an unstable physical condition. In order to finish education succesfully, or to find and keep a suitable job, these patients have to put in extra effort. Having low energy levels and not being able to drink alcohol are possible explanations for not going out as often as adolescents without these disorders. Being a carrier of a sexual transmittable disease, such as viral hepatitis, makes it even more difficult to mix with other adolescents.

IBDs are accompanied by several physical barriers, so that extra effort is needed to live a life like those of healthy peers. In a study in adult Crohn's disease patients [2], it was stated that more effort was needed to reach the same educational level as the general population. Drossman et al. [3] also concluded that IBD patients were mostly impaired in work, recreation and in the psychosocial area of social interaction, even with only minor physical dysfunction. In a recent study in adult patients with IBD [16], it was found that all dimensions of the Health Related Quality Of Life (HRQOL), including the social dimension, were impaired during relapses of the disease.

The social position of adolescents being diagnosed with food allergy appeared to be affected, but to a lesser degree. In the domain of education, it appears that adolescents with food allergy report a higher absence from school due to illness compared with peers. Furthermore, results indicate that adolescents with food allergy have less self-confidence in making a pass at someone. Food allergy can be considered a disease that is controllable very well by following a diet in which the product causing the allergic reaction is left out. In general, when the prescribed diet is followed strictly, it is possible to live a normal life. However, dietary non-adherence can cause immediate allergic reactions, varying from very mild symptoms caused by a broad scale of food products to very serious symptoms following the intake of only one food product.

Being diagnosed with a congenital disorder appears to have few consequences on the position of adolescents compared with peers. Findings from a study on functional health after neonatal surgery [17] suggest that the impact of a congenital digestive disorder on the social position can largely be reduced by surgery. In the present study, one aspect in the domain of sexuality appeared to be affected: adolescents with a congenital disorder feel more restrictions in making love than adolescents without chronic digestive disorders. In the other domains of social position, no effects were found. In a study in adult patients with anorectal malformations [1], it was concluded that many patients feel restricted in (building) relationships. No restrictions were found regarding labour partipation and leisure activities compared with the general popuplation.

Finally, as appears from this study, being diagnosed with coeliac disease does not necessarily have to induce restrictions in the social position of adolescents. In the present study, no aspect appeared to be affected by coeliac disease. Coeliac disease is a disorder which can be controlled well when following a gluten-free diet. When this diet is adhered to, it is possible for patients to live a normal life. When this diet is not followed strictly, it does not have immediate physical consequenses. Although the diet requires a lot of creativity in replacing cereal products, it conclusively does not have social consequenses, as measured in this study.

In interpreting these results, some points of consideration have to be taken into account. First, although the included five diagnostic groups represent the majority of chronic digestive diseases, not every chronic digestive disease is represented. For example, chronic digestive disorders in cystic fibrosis were excluded because a study [18] on medical, psychological and social concequenses of CF was carried out in The Netherlands in the same period. Second, the fact that many patients were recruited by clinicians in academic centres may have led to selection bias. However, there is no indication that a selection was made of the more seriously ill patients, as the Dutch health care system is organized in such a manner that most adolescents, and especially younger children, with a chronic disease are treated and controlled in specialized centres. A third point of consideration involves the representativeness of participating controls. In order to verify wether the control group was representative for the Dutch population between the ages of 12 and 25 years, some data were compared with available national statistics. Although not every aspect was compared with national statistics (not every aspect was suitable for comparison), the control group was considered representative for the general population. Another limitation concerns the measurement of puberty. Puberty status was taken into account because of the assumption that chronic disorders can be accompanied with a delayed puberty [5], a factor that could play a role in several aspects of social position. Although not as strong as it could be, we judged puberty status from self-reports on some physical characteristics. Finally, because of the small numbers in subgroups, small effects could not be shown in this study.

When these considerations are taken into account, it can be concluded that being diagnosed with a chronic liver disease or IBD has consequences for the social position of adolescents. Apart from physical functioning, it is important to recognize this impact in assessing the health status, so that potential restrictions can be identified by clinicians, and adolescents can be supported in the prevention of social restrictions. In order to provide concrete points of application for prevention and support, further research is needed into how these adolescents cope with their diseases and what other factors, such as illness characteristics and personal and environmental characteristics, play a mediating role in experiencing social restrictions.

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3 School and leisure activities in adolescents and young adults with chronic digestive disorders: impact of burden of disease

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Abstract

First, burden of disease (i.e. manifestations of the disease in daily life) in adolescents and young adults with various chronic digestive disorders was compared with controls. After that, it was investigated whether burden of disease constitutes a risk factor for difficulties in school and leisure activities of adolescents and young adults with various digestive disorders. For this purpose, a multi-centre study was performed in five diagnostic groups (total n=758, ages 12 to 25), including inflammatory bowel diseases (IBD), chronic liver diseases, congenital disorders, coeliac disease and food allergy and a population based control group (n=306), using a self-report questionnaire. Especially adolescents and young adults with a chronic liver disease, IBD and food allergy were found to experience daily manifestations of their disease. Several indices, including depression, disability in endurance, medical treatment, need to diet adherence and toilet use, were identified as risk factors regarding school and leisure activities.

Keywords: burden of disease, chronic digestive disorders, adolescents and young adults, school and leisure activities

Introduction

Due to medical advances, chronic disease has replaced acute illness as the most serious issue in pediatric medicine[1, 2]. Besides the challenges of achieving optimal growth and development, adolescents with a chronic disease must learn to manage their disease [3]. Adolescence is an important period in which choices are being made that are directive for future life. Having a chronic disease adds specific tasks and challenges which must be met, like learning to comply with medical treatment [4, 5].

Suffering from a chronic digestive disorder means -to a certain extent- being burdened with diet commitments, fatigue, pain, growth failure, a decreased physical condition, hospital admission, surgery, use of medication, flatulence or incontinence. In a recent study in adult patients with an inflammatory bowel disease (IBD) [6], it was found that patients, even in remission, were more fatigued compared with healthy controls. This tiredness correlated negatively with quality of life.

The vast majority of research on the effect of chronic digestive disorders on the social position is directed at the adult population [6-11]. In the few studies in younger populations on hand, often a non-controlled design is used [12, 13]. Nevertheless, it is clear that a chronic digestive disorder also can have a negative influence on the performance in school and leisure activities of adolescents and young adults. In the authors' own study [14], it was found that in particular being diagnosed with a chronic liver disease or IBD can have consequences for school and leisure activities: in comparison with healthy peers these adolescents and young adults reported a higher school-absenteeism due to illness and less often going out. Patients with other chronic digestive disorders (i.e. food allergy and congenital digestive disorders) were found to experience some social restrictions as well but to a lesser degree, whereas coeliac disease did not appear to bring about suchlike difficulties compared with healthy controls.

Thus, being diagnosed with a chronic digestive disorder does not necessarily induces a worse performance in school and leisure activities. Variations as aforementioned probably can be explained by differences in the way digestive disorders manifest themselves; the burden of disease which must be met can be expected to vary between patients with various digestive disorders as well as within diagnostic groups.

More insight in the risk factors for the performance in school and leisure activities can be helpful for clinicians in supporting young patients for a more adequately prevention of social restrictions. The aim of the present study was twofold. First, to describe the burden of disease in various diagnostic groups (including IBD, chronic liver diseases, congenital disorders, food allergy and coeliac disease) in comparison with healthy controls. Second, to determine whether burden of disease constitutes a risk factor for difficulties in school and leisure activities of adolescents and young adults with various digestive disorders.

Methods

Sample

The sample included 758 adolescents and young adults classified into five disease categories: IBD (n= 305), chronic liver diseases (n=94), congenital disorders n=137), food allergy (n=98) and coeliac disease (n=124). Mean response was 57.1%, varying from 48.7% in chronic liver disease patients to 67.2% in the IBD group. Patients were recruited via 25 medical specialists in 11 academic and specialized hospitals using the following criteria: being diagnosed within one of the five diagnostic categories stated by a certified medical specialist, illness duration of at least six months, age from 12 to 25, being non-institutionalized, being aware of diagnosis, not being terminally ill, being mentally capable to participate and mastering the Dutch language sufficiently. In classifying patients into five diagnostic groups as mentioned before, the International Classification of Diseases, 10th revision (ICD-10) [15] was used. Extra patients with coeliac disease needed to be recruited through a patient organization, using the same criteria (diagnosis had to be confirmed by at least one small-bowel biopsy). There was no selection on illness activity or severity of complaints and disability.

The various patient groups were compared with a control group, including 306 healthy controls (response rate 54.7%). These controls were randomly recruited from the patient files of 173 general practitioners who were also the general practitioner of participating patients. In The Netherlands (almost) every inhabitant is registered with a general practitioner. In recruiting controls, the same criteria were used as for the recruitment of patients, except being diagnosed within one of five diagnostic categories. General practitioners were provided with a random set of three different letters of the alphabet on the basis of which they were requested to select three controls with surnames starting with the indicated letters and fitting the specified criteria.

In order to realize an adequate response, non-respondents were up to three times reminded of the study. The study was approved by all participating hospitals' ethical committees. All participants gave written informed consent.

Measurement

Data were collected by a mailed questionnaire. Four background variables were measured: gender, age, socio-economic status and puberty status. Socio-economic status was operationalized by the highest education of one of the parents or carers on a 7-point-scale, from (1) no education or only primary school to (7) a completed university training. Puberty status was assessed by physical characteristics: having had the first menstruation in case of female respondents and the presence of a heavy voice in combination with axillary hair in male respondents.

Five aspects of *school and leisure activities* were assessed [14]: school-absenteeism due to illness, educational level, going out, cultural activities and friendship. Firstly, school-absenteeism was measured by the number of whole weeks absence during the total school period. Educational level was assessed by the highest educational level at the moment of this study, on a 7-point-scale from (1) no education or only primary school to (7) university level. Going out and cultural activities were assessed by two scales derived from the Netherlands Health Interview Survey [16]. The scale 'going out' consisted of 3 items: going to the movies, going to a disco- or house party and visiting a pub (Cronbach's alpha .63). Undertaking cultural activities was assessed by 4 items: visiting a library, going to a play or concert, visiting a museum and reading books (Cronbach's alpha .63). All items were scored on a four-point-scale. In order to facilitate interpretation the scale scores were transposed to the same four-point format. Finally, friendship was assessed by one scale derived from the national survey Youth and Sex [17] consisting of two items: 'having friends' and 'undertaking activities with friends' (Cronbach's alpha .64). As both items were scored on a five-point-scale, the scale score was transposed to the same format to facilitate interpretation.

Burden of disease was quantified by a set of eight possible tasks and challenges patients with a chronic digestive disorder can be confronted with: physical complaints, anxiety, depression, disability in endurance, hospitalisation, use of medication, the need to adhere to a diet and toilet use. Physical complaints were assessed by a set of 23 complaints, for example abdominal pain, diarrhea, skin rash, fatigue and flatulence, based on literature and brochures of physicians and patients' associations. All items were scored on a 3-point-scale from (0) no trouble to (2) much trouble during the last four weeks. Anxiety and depression were measured by the

Hospital Anxiety and Depression Scale (HADS) [18, 19], both consisting of 7 items (Cronbach's alphas respectively .78 and .69), and scored on a 4-point scale. Disability in endurance was assessed by a scale derived from the Children Quality Of Life questionnaire (TACQOL) [20], consisting of 3 items (Cronbach's alpha .86). Hospitalisation was measured by a scale existing of two items: 'number of times hospital admission' and 'number of times undergoing surgery' (Cronbach's alpha .68). Daily use of medication was assessed by the number of times of medicine intake a day, at the moment of this study. The need to diet adherence was measured on a 4-point-scale, from (0) no diet at all ("I can eat and drink what I want") to (3) strict diet adherence ("necessary"). Finally, toilet use refers to going to the toilet at night because of bowel movement/defecation or stoma care. This measure was assessed on a 5-point-scale, ranging from (0) never to (4) always.

Statistical analyses

Socio-demographic descriptives of the sample were analysed with analyses of variance or Chi-square tests to test differences between groups. In analysis of variance, Scheffé- (homogeneous groups) or Tamhane's T2- (non-homogeneous groups) procedure was used.

To describe the burden of disease in adolescents and young adults with various chronic digestive disorders in comparison with controls (first research question), analysis of variance was applied (one tailed significance level of .01). In this procedure age, gender and socio-economic status were added as covariates. These three background variables appeared to differ significantly between groups (see results section), while being associated with most of the outcome measures. After that, to investigate the relationship between burden of disease and school and leisure activities (second research question), two statistical procedures were performed. First, Pearson correlation coefficients were computed between burden of disease measures and aspects of school and leisure activities in the patients group (two tailed significance level of .01). Second, multiple regression analyses were performed on each aspect of school and leisure activities. These regression analyses were carried out in three steps using the enter method in all steps. In the first step control variables were entered into the regression equation (age, gender and socio-economic status); in the second step four dummies of diagnostic groups were entered with one diagnostic group as reference group; and in the final step, the eight burden of disease measures were entered into the equation.

Results

In Table 1 the characteristics of each diagnostic group and the control group are summarized. The *mean age* in the different groups varied from 17.5 years to 20.0 years, the IBD group being significantly older than the control group. No significant differences were found among the diagnostic groups. The *percentage female respondents* varied from 47% to 69% in the various groups. No significant differences were found between diagnostic groups and control group; differences were only found among three diagnostic groups, the congenital disorders group showing less females than the food allergy and coeliac disease groups. The mean score on *socio-economic status* varied from 3.9 to 4.8. None of the diagnostic groups differed significantly from the control group, differences only existed among three diagnostic groups, with lower scores in the IBD and chronic liver disease groups compared with the coeliac disease group. The percentage participants that had not reached *puberty status* varied from 9% to 19%, showing neither significant differences between the diagnostic groups and control group, nor among the diagnostic groups.

Table 1 Characteristics of patients and controls

	I Inflammatory bowel disease n=305	II Chronic liver disease n=94	III Congenital digestive disorders n=137	IV Food allergy n=98	V Coeliac disease n=124	Control group n=306	
Age (Mean,SD)	20.0(3.7)*	19.4 (4.0)	18.1 (3.8)	18.5 (3.8)	17.5 (3.7)	18.5 (3.9)	F(5,1058)=11.13, p=.000
Gender (% women)	54.8	56.4	46.7$^{\#}$ IV,V	69.4$^{\#}$ III	64.5$^{\#}$ III	54.9	Chi^{2}(5)=15.88, p=.007
Socio-economic status (Mean, SD)	4.2 (1.7)$^{\#}$ V	3.9 (2.0) $^{\#}$V	4.3 (1.7)	4.7 (1.6)	4.8 (1.6) $^{\#}$ I, II	4.5 (1.6)	F(5, 1025)=4.65, p=.000
Puberty status (% reached)	86.6	86.7	81.3	90.8	88.6	87.8	Chi^{2}(5)=5.54, ns

*p ≤.01 in comparison with control group

$^{\#}$ p ≤.01 in comparison with indicated diagnostic group

Table 2 displays mean scores on burden of disease measures for each diagnostic group and control group. In general, respondents in all diagnostic groups were found to report significantly higher scores on one or more measures in comparison with controls. Especially, the chronic liver disease group and IBD group were found to experience additional tasks and challenges due to their disease, showing significantly higher scores on many indices compared with the control group. Both participants with a chronic liver disease and IBD experienced more physical complaints and more disability in endurance. Besides, they were hospitalised more frequently, used more medication and they had to watch their food intake more often than controls. Furthermore, patients with a chronic liver disease reported more anxiety and more depression. 'Toilet use' appeared to be the only measure on which the chronic liver patients were comparable to controls. This in contrast with the IBD group, the only diagnostic group in which toilet use was more reported. The food allergy group also appeared to experience more disease burden compared with the control group. This includes physical complaints, disability in endurance, hospitalisation, use of medication and, obviously, the need to diet adherence. In particular with regard to physical complaints, a remarkably high score was found in this diagnostic group. Compared with controls, patients with congenital digestive disorders and coeliac disease appeared to report some significantly higher scores as well. Both groups appeared to be hospitalised more frequently than the control group; respondents with congenital digestive disorders reported to use more medication, whereas the coeliac disease group evidently reported the need to diet adherence more frequently.

Table 2 Mean scores (SD) for eight burden of disease measures in patients and controls

	Inflammatory bowel disease n=305	Chronic liver disease n=94	Congenital digestive disorder n=137	Food allergy n=98	Coeliac disease n=124	Controls n=306	
Physical complaints (0-46)	8.3 (5.8)*	6.8 (5.7)*	4.9 (5.0)	10.5 (6.7)*	5.5 (4.4)	4.4 (3.4)	F(5,1016)=32.85, p=.000
Anxiety (0-21)	5.0 (3.8)	6.2 (4.4)*	4.5 (3.9)	5.1(3.9)	3.7 (3.2)	4.3 (3.0)	F(5,1010)=4.59, p=.000
Depression (0-21)	2.8 (2.9)	3.6 (3.5)*	2.4 (2.7)	2.6 (2.5)	2.0 (2.2)	2.6 (2.5)	F(5,1011)=2.20, p=.026
Disability in endurance (0-6)	2.3 (2.1)*	2.1 (2.1)*	1.3 (1.9)	1.9 (2.1)*	1.1 (1.6)	1.1 (1.4)	F(5,996)=14.40, p=.000
Hospitalisation (0-12)	2.7 (2.2)*	3.0 (2.6)*	4.3 (3.1)*	1.6 (1.6)*	1.6 (1.3)*	1.1 (1.4)	F(5,977)=48.08, p=.000
Use of medication (0-4)	2.4 (1.2)*	1.2 (1.3)*	0.5 (1.0)*	1.4 (1.1)*	0.4 (0.9)	0.2 (0.6)	F(5,987)=152.19, p=.000
Need to diet adherence (0-3)	0.8 (0.8)*	0.7 (0.8)*	0.5 (0.7)	2.0 (0.8)*	2.7 (0.8)*	0.4 (0.7)	F(5,1021)=213.33, p=.000
Toilet use (0-4)	0.9 (1.1)*	0.7 (0.9)	0.5 (0.7)	0.5 (0.7)	0.3 (0.5)	0.5 (0.7)	F(5,1019)=12.29, p=.000

* p ≤.01 (one-tailed) compared with controls, after controlling for differences in age, gender and socio-economic status

Pearson correlation coefficients between burden of disease indices and aspects of school and leisure activities are shown in Table 3. Although most correlations were weak, significant relationships were found between all school and leisure aspects on the one hand and one or more burden of disease measures on the other hand. Significant correlations were mostly found with respect to friendship, school-absenteeism and educational level. Going out and undertaking cultural activities were found to be negatively correlated with only one measure.

Table 4 shows the results of the multiple regression analyses of school and leisure aspects on background variables, diagnosis and burden of disease. With regard to *school-absenteeism*, the model explained 20% of the variance, of which the largest part was explained by disease burden. Disability in endurance, hospitalisation and the need to diet adherence were found to be significant predictors of school-absenteeism. In addition to burden of disease, it appeared that IBD showed a significant contribution to the model as well.

Second, the model explained 23% of the variance regarding *educational level.* Background variables, in particular age and socio-economic status accounted for the largest part of explained variance. Apart from these measures, the following burden of disease indices were found to be significant predictors of a lower educational level: depression, hospitalisation and toilet use.

With respect to *going out*, the regression model accounted for 12% of the variance, the largest part being explained by background variables, in particular age. However, burden of disease indices accounted for a small but significant part of the explained variance, with depression as a significant negative contributor in the regression model.

Regarding *cultural activities*, again 12% of the variance was found to be explained by the model, of which background variables accounted for 9% of the variance. Apart from these background variables, physical complaints and depression were identified as significant contributors, with physical complaints being a positive and depression a negative predictor of undertaking cultural activities.

Finally, with regard to *friendship*, the model only accounted for 7% of the variance, almost entirely explained by disease burden. Except age, depression and disability in endurance were indicated as significant predictors in the model, both being negatively related with friendship.

In sum, several burden of disease measures, including depression, disability in endurance, hospitalisation, need to diet adherence and toilet use, were identified as risk factors for difficulties in school and leisure activities, controlling for the medical diagnosis. Only physical complaints were found to be positively associated with more cultural activities. More feelings of depression appeared to be a predictor of a lower educational level, less going out, less cultural activities and less activities with friends. Second, experiencing more disability in endurance was associated with a higher school-absenteeism and less friendship activities. More hospitalisation was found to be a predictor of a higher school-absenteeism and a lower educational level. The need to diet adherence was associated with a higher school-absenteeism, and finally, more toilet use at night was associated with a lower educational level.

Table 3 Correlation[1] between burden of disease measures and school and leisure aspects in patients (n=758)

	School-absenteeism	Educational level	Going out	Cultural acitivities	Friendship
Physical complaints	0.180*	0.001	0.010	0.028	-0.123*
Anxiety	0.064	-0.071	0.003	-0.079	-0.143*
Depression	0.041	-0.156*	-0.102*	-0.178*	-0.229*
Disability in endurance	0.242*	-0.108*	-0.075	-0.021	-0.193*
Hospitalisation	0.285*	-0.134*	0.012	-0.022	-0.102*
Use of medication	0.243*	-0.066	-0.021	0.019	-0.087*
Need to diet adherence	0.009	0.085	-0.016	0.018	0.009
Toilet use	0.112*	-0.095*	0.013	0.012	-0.110*

[1] Pearson correlation coefficients
*= p≤.01 (two-tailed)

Table 4 Regression of school and leisure aspects on burden of disease measures in patients (n=758)

	School-absenteeism			Educational level			Going out			Cultural acitivities			Friendship		
	β	AR^2	Δp	β	AR^2	Δp	β	AR^2	Δp	β	AR^2	Δp	β	AR^2	Δp
Background variables:		.019	**		.173	**		.103	**		.090	**		.004	ns
Age	.077			.361**			.338**			-.082*			.089*		
Gender	.014			.013			.025			.200**			.019		
Socio-economic status	.041			.271**			.039			.208**			.045		
Diagnosis[1] :		.055	**		.185	*		.105	ns		.097	ns		-.001	ns
IBD	.212*			-.062			.102			-.016			.175		
Chronic liver disease	.054			-.009			-.004			.060			.103		
Congenital digestive disorder	-.047			-.054			.097			.077			.055		
Food allergy	.053			.011			.015			.082			.021		
Burden of disease:		.199	**		.225	**		.118	*		.119	**		.069	**
Physical complaints	.061			.088			.006			.138**			.026		
Anxiety	-.046			-.039			.070			-.015			.017		
Depression	-.040			-.150**			-.152**			-.172**			-.181**		
Disability in endurance	.166**			-.022			-.058			-.018			-.135**		
Hospitalisatiom	.332**			-.087*			.004			.009			-.068		
Use of medication	.044			-.049			-.026			.054			-.069		
Need to diet adherence	.123*			-.009			.053			-.034			.040		
Toilet use	-.041			-.106**			-.031			-.022			-.083		

[1] with coeliac disease as reference group

* p≤.05 ** p≤.01 (two-tailed)

Discussion

The first aim of this study was to describe the burden of disease in adolescents and young adults with various chronic digestive disorders in comparison with healthy controls. Compared with controls, results show that participants in all diagnostic groups scored higher on one or more measures of disease burden. In particular those with a chronic liver disease, IBD and food allergy were found to experience burden of disease with regard to several indices.

A chronic liver disease can be considered a threatening disorder: morbidity is high and there is the prospect or undergoing of a liver transplantation. In addition, a chronic liver disease is associated with a more restrictive life expectancy. Findings in our study show that, compared with healthy controls, chronic liver disease patients reported more disease burden with regard to almost every measured indicator. This includes depression and anxiety, both aspects only reported higher in the chronic liver disease group.

Suffering from an inflammatory bowel disease also means that additional tasks and challenges have to be met during the transition from adolescence to adulthood. Among other gastrointestinal symptoms, IBD is usually accompanied by diarrhea, abdominal pain, weight loss and anaemia [21]. In addition to these symptoms, adolescents may exhibit a growth failure and delayed puberty [21, 22]. In managing IBD, often medical and nutritional therapy, and sometimes surgery is necessary. Findings of the present study show that, compared with healthy controls, adolescents with IBD experience more physical complaints, more disability in endurance, have been more frequently hospitalised, use more often medication, have to adhere to a diet more strictly and have to use the toilet more often at night. In contrast with findings of Engstrom [23], participants in our study did not appear to experience more feelings of depression or anxiety than controls. According to Engstrom, depressive disorders are commonly encountered in children and adolescents with IBD. This can be explained by the character and nature of the symptoms, often socially embarrassing and hard to discuss [23]. A possible explanation for the different results can be related to age: the mean age in our IBD group was 20 years (range 12-24), whereas the mean age in the study of Engstrom was 12 years (range 7-16 years). Perhaps older adolescents are psychologically better adjusted to having an inflammatory bowel disease or are less tended to report on such kind of feelings.

Adolescents and young adults with food allergy also were found to report high scores on most of the measured burden of disease indices. Obviously, the need to diet adherence can be considered an important consequence of being diagnosed with food allergy. But, apart from diet adherence, results indicate that food allergy patients use medication more often, are hospitalised more frequently and experience more disability in endurance compared with peers. Furthermore, surprisingly, the highest mean score on physical complaints was reported in this diagnostic group. This is not fully understood. A possible explanation is that dietary non-adherence can cause immediate allergic reactions, for example as a consequence of the intake of only a little of a broad range of food products. In addition, food allergy is often associated with other allergies which, as a consequence, cause additional physical complaints.

With regard to the second objective of this study, to determine whether burden of disease constitutes a risk factor for difficulties in school and leisure activities in adolescents and young adults with chronic digestive disorders, several measures were identified as significant predictors for school and leisure aspects, after controlling for medical diagnosis and socio-demographic variables.

Surprisingly, experiencing more physical complaints appeared to be positively related to undertaking cultural activities. A possible explanation is that cultural activities, as measured in this study, can be considered relatively quiet activities, requiring less energy and endurance. Further analysis of the separate items (data not shown) showed that in particular reading books and visiting a library are activities that regularly or very often are being undertaken, in contrast with going to a play or concert or visiting a museum.

Opposite, several disease burden indices, were found to be risk factors for difficulties in one or more school and leisure aspects. Especially having feelings of depression appeared to be a predictor for many school and leisure activities in a negative way. However, only participants with a chronic liver disease reported to experience more feelings of depression compared with the control group. Second, experiencing more disability in endurance was associated with a higher school-absenteeism and less friendship activities. This means that energy is an important factor in performance in school and leisure activities. Third, hospitalisation appeared to be negatively associated with school-absenteeism and educational level. Hospitalisation was measured by a combination of the frequency of hospital admission and undergoing surgery, both consequences obviously relevant to adolescents and young adults with chronic digestive disorders. Finally, and less clearly understandable, the need to diet adherence was related to a higher school-absenteeism, and more toilet use at night was associated with a lower educational level. Probably, other interactions play a role in these relationships.

In considering these results, some methodological issues should be mentioned. A first point of attention involves the response of the research group, 57% in patients and 54% in controls. It appeared that in patients, respondents were on the average one year younger than non-respondents (respectively 19 and 20 years), and a higher percentage was female (respectively 57% en 48% females). The same pattern existed in the control group: the mean age in the respondents group was 18,5 years, compared with 20 years in non-respondents and 55% of the respondents was female in relation to 42% in the non-respondents group. In addition, to verify whether the control group was representative for the Dutch population between the ages of 12 and 25, data regarding educational level, failing classes and relationships were compared with national statistics (data not shown). With regard to these aspects, our controls were practically similar to the national statistics. In consequence, given a small deviation with regard to age and gender, the findings in our study can be considered rather representative.
Secondly, as the design of this study is cross sectional, causal conclusions cannot be drawn. For example, in the negative association between depression and going out, it can not be stated that depression is the cause of less frequently going out.
A third point of consideration involves the magnitude of the regression coefficients found in this study. Although they were generally small, they were consistently associated with rather distal outcome measures, like educational level and undertaking certain activities. These outcome measures involve complex events and behaviours which are usually influenced by many personal and environmental characteristics. Despite the complex nature of our outcome measures, the relationships with the several burden of disease indices were consistent.

Conclusions

Taking these considerations into account, it can be concluded that especially adolescents and young adults with a chronic liver disease, IBD and food allergy experience additional tasks or challenges with regard to burden of disease. Furthermore, apart from socio-demographic characteristics and type of digestive disorder, several burden of disease measures can be considered risk factors for school and leisure activities. Feelings of depression, disability in endurance, hospitalisation, need to diet adherence and toilet use were identified to relate negatively with one or more school and leisure activities. Recognition of the importance and attention for the occurrence of these problems by parents, teachers and physicians can be helpful in supporting adolescents and young adults with various digestive disorders for a more adequately prevention of social restrictions.

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4 Disease characteristics as determinants of the labour market position of adolescents and young adults with chronic digestive disorders

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Submitted

Abstract

Background Job prospects can be problematic for young patients with chronic digestive disorders.
Objectives (1) To compare labour participation and disease burden in young adult patients with several chronic digestive disorders with healthy controls, and (2) to determine whether labour participation depends on disease characteristics, such as type of diagnosis and burden of disease.
Subjects 622 patients, categorized in five diagnostic groups: IBD (n=274), chronic liver diseases (n=78), congenital digestive disorders (n=104), food allergy (n=77), coeliac disease (n=89), and a population-based control group (n=248), age 15-24 years.
Methods Labour participation and burden of disease (i.e. consequences of the disease in daily life) were assessed by a postal questionnaire.
Results Patients with IBD or chronic liver diseases were found to have limited job prospects. Patients with chronic liver diseases, IBD and food allergy reported more disease burden regarding several indicators compared with controls. Logistic regression analyses including background characteristics, revealed socio-economic status (educational level of parents) and toilet use as important determinants of employment. In addition, gender and medication intake were found to be most determinative for a full-time position.
Conclusions Patients with IBD or chronic liver diseases are less likely to participate on the labour market compared with controls. Besides, especially patients with IBD, chronic liver diseases and food allergy experience daily inconveniences due to their disorder. Apart from socio-economic status and gender, the extent of medication intake and toilet use are important determinants of a limited labour market position.

Keywords: inflammatory bowel disease, IBD; chronic liver disease; congenital digestive disorder; coeliac disease; food allergy; labour participation; burden of disease; adolescents and young adults

Introduction

Due to advances in medical knowledge and treatment possibilities, the number of children with a life-threatening or chronic illness reaching adulthood has enormously increased in the past decades. As a result, the interest in the influence of disease and treatment on the course of life of these patients has intensified [1]. Research on long term effects of having a chronic illness during the transition from adolescence to adulthood is relatively new, and, with regard to digestive disorders, often involves inflammatory bowel disease (IBD) patients [2-5]. Generally, these studies address the effects of IBD on the quality of life of children and adolescents, such as the impact on social functioning (family, friends), physical functioning (body complaints, motor functioning), and psychological functioning (depression, anxiety). So far, little is known about the influence of being diagnosed with a chronic digestive disorder during adolescence on job prospects. Most knowledge on labour market implications is available from studies in adult populations [6]. In general, the labour market position of people with a chronic disease can be characterized as problematic, with regard to getting a job as well as job continuation. Indications exist that young IBD patients also have to face difficulties in trying to enter the employment market [7-9]. Furthermore, a recent case control study [10] showed that work disability and sick leave are more prevalent in IBD-patients compared with controls, especially in younger patients. Also, in the authors' own study [11] in a younger target group, IBD patients and patients with chronic liver diseases appeared to have less employment prospects compared with population controls. Additionally, chronic liver disease patients reported more often the need for re-education in order to find a job.

A possible explanation for variations between and within several chronic digestive disorders regarding labour participation is the extent of burden of disease. According to Boonen et al. [10] the course of disease in IBD-patients can be considered an important factor of chronic work disability and sick leave. Correspondingly, some disease burden indicators, e.g. disability in endurance, medical treatment and diet adherence, were identified as risk factors for school and leisure activities of adolescent patients with chronic digestive disorders [Calsbeek, Rijken, Bekkers, Dekker & Van Berge Henegouwen, subm.].

In the present study, labour participation in several patient groups with chronic digestive disorders was first compared with population controls. A distinction was made between students (attending daytime classes) and non-students, as limited or no employment in non-student patients can be considered more problematic. Subsequently, burden of disease in non-student patients was compared with controls. Finally, it was investigated whether labour participation in non-student patients with chronic digestive disorders is dependent on disease characteristics such as type of diagnosis and disease burden. The present study is a sequel to a study reported previously [11].

Methods

Sample

The sample included 622 patients (age 15- 24), suffering from inflammatory bowel disease (IBD) (n=274), chronic liver diseases (n=78), congenital digestive disorders (n=104), food allergy (n=77) or coeliac disease (n=89). Subjects were recruited via 25 medical specialists in 11 academic and specialized hospitals, using the following criteria: being diagnosed within one of the five diagnostic categories stated by a certified medical specialist, illness duration of at least six months, age from 15 to 24, being non-institutionalized, being aware of diagnosis, not being terminally ill, being mentally capable to participate and mastering the Dutch language sufficiently. In classifying patients, the International Classification of Diseases, 10th revision (ICD-10) [12] was used. Extra patients with coeliac disease were recruited through a patient organization, using the same criteria (diagnosis had to be confirmed by at least one small-bowel biopsy). There was no selection on illness activity or severity of complaints and disability. Mean response was 55%, ranging from 47% in chronic liver disease patients and in patients with congenital digestive disorders, to 66% in the IBD group. The sample also included population controls (n=248, response rate 55%). Controls were randomly recruited from the patient files of 147 general practitioners of participating patients. In The Netherlands (almost) every inhabitant is registered with a general practitioner. Except for a diagnosis within one of five diagnostic categories, the same recruitment criteria were used as for patients. For the recruitment procedure, general practitioners were provided with a random set of three different letters of the alphabet on the basis of which they selected three controls with surnames starting with the indicated letters and fitting the specified criteria.

In order to increase the response, subjects were up to three times reminded of the study. The study was approved by all participating hospitals' ethical committees. All respondents gave written informed consent.

Measurement

Data were obtained by a postal survey. Gender, age, socio-economic status, age of diagnosis and co-morbidity were measured *as background variables*. Socio-economic status was operationalized by the highest education of one of the parents or carers on a 7-point-scale, ranging from (1) no education or primary school to (7) university training. Co-morbidity was dichotomized (yes versus no).

Labour participation was assessed by the number of hours being employed per week. According to national classifications [12,13], four categories were used: 0-11 hours, 12-19 hours, 20-34 hours and 35 hours or more. Following the common definition of labour participation [13,14] a working week of less than 12 hours was considered as not participating on the labour market. Therefore, the 0-11 category was interpreted as not having a paid job. Also, a working week of 35 hours or more was interpreted as having a full-time job, and both categories of 12-19 hours and 20-34 hours as having a part-time job. Subsequently, three dichotomous variables were composed: (1) having a paid job (as from 12 hours a week) versus not having a paid job (0-11 hours), (2) having a paid job as from 20 hours a week versus not having a paid job or a small part-time job (0-19 hours) and (3) having a full-time job (35 hours or more) versus not having a paid job or having a part-time job (0-34 hours). In order to interpret labour participation properly, pupils and students - those who reported to attend daytime classes, e.g. secondary school, high-school or vocational training - were excluded from further analyses.

Burden of disease was quantified by a set of eight measures: physical complaints, anxiety, depression, disability in endurance, hospitalisation, use of medication, the need to adhere to a diet and toilet use. Physical complaints was assessed by a set of 23 complaints, e.g. abdominal pain, diarrhea, skin rash, fatigue and flatulence, based on medical literature and brochures of physicians and patients' associations. All items were scored on a 3-point-scale from (0) no trouble to (2) much trouble during the last four weeks. Anxiety and depression were measured by the Hospital Anxiety and Depression Scale (HADS) [15,16]. Both measures consisted of 7 items (Cronbach's alphas respectively 0.79 and 0.72), and were scored on a 4-point scale. Disability in endurance was assessed by a scale derived from the Children Quality Of Life questionnaire (TACQOL) [17] consisting of 3 items (Cronbach's alpha 0.86). Hospitalisation was measured by a scale existing of two items: 'number of times hospital admission' and 'number of times undergoing surgery' (Cronbach's alpha 0.70), scored on 12-point scale. Daily use of medication was assessed by the number of times of medication intake per day, at the moment of the survey. The need to diet adherence was measured on a 4-point scale, from (0) no diet at all to (3) strict diet adherence. Finally, toilet use refers to urge to go to the toilet at night. This measure was assessed on a 5-point-scale, ranging from (0) never to (4) always.

Statistical analyses

Analyses of variance or Chi-square tests were used to test differences between groups with regard to the background characteristics. In analysis of variance, Scheffé or Tamphanes T2 procedure (respectively homogeneous groups and non homogeneous groups) were applied as post-hoc tests. Descriptive statistics of labour participation were computed in student- as well as in non-student- respondents. Subsequently, in non-student participants the several diagnostic groups were compared with the control group. For this purpose, logistic regression procedure was performed with age, gender and socio-economic status added as covariates. Next, mean scores on burden of disease measures were computed in the diagnostic groups and compared with the control group (non students), applying analyses of variance (with age, gender and socio-economic status as covariates).

Two pre-analyses were performed in non-student patients. First, relationships between burden of disease measures and labour participation were explored by applying bivariate logistic regression analyses. Second, Pearson correlation coefficients were computed between burden of disease measures in order to examine mutual correlations.

Finally, multivariate logistic regression analyses of labour participation on background characteristics and burden of disease measures were performed, again in non-student patients. In these analyses, a stepwise (forward) selection procedure was employed, to prevent important variables from exclusion from the model as a result of mutual correlations. The likelihood-ratio (LR) test was used for selecting variables from the model [18,19] (alpha level 0.05).

Results

In Table 1 the background characteristics are summarized. With regard to all characteristics, differences were found between several diagnostic groups. Furthermore, IBD patients were found to be significantly older than controls. The age of diagnosis and the duration of disease, obviously showed large variations between several diagnostic groups. Only the mean age of diagnosis regarding chronic liver diseases and food allergy appeared to be the same (between the ages of 11 and 12 years). Except for the food allergy group, approximately 30% of the patients reported comorbidity. Over 80% of the food allergy patients reported comorbidity (mainly other allergic diseases often associated with food allergy), which resulted in significant differences with the other diagnostic groups.

Approximately 40% of the sample (n=331) included non-students, varying from 25% in coeliac disease patients to 45% in the IBD group (Table 2a). Most respondents who reported not to be active on the labour market (0-11 hours) attended daytime classes. Also, except for IBD patients, relatively most of the respondents with a small part-time job (12-19 hours) were students. In the categories 20-34 hours and 35 hours or more, most respondents had finished their daytime education.

Looking more closely at the non-student group (Table 2b), relatively high percentages of patients with IBD, chronic liver disease and food allergy, not participating on the labour market (0-11 hours), were found. In addition, having a full-time job (35 working hours or more per week), was mostly found in patients with coeliac disease or congenital digestive disorders, and in controls. Controlling for age, gender and socio-economic status, patients with IBD and chronic liver diseases were found to differ negatively from the controls, in all categories of labour participation.

Table 1 Background characteristics of patients and controls

	I Inflammatory bowel disease n=274	II Chronic liver disease n=78	III Congenital digestive disorders n=104	IV Food allergy n=77	V Coeliac disease n=89	Control group n=248	
Socio-demographic characteristics of patients and controls (n=870)							
Age (Mean,SD)	20.8(3.1)*[#]V	20.7 (3.0)	19.8 (2.7)	19.9 (2.9)	19.3 (2.8)[#]I	19.7 (3.2)	F(5,864)=6.30, p=.000
Gender (% women)	56.2[#]IV	55.1	52.9[#] IV	74.0[#] I, III	65.2	56.0	Chi^2(5)=12.13, p=.033
Socio-economic status of the parents (Mean,SD)	4.2 (1.7)	3.8 (1.9)[#]V	4.4 (1.7)	4.8 (1.6)	4.8 (1.5)*II	4.4 (1.6)	F(5,837)=4.60, p=.000
Disease related characteristics of patients (n=622)							
Age of diagnosis (Mean, SD)	15.2 (4.4)[#] II,III,IV,V	11.5 (7.3)[#] I,III,V	0.2 (1.7)[#] I,II,IV,V	11.8 (7.5)[#]I,III,V	6.8 (6.5)[#] I,II,III,IV	-	F(4,600)=159.05, p=.000
Duration of disease (Mean, SD)	5.7 (3.8)[#] II,III,IV,V	9.3 (6.4)[#] I,III	19.5 (2.9)[#] I,II,IV,V	8.3 (6.0)[#] I,III,V	12.5 (6.0)[#] I,III,IV	-	F(4,600)=169.01, p=.000
Comorbidity (% yes)	29,4[#] IV	30.3[#] IV	32.0[#]IV	81.1[#] I,II,III,V	30.9[#]IV	-	Chi^2(4)=71.76, p=.000

*p≤.01 (two-tailed) in comparison with control group ; [#] p≤.01 (two-tailed) in comparison with indicated diagnostic group

Table 2a Labour participation in patients and controls, % (total n=851)

	Inflammatory bowel disease n=268	Chronic liver disease n=76	Congenital digestive disorders n=102	Food allergy n=76	Coeliac disease n=87	Control group n=242
Number of working hours per week						
In students[1] (n=520):						
0-11 (not participating on labour market)	50.7	53.9	55.9	56.6	67.8	59.1
12-19 (part-time job)	0.4	3.9	2.0	1.3	5.7	2.5
20-34 (part-time job)	2.6	3.9	0.0	2.6	1.1	2.5
≥35 (full-time job)	0.7	0.0	0.0	0.0	0.0	0.8
In non-students[2] (n=331):						
0-11 (not participating on labour market)	10.4	10.5	3.9	9.2	2.3	4.1
12-19 (part-time job)	1.5	0.0	1.0	0.0	0.0	0.0
20-34 (part-time job)	10.1	10.5	10.8	13.2	4.6	7.4
≥35 (full-time job)	23.5	17.1	26.5	17.1	18.4	23.6
TOTAL	100%	100%	100%	100%	100%	100%

[1] Attending daytime classes like secondary school, high-school or vocational training

[2] Including evening courses, part-time education (e.g. one educational day in two weeks) or dualistic education (combination of working and learning with a contract of employment)

Table 2b Labour participation in non-student patients and controls, % (n=331)

	Inflammatory bowel disease n=122	Chronic liver disease n=29	Congenital digestive disorder n=43	Food allergy n=30	Coeliac disease n=22	Control group n=85	Reference group (National statistics)[1] n=594,061
Number of working hours per week							
0-11 (not participating on labour market)[2]	23.0*	27.6*	9.3	23.3	9.1	11.8	9
12-19 (part-time job)	3.3	0.0	2.3	0.0	0.0	0.0	2
Cumulative percent 0-19 hours[3]	*26.3***	*27.6**	*11.6*	*23.3*	*9.1*	*11.8*	*11*
20-34 (part-time job)	22.1	27.6	25.6	33.3	18.2	21.2	21
Cumulative percent 0-34 hours	*48.4*	*55.2*	*37.2*	*56.6*	*27.3*	*33.0*	*32*
≥35 (full-time job)[4]	52.6*	44.8**	62.8	43.3	72.7	67.1	68
TOTAL	100%	100%	100%	100%	100%	100%	100%

* p≤.02 ** p ≤.01 (one -tailed) in comparison with control group, after controlling for age, gender and socio-economic status (of the parents)

[1] Statistics Netherlands [13,20] and Social and Cultural Planning Office of the Netherlands [14]

[2] test: having a paid job (≥12 hours) versus not working (0-11 hours): Chi^2(5)=11.69, p=.020

[3] test: working ≥ 20 hours versus not working or small part-time job (0-19 hours): Chi^2(5)=13.00, p=.012

[4] test: full-time working (≥35 hours) versus not working or part-time working (0-34 hours): Chi^2(5)=11.49, p=.021

In order to verify the representativeness of the control group concerning labour participation, percentages of non-student controls were compared with national statistics [13,14,20] (Table 2b). Apart from a slightly over-representation in the lowest category and under-representation in the 12-19 hours category, the percentages in the control group were almost the same as in the general population and can therefore be considered representative.

Table 3 shows the mean scores on burden of disease measures for each diagnostic group and control group (non-students). All diagnostic groups showed higher scores on at least one measure compared with the control group (after controlling for socio-demographic characteristics). Patients with chronic liver diseases and IBD were found to experience more physical complaints, more disability in endurance, were hospitalised more frequently, used more medication, had to watch their food intake more often and had more frequent nocturnal toilet use than controls. Furthermore, chronic liver disease patients reported more anxiety and depression. Food allergy patients also appeared to experience more physical complaints, disability in endurance, use of medication and, obviously, the need to diet adherence. A remarkably high score was found on physical complaints. Patients with coeliac disease and congenital digestive disorders were found to report significantly higher scores regarding the need to diet adherence and hospitalisation, respectively.

Bivariate logistic regression analyses revealed several burden of disease measures to be negatively associated with labour participation: daily medication intake and nocturnal toilet use appeared to relate negatively to labour participation, regardless of the number of working hours per week. In addition, disability in endurance was found to be negatively associated with having a full-time job.

Table 3 Burden of disease measures (Mean scores, SD) in non-student patients and controls (n=344)

	Inflammatory bowel disease	Chronic liver disease	Congenital digestive disorder	Food allergy	Coeliac disease	Controls	
	n=126	n=30	n=45	n=24	n=31	n=88	
Physical complaints (0-46)	9.2 (6.6)**	7.3 (7.1)**	5.8 (5.5)	12.5 (7.5)**	6.4(4.8)	4.2 (3.7)	F(5,321)=11.42, p=.000
Anxiety (0-21)	5.8 (4.3)	7.7 (4.9)**	5.7 (4.8)	6.5 (4.3)	4.3 (4.0)	4.5 (3.7)	F(5,318)=3.42, p=.003
Depression (0-21)	3.6 (3.4)	4.9 (3.9)**	3.1 (3.1)	3.3 (2.7)	2.0 (2.1)	3.1 (3.2)	F(5,319)=2.19, p=.028
Disability in endurance (0-6)	2.4 (2.2)*	2.2 (2.0)**	1.8 (2.1)	2.3 (2.1)**	1.1 (1.3)	1.3 (1.5)	F(5,309)=3.76, p=.002
Hospitalisation (0-12)	2.6 (2.3)**	3.0 (2.6)**	4.0 (3.0)**	1.5 (1.4)	1.8 (1.3)	1.4 (1.6)	F(5,308)=9.27, p=.000
Use of medication (0-4)	2.4 (1.3)**	1.2 (1.4)**	0.6 (1.1)	1.3 (1.1)**	0.2 (0.4)	0.2 (0.6)	F(5,308)=49.34, p=.000
Need to diet adherence (0-3)	0.8 (0.8)**	0.7 (0.8)*	0.6 (0.8)	2.0 (0.7)**	2.7 (0.9)**	0.4 (0.7)	F(5,322)=41.24, p=.000
Toilet use (0-4)	1.1 (1.2)**	1.0 (1.1)**	0.7 (0.9)	0.7 (0.9)	0.1 (0.4)	0.5 (0.9)	F(5,321)=5.02, p=.000

* p≤.02 ** p ≤.01 (one-tailed) compared with controls, after controlling for age, gender and socio-economic status of the parents

Table 4 Relation[1] between burden of disease measures and labour participation in non-student patients (n=246)

	Having a paid job (as from 12 hours/week) versus not having a paid job		Having a paid job (as from 20 hours/week) versus not having a paid job or a small part-time job		Having a full-time job (≥35 hours/week) versus not having a paid job or a part-time job	
	OR	(95% C.I.)	OR	(95% C.I.)	OR	(95% C.I.)
Physical complaints	0.99	(0.94-1.03)	0.98	(0.94-1.03)	0.97	(0.94-1.01)
Anxiety	0.94	(0.88-1.01)	0.94	(0.88-1.01)	0.96	(0.91-1.02)
Depression	0.98	(0.89-1.07)	0.99	(0.91-1.09)	1.01	(0.93-1.09)
Disability in endurance	0.93	(0.80-1.08)	0.92	(0.79-1.06)	0.84**	(0.74-0.95)
Hospitalisation	0.91	(0.80-1.03)	0.90	(0.80-1.02)	0.90	(0.81-1.01)
Use of medication	0.78*	(0.62-0.98)	0.78*	(0.63-0.97)	0.74**	(0.61-0.89)
Need to diet adherence	1.04	(0.76-1.43)	1.02	(0.75-1.38)	0.91	(0.71-1.17)
Toilet use	0.70**	(0.53-0.91)	0.72*	(0.55-0.93)	0.76**	(0.60-0.96)

[1] bivariate logistic regression analyses

* p ≤.05 ** p ≤.01 (two-tailed)

In order to assess mutual variance, Pearson correlations coefficients were computed between burden of disease measures in non-student patients (data not shown). They ranged from 0.01 to 0.65, showing several mutual correlations. Strong correlations (r≥0.50) were found between anxiety and depression, physical complaints and disability in endurance, and between physical complaints and anxiety.

Finally, a stepwise multivariate logistic regression analysis of each labour participation measure on background characteristics and burden of disease measures was performed in non-student patients (Table 5). Socio-economic status and gender appeared to be the most important factors in the regression models. Apart from these background characteristics, toilet use and medication intake were found to be significant contributors as well.
Being employed as from 12 hours per week versus not having a job, as well as being employed as from 20 hours a week versus not having a job or a limited part-time job (up till 19 hours), were found to be negatively associated with socio-economic status. This means, with more highly educated parents, patients are less likely to find a job or to be employed as from 20 hours per week. Similarly, a more frequent toilet use during the night was found to relate negatively to both employment measures. Furthermore, male patients appeared to be more likely to have a full-time job than females. Also, medication intake was found to relate negatively to a full-time position.

Table 5 Multivariate regression[1] of labour participation on background characteristics and disease burden in non-student patients (n=246)

	Having a paid job (as from 12 hours/week) versus not having a paid job		Having a paid job (as from 20 hours/week) versus not having a paid job or a small part-time job		Having a full-time job (≥35 hours/week) versus not having a paid job or a part-time job	
	OR	(95% C.I.)	OR	(95% C.I.)	OR	(95% C.I.)
General characteristics:						
Age	-		-		-	
Gender (ref. female)	-		-		2.50	(1.29-4.84)**
Socio-economic status	0.70	(0.55-0.90)**	0.71	(0.56-0.90)**	-	
Disease related characteristics:						
Diagnosis (ref. coeliac disease):						
IBD	-		-		-	
Chronic liver disease	-		-		-	
Congenital digestive disorder	-		-		-	
Food allergy	-		-		-	
Comorbidity (ref. yes)	-		-		-	
Age of diagnosis	-					
Burden of disease:						
Physical complaints	-		-		-	
Anxiety	-		-		-	
Depression	-		-		-	
Disability in endurance	-		-		-	
Hospitalisation	-		-		-	
Use of medication	-		-		0.74	(0.59-0.92)**
Need to diet adherence	-		-		-	
Toilet use	0.67	(0.48-0.92)*	0.70	(0.51-0.95)*	-	

[1] forward stepwise * $p \leq .05$ ** $p \leq .01$ (two-tailed)

Discussion

Labour participation was studied in non-students, approximately 40% of our sample, as being unemployed or having a limited part-time job (up till 19 hours) in this group can be considered to have a more severe impact on social life. Focussing on this group, patients with IBD and chronic liver diseases were found to be unemployed or involved in a part-time job more often than healthy peers. Furthermore, in IBD and chronic liver disease patients, most burden of disease measures were found to be worse compared with the control group. In other words, patients with IBD and chronic liver diseases have to cope with more physical complaints, disability in endurance, hospitalisation, daily medication intake, need to diet adherence and nocturnal toilet use. Besides, chronic liver disease patients experience more anxiety and depression than healthy peers. In the food allergy group also high scores were found regarding several burden of disease measures. It must be noted that 80% in this diagnostic group reported comorbity, an exceptional high percentage, compared with approximately 30% in the other diagnostic groups. This can probably be explained by suffering from other allergies that often accompany food allergy, causing extra physical complaints. This is also likely to account for the relatively high score on physical complaints.

Bivariate regression analyses of labour participation and burden of disease revealed several burden of disease measures to be negatively associated with labour participation: medication intake, toilet use and disability in endurance. Disability in endurance appeared to be negatively related to full-time working, whereas medication intake and toilet use showed negative relationships with having a paid job as from 12 hours per week and 20 hours per week. Adding background characteristics to the regression models, medication intake and toilet use again emerged as significant risk factors. Therefore, the extent of (daily) medication intake and (nocturnal) toilet use can be considered important risk factors for a reduced labour market position of young adults with chronic digestive disorders. In interpreting these results, it must be mentioned that many disease burden measures correlated with one another. However, highest correlations were found between other disease burden indicators than toilet use and medication intake. Furthermore, because of multicollinearity, a stepwise regression procedure was chosen.

Apparently, daily hassles such as toilet use and medication intake are most determinative in labour participation. In this respect, our results supply a concrete basis for possible work adjustments, supporting previous recommendations in the direction of adjustments at the workplace among chronically ill workers [21].

The multivariate regression models also revealed socio-economic status (educational level of the parents) and gender as important factors related to labour participation: the higher parents are educated, the less likely patients were found to be employed (in jobs as from 12 hours or 20 hours per week). In addition, male patients appeared to be more likely to find a full-time job. This finding is a phenomenon which also occurs in the general population [20]. More surprizing is the negative relationship between the educational level of the parents and labour participation of the subjects. In the general population, as well as in chronically ill populations, this relationship is the opposite [6,13,14]. One exception is a study in (adult) IBD patients [10] in which higher educated patients were found to be more at risk to be chronic work disabled. It must be mentioned that socio-economic status usually refers to the educational level of the subjects and not, as in the present study, of the parents. Further analysis showed a significant correlation between the educational level of the parents and that of the (non- student) patients (Pearson r=0.23, p=0.001). However, when the educational level of the parents was replaced by that of the subjects in the regression model, the only change in the results was that the educational level of the patients did not contribute to the model. In other words, in this age group, the educational level of the parents clearly is an important determinant of a problematic labour market position. Possibly, this has to do with parental (over)protection. In general, maternal overprotection makes separation and independence more difficult for adolescents with chronic conditions [22, 23]. However, no literature was found on the hypothesised reasoning that higher educated parents are more protective, nor whether overprotection prevents young adults from participating on the labour market. Otherwise, as the educational level of the parents was found to be related to that of the patients, it is suggested that jobs requiring lower educational levels are easier to find and easier to get. More research on this differential effect is needed.

A first limitation of this study concerns the response rate, in both the patient and control group 55%. The mean age in the respondent patient group (20 years) appeared to be one year younger, compared with the non-respondent group (21 years). In addition, the respondent group consisted of more females (58%) than the non-respondent patients (50%). The same pattern was found in the control group, with equal mean ages and 56% females in respondents, compared with 43% in non-respondents. In addition, to verify whether the control group was representative for the general population, data regarding labour participation were compared with national statistics, resulting in a virtually similar distribution of the number of working hours per week. Therefore, apart from small deviations in age and gender, the findings in this study can be considered rather representative.

A second point of consideration involves the cross-sectional character of the study. Because of this, relationships between burden of disease and labour participation can theoretically be interpreted in both directions and therefore do not necessarily express causal conclusions. In addition, it would be worthwhile to conduct a follow-up study in the same IBD and chronic liver disease patients to gain more insight in the long-term effects.

Furthermore, the statistical analyses can use some reflection. Applying a stepwise selection procedure in regression analysis, implies that at any step in the procedure, the most important variable is selected on the basis of statistical terms (by producing the greatest change in log-likelihood relative to a model not containing the variable) [19]. In addition, our ‘alpha’ level of 0.05 is generally being considered as very stringent, making it possible to exclude important variables from the model [19]. This is in particular undesirable in studying relatively new outcomes, when many possible covariates are collected and screened for significant associations. In such studies, an alpha range of 0.15-0.20 is recommended [19]. Specifying an alpha of 0.15 in our analyses indeed resulted in an extra burden of disease indicator (namely ‘hospitalisation’). In the present study, an alpha of 0.05 was being maintained, resulting in two disease related risk factors for a reduced labour market position.

Finally, due to small numbers in the non-student subsample, only large effects could be shown. However, labour participation is a rather distal outcome measure, mediated by many personal and environmental factors. Nevertheless, in spite of the generally weak associations, some significant disease burden measures could be identified, which indicates that apart from diagnosis and background characteristics, disease burden in view of daily consequences does interfere with labour participation.

It can be concluded that young patients with IBD or chronic liver diseases are less likely to participate on the labour market compared with population controls. Except for socio-economic status and gender, medication intake and toilet use were identified as risk factors for a limited labour market position. Apart from the physical consequences of chronic digestive disorders, these additional effects deserve extra attention of phycisians.

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5 Factor structure of the Coping Inventory for Stressful Situations (CISS-21) in adolescents and young adults with chronic digestive disorders

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Abstract

The Coping Inventory for Stressful Situations-21 (CISS-21) is a valid and reliable measure of generic coping strategies in adult samples with various chronic diseases. Little is known about application to a younger target group. In the present study, confirmatory factor analysis on the CISS-21 was performed in adolescents and young adults with various chronic digestive disorders (total n=521) and healthy peers (n=274), aged 12-25 years. Results provide evidence for a satisfactory fit and the invariance of the three-factor model (task-oriented, emotion-oriented and avoidance coping scales), in several age groups as well as in patients and controls. In conclusion, the factor structure of the CISS-21 is being maintained when applied to younger adolescents with and without chronic digestive disorders. This makes it possible to compare the use of coping strategies by chronically ill adolescents and young adults of different ages, as well as between healthy and chronically ill adolescents and young adults.

Keywords: coping assessment, adolescents, young adults, chronic digestive disorders

Introduction

Coping can be considered a key-concept in health psychology and related disciplines, as coping helps to explain the impact of stressors on health and well-being [1]. Having a chronic disease can be experienced as stressful for the daily life of patients [2]. Also, being diagnosed with a chronic digestive disorder, in particular suffering from a chronic liver disease or IBD, can have a serious impact on the social position of adolescents and young adults in daily life [3]. It was found that negative consequences occur in education, leisure activities, labor participation, financial situation, partnership and sexuality. As coping possibly helps to explain this impact on the social position, we wished to investigate, and thus assess, the role of coping in adolescents and young adults with chronic digestive disorders.

Various coping instruments have been presented in the literature [1,2,4,5]. However, little attention has been paid to assessment issues, resulting in many coping instruments of poor validity and reliability [1]. According to De Ridder [1], it is imperative to elaborate on a theoretical rationale of coping dimensions to make progress in coping assessment.

The current measurement of coping in adolescents and young adults include both theoretically and empirically derived measuring instruments, whereby the majority has been empirically derived. In creating scales, researchers generally rely on exploratory factor analysis, often, however, generating different results across samples. However, in theoretically based measures, factors are tested through confirmatory factor analyses, supporting the hypothesized structure of coping [5].

Compas et al. [5] identified only two measuring instruments in which confirmatory factor analyses strongly supported the theoretical structure, i.e. the Children's Coping Strategies Checklist (CCSC), measuring general coping styles and tested in age samples of 7-13 years [4] and the Responses to Stress Questionnaire (RSQ), measuring coping in response to specific stressors, tested in age samples 11 to 19 years [6]. However, we searched for a generic measuring instrument that could be applied to adolescents and young adults in the age of 12 to 25 years, with and without various chronic digestive disorders, as we wished to compare the use of coping strategies by adolescents and young adults of different ages and health status. Therefore, the Coping Inventory for Stressful Situations-21 (CISS-21) [7,8] was chosen. The CISS-21 is a theoretically derived, generic measuring instrument that has proven to have good psychometric characteristics in adult samples (as from 16 years). In the present study, we examined whether the theoretically assumed factor structure of the CISS-21 is being maintained in younger adolescents, as from the age of 12 years.

The CISS-21 has been developed to assess three coping strategies: task-oriented, emotion-oriented and avoidance coping. Task-oriented coping refers to purposeful task-oriented efforts aimed at solving the problem, cognitively restructuring the problem or attempts to alter the situation. The emphasis is on the task or planning, and to attempts to solve the problem. Emotion-focused coping refers to emotional reactions that are self-oriented. The aim is to reduce stress. Reactions include emotional responses, self-preoccupation and fantasizing. Avoidance coping refers to activities and cognitive changes aimed at avoiding the stressful situation via distracting oneself with other situations or tasks or via social diversion as a means of alleviating stress [7]. The development of these three dimensions was grounded on consensus in the coping literature that there should be a basic distinction between emotion-focused and problem-focused coping, whereby emotion-focused coping strategies refer to a person orientation and problem-focused coping strategies to a task orientation [7]. On the basis of empirical research Endler and Parker [9] also suggested a third basic coping strategy, namely avoidance, which included either person-oriented (social diversion) and task-oriented (distraction) strategies.

As aforementioned, the CISS originally was developed for use in adults. The aim of this study was to investigate whether a valid and reliable measure of coping strategies could be adopted for use in a younger target group with and without chronic digestive disorders. For this purpose, the theoretically assumed three-factor structure was examined by means of confirmatory factor analysis.

Method

Study population

This study was carried out in 521 adolescents and young adults with chronic digestive disorders and 274 healthy controls. Digestive disorders were categorized in five diagnostic groups, including inflammatory bowel diseases (IBD) (n=190), chronic liver diseases (n=51), congenital digestive disorders (n=122), coeliac disease (n=61) and food allergy (n=97). Patients were recruited via their medical specialists in academic and specialized hospitals using the following criteria: being diagnosed within one of the five diagnostic categories stated by a certified medical specialist, illness duration of at least six months, age from 12 to 25, being non-institutionalized, being aware of diagnosis, not being terminally ill, being mentally capable to participate and mastering the Dutch language sufficiently. Extra patients with coeliac disease were recruited through a patient organization, using the same criteria (diagnosis had to be confirmed by at least one small-bowel biopsy). There was no selection on illness activity or severity of complaints and disability.

Healthy controls were randomly recruited from the patient files of general practitioners of participating patients. Except being diagnosed within one of the five previously named diagnostic categories, the same criteria were used as for the recruitment of patients. For the recruitment procedure, general practitioners were provided with a random set of three different letters of the alphabet on the basis of which they were requested to select three controls with surnames starting with the indicated letters and fitting the specified criteria.

The study was approved by all participating hospitals' ethical committees. All subjects gave written informed consent. Only after informed consent was received, a written questionnaire was sent to the respondents.

In Table 1 the characteristics of the research group are summarized. The mean age in the different groups, diagnostic groups and control group, varied from 18.4 years in adolescents and young adults with congenital digestive disorders to 22.1 years in the IBD group. The percentage female patients varied from 45.9% (congenital digestive disorders group) to 70.1% (food allergy group). The mean score on socio-economic status varied from 3.8 (chronic liver disease group) to 4.7 (coeliac disease group).

Table 1 Characteristics of the total sample, five separate diagnostic groups and control group (total n=795)

	I Inflammatory bowel disease	II Chronic liver disease	III Congenital digestive disorders	IV Coeliac disease	V Food allergy	Control group
	n=190	n=51	n=122	n=61	n=97	n=274
Age (Mean,SD)	22.1 (2.3)	22.0 (2.7)	18.4 (3.7)	18.4 (3.7)	18.4 (3.8)	18.5 (3.8)
% 12-14	0.5	2.0	21.3	18.0	21.6	17.9
% 15-17	4.2	3.9	18.0	21.3	17.5	26.6
% 18-20	17.4	23.5	24.6	23.0	27.8	19.0
% 21-24	77.9	70.6	36.1	37.7	33.0	36.5
Gender (% women)	58.9	51.0	45.9	67.2	70.1	55.5
Socio-economic status (Mean, SD)[1]	4.2 (1.7)	3.8 (2.0)	4.3 (1.7)	4.7 (1.6)	4.6 (1.6)	4.5 (1.6)

[1] Operationalized by the highest education of one of the parents or caregivers on a 7-point-scale: (1) no education or only primary school to (7) a completed university training.

CISS-21

The CISS-21 [7] is assumed to assess coping by three basic coping strategies: emotion-oriented, task-oriented and avoidance coping. We used the Dutch translation as proposed and validated by De Ridder and Maes [8]. Each scale of the CISS-21 consists of 7 items, randomly distributed within the form to control for order effects (see Appendix). Respondents were asked to rate each item on a five point scale ranging from (1) “not at all” to (5) “very much”.

Data analysis

In order to assess the fit of the theoretical supposed three-factor structure and the factor invariance of the CISS-21 in a younger target group and in adolescents and young adults with and without chronic digestive disorders, confirmatory factor analysis was applied, following the procedure of Rahim and Magner [10]. Confirmatory factor analysis is a powerful method of investigating the construct validity of a scale [5,10,11]. In the present study confirmatory analysis was performed with the LISREL 8 computer package [12].

In order to test the *three-factor structure*, a series of confirmatory factor analyses was performed: in 4 age groups (age 12-14, 15-17, 18-21 and 21-24 years); in patients (as 1 group); controls (1 group) and in 5 separate diagnostic groups (IBD, chronic liver diseases, congenital digestive disorders, coeliac disease and food allergy). In the measurement model, each of the 21 items was allowed to load on only its associated factor (which was identified a priori), and the factors (three coping strategies) were allowed to correlate. The covariance matrix for the 21 items was used for performing the analysis, and parameter estimates were made under the maximum-likelihood method.

Following Rahim and Magner [10], the extent to which the theoretical three-factor model fits the data in the different samples was assessed first. For this purpose, LISREL provides several measures, one of which is the *chi-square statistic*. Non-significant chi-squares suggest a satisfactory fit for the tested model; significant chi-squares an unsatisfactory fit. However, the chi-square is dependent on sample size, such that a large sample is likely to produce a significant result, even when there is a reasonable good fit to the data [13]. Except the chi-square, LISREL provides other statistics, such as the *goodness-of-fit index* (GFI), which is based on the chi-square. In general, this measure ranges between 0 and 1, with higher values indicating a better fit. Next to the GFI, the *normed-fit index* (NFI) was computed. This measure assesses the fit of the proposed model relative to that of the null model, and is independent of sample size. It is suggested that .90 is a minimum value for satisfactory fit when using both indices [13]. In addition, the *Root Mean Square Error of Approximation* (RMSEA) was used (12,14,15]. The RMSEA takes account of the error of approximation in the population and the precision of the fit measure itself. A close fit of the model is indicated by a value lower than of .05 [14] or .06 [16], whereas values up to .08 represent reasonable errors in the population [14]. According to Jöreskog and Sörbom [12], we used a test of RSMEA < .05 (90 percent confidence interval).

To provide additional reference points [10,13], indices were also computed for a null model, i.e no relationship between the observed variables, and a one-factor model, i.e. all observed variables refer to only one factor: an undifferentiated coping strategy.

However, models with many variables and degrees of freedom will almost always have significant chi-squares due to high levels of random error found in typical items and the many parameters that must be estimated [10]. To address this problem, several authors [17,18] proposed a method in which subsets of items within factors are summed to create aggregate variables. Using these parcels, it is appropriate to have two aggregate variables per factor when the number of measured items per factor is five to seven. Like Rahim and Magner [10], we followed this method, and thus formed two parcels for each factor, creating six parcels in total. In the formation of these parcels, the first four items and the second three items within a factor (see Appendix) were summed (divided by respectively 4 and 3 to obtain the same scale scores) to create two parcels per factor. So, instead of 21 variables (seven items per factor, three factors), we created 6 aggregate variables (two variables per factor, three factors). Next to analyses based on the 21 observed items, measures of fit were also computed on the basis of these parcels.

After testing the three-factor model, two multi group analyses were conducted in order to examine the *invariance of the three-factor model* across different groups: across age groups (1) and across patients, controls and different diagnostic groups (2). For each multi group analysis a covariance matrix was computed for each group. Then the following four models were estimated and compared sequentially on the basis of fit [10,11]: model 1, in which the pattern of factor loadings was held invariant across groups; model 2, the pattern of factor loadings and the factor loadings were held invariant across groups; model 3, the pattern of factor loadings, the factor loadings and the errors were held invariant across groups; and model 4, the most restrictive model, in which the pattern of factor loadings, the factor loadings, the errors as well as the variances and covariances were held invariant across groups. For each model, the covariance matrices for all groups were analyzed simultaneously. In performing these tests, the following statistics were computed: chi-square, GFI, NFI and RMSEA. As a test for equal factor loadings across groups, the chi-square of model 2 was compared with the chi-square of model 1. A non-significant difference means that the hypothesis of equal factor loadings cannot be rejected on a statistical basis. In the same way, model 3 was compared with model 2 and model 4 with model 3.

Finally, the *internal consistency* (Cronbach's alpha) of the constructed scales was computed in the several samples.

Results

Factor structure, separate items

Table 2 (columns left) shows indices that were used to assess the extent to which the proposed three-factor model fits the data in the four age samples. For comparative purposes, fit indices are also presented for a null model and a one-factor model.

Chi-square tests for the three-factor model were significant, suggesting an unsatisfactory fit. However, the chi-square is dependent on sample size: a large sample is likely to produce a significant result even when there is a reasonably good fit to the data (see Methods section). Applying the .90 criterion for GFI and NFI, the three-factor model only has a moderate fit: the GFI, ranges from .74 to .87, showing the best fit in the oldest sample and the worst fit in the youngest sample. The NFI also indicates a moderate fit, ranging from .59 in the youngest sample to .77 in the oldest sample. Applying the .05-.08 criterium for the RMSEA, results show a moderate fit of the three-factor model in two age-groups. However, significant p-tests indicate high errors of approximation.

After this, the three-factor model was tested in patients (as 1 group) and the control group and in the different diagnostic groups. The results are summarized in Table 3 (columns left). Again, significant chi-squares were found in combination with measures of fit ranging from .53 to .87, and significant RMSEA's. These results only indicate a moderate fit.

As expected, these results suggest that the theoretical three-factor model has only a moderate fit to the data. As pointed out before, parcels were introduced in the analyses instead of separate items.

Factor structure, parcels

Table 2 (columns right) presents goodness-of-fit indices for the three-factor model in the four age samples based on analyses with parcels. Only in the two oldest age groups significant chi-squares were found. The GFI was high, ranging from .97 to .99. Furthermore, the NFI also exceeds the .90 criterion in all age samples. The RMSEA ranged from zero to .10, only significant in the oldest age group. These results indicate that the three-factor model has a satisfactory fit in the four age samples.

The same analyses were conducted in patients (as one group) and in controls, and in the five different diagnostic groups (Table 3, columns right). GFI and NFI both exceeded the .90 criterion in all samples. In two samples the RMSEA was found significant. These results indicate a reasonable to satisfactory fit in the different samples.

Table 2 Measures of fit for separate age samples, based on analysis of 21 separate variables (columns left) and 6 parcels (columns right) of the CISS-21

Sample and model	**n**	**Chi²**	**df**	**GFI**	**NFI**	**RMSEA**	**Chi²**	**df**	**GFI**	**NFI**	**RMSEA**
Age 21-24 years	381										
null model		2,675*	210				809*	15			
1-factor model		1,813*	189	.60	.32	.15*	539*	9	.73	.33	.39*
3-factor model		606*	186	.87	.77	.08*	30*	6	.97	.96	.10*
Age 18-20 years	167										
null model		1,434*	210				380*	15			
1-factor model		913*	189	.58	.36	.15*	194*	9	.77	.49	.35*
3-factor model		445*	186	.80	.69	.09*	15*	6	.97	.96	.10 (ns)
Age 15-17 years	131										
null model		1,007*	210				302*	15			
1-factor model		653*	189	.60	.35	.14*	156*	9	.76	.48	.35*
3-factor model		303*	186	.84	.70	.07*	3	6	.99	.99	.00 (ns)
Age 12-14 years	103										
null model		923*	210				245*	15			
1-factor model		554*	189	.62	.40	.14*	95*	9	.78	.61	.31*
3-factor model		376*	186	.74	.59	.10*	10	6	.97	.96	.08 (ns)

Note: GFI=goodness-of-fit index; NFI=normed fit index; RMSEA=Root Mean Square Error of Approximation

- $p \leq .05$; ns = non significant

Table 3 Measures of fit for controls, patients (total group) and separate diagnostic groups, based on analysis of 21 separate variables (columns left) and 6 parcels (columns right)

Sample and model	n	Chi^2	df	GFI	NFI	RMSEA	Chi^2	df	GFI	NFI	RMSEA
Controls	269										
null model		1,941*	210				601*	15			
1-factor model		1,282*	189	.60	.34	.15*	371*	9	.73	.38	.39*
3-factor model		477*	186	.85	.75	.08*	22*	6	.97	.96	.10*
Patients (total group)											
null model	513	3,736*	210				1,197*	15			
1-factor model		2,279*	189	.59	.39	.15*	728*	9	.72	.39	.39*
3-factor model		760*	186	.87	.80	.08*	39*	6	.97	.97	.10 (ns)
IBD	190										
null model		1,512*	210				428*	15			
1-factor model		1,037*	189	.57	.31	.15*	285*	9	.72	.33	.40*
3-factor model		464*	186	.81	.69	.09*	27*	6	.96	.94	.14*
Chronic liver disease	51										
null model		618*	210				137*	15			
1-factor model		466*	189	.50	.25	.17*	79*	9	.71	.42	.40*
3-factor model		275*	186	.69	.55	.10*	7	6	.95	.95	.04 (ns)

Table 3 *continued*

Sample and model	**n**	**Chi^2**	**df**	**GFI**	**NFI**	**RMSEA**	**Chi^2**	**df**	**GFI**	**NFI**	**RMSEA**
Congenital disorders	115										
null model		1,071*	210				273*	15			
1-factor model		633*	189	.61	.41	.14*	106*	9	.79	.61	.31*
3-factor model		393*	186	.76	.63	.10*	11	6	.97	.96	.09 (ns)
Coeliac disease	60										
null model		711*	210				162*	15			
1-factor model		488*	189	.53	.31	.16*	99*	9	.71	.39	.41*
3-factor model		336*	186	.67	.53	.12*	7	6	.96	.95	.07 (ns)
Food allergy	97										
null model		1,258*	210				254*	15			
1-factor model		923*	189	.50	.27	.20*	162*	9	.69	.36	.42*
3-factor model		591*	186	.69	.53	.15*	10	6	.97	.96	.09 (ns)

Note: GFI=goodness-of-fit index; NFI=normed fit index; RMSEA=Root Mean Square Error of Approximation

Note: measures of fit in sample chronic liver diseases are based on preliminary solutions (model did not converge after X iterations)

* p.≤05; ns=not significant

Factor invariance

Two multi-group analyses were conducted to examine the invariance of the three-factor model of the CISS-21 across different samples: in age groups and in patient groups. In these analyses we continued using parcels. In each multi-group analysis 4 models were tested (see methods section). The first multi-group analysis was performed in age samples to test the invariance of the structure across age groups. Results of this analysis are presented in Table 4. Although the chi-square of each model was significant, the other indices (GFI, NFI and RMSEA) provided evidence that the first three models have a good fit: the goodness-of-fit index for each of these models was found .95 or higher, each normed fit index .94 or higher and each RMSEA lower than .05. Furthermore, as a test of the hypothesis of equal factor loadings across the groups, the chi-square of model 2 was compared with the chi-square of model 1, whereas the difference was found to be non-significant, meaning that the hypothesis of equal factor loadings cannot be rejected on a statistical basis. In the same manner, model 3 was compared with model 2 and model 4 with model 3, to test -respectively- the hypothesis of equal errors and equal variances. Table 4 shows that the hypotheses of equal pattern, loadings and errors cannot be rejected; the hypothesis of equal variances / covariances should be rejected. In other words, these findings not only indicate a satisfactory fit of the hypothesized three-factor structure, also the factor loadings and error terms appear to be practically identical in the different samples. Only the variance was found to be different in the various samples.

Table 4 Invariance analysis across four age samples

Model and sample	Chi^2-contribution	Chi^2 (total model)	df	Chi^2 (difference)	df	GFI (total model)	NFI	RMSEA
Null model		1,735*	60					
Equal factor pattern(1)		58*	24			.97	.97	.04(ns)
***12-14**	10(18%)							
***15-17**	3(5%)							
***18-20**	15(26%)							
***21-24**	30(51%)							
Equal factor pattern and laodings(2)		88*	42	30(ns)	18	.96	.95	.04(ns
***12-14**	15(17%)							
***15-17**	14(16%)							
***18-20**	21(24%)							
***21-24**	38(44%)							
Equal factorpattern, laodings and errors(3)		98*	60	10(ns)	18	.95	.94	.03(ns)
***12-14**	18(18%)							
***15-17**	16(16%)							
***18-20**	24(24%)							
***21-24**	41(42%)							
Equal factor pattern, loadings, errors, and variances / covariances(4)		1,648*	69	1,550*	9	.60	.05	.17*
***12-14**	213(13%)							
***15-17**	290(18%)							
***18-20**	355(22%)							
***21-24**	790(48%)							

Note: GFI=goodness-of-fit index; NFI=normed fit index; RMSEA=Root Mean Square Error of Approximation
p ≤.05; ns=not significant

Table 5 presents results of the second multi group analysis of the three-factor model: across patients and controls (two samples). Again, the chi-square of each model was significant, but the other indices provide evidence that the first three models have a good fit: the goodness-of-fit index for each of these models was found .97 or higher, each normed fit index .96 or higher and the RMSEA between .05 and .07. In the first model the RMSEA was found significant, however, with a score of .07 representing reasonable errors. Comparisons between the models provide evidence for the hypotheses of an equal pattern of factor loadings, equal factor loadings and invariant errors. The significant chi-square difference between model 4 and model 3 indicates, again, that the hypothesis of equal variances and covariances should be rejected.

The LISREL-model did not converge in testing the factor invariance across the five different diagnostic groups. Therefore, these analyses were only carried out in patients as one group, compared with the control group.

In general, these results provide strong support for the invariance of the three-factor model across age groups, as well as controls and patients, with respect to factor pattern, factor loadings and error terms.

Table 5 Invariance analysis across control sample and patient sample

Model and sample	**Chi^2-contribution**	**Chi^2 (total model)**	**df**	**Chi^2 (difference)**	**df**	**GFI (total model)**	**NFI**	**RMSEA**
Null model		1,797*	30					
Equal factor pattern(1)		61*	12			.97	.97	.07*
***patients**	39(64%)							
***controls**	22(36%)							
Equal factor pattern and laodings(2)		63*	18	2(ns)	6	.98	.96	.06(ns)
***patients**	40(63%)							
***controls**	23(37%)							
Equal factorpattern, laodings and errors(3)		73*	24	10(ns)	6	.97	.96	.05(ns)
***patients**	43(59%)							
***controls**	30(41%)							
Equal factor pattern, loadings, errors, and variances / covariances(4)		1,663*	27	1,590*	3	.66	.08	.28*
***patients**	1,096(66%)							
***controls**	567(34%)							

Note: GFI=goodness-of-fit index; NFI=normed fit index; RMSEA=Root Mean Square Error of Approximation

$p \leq .05$; ns=not significant

Scale construction

Although the previous results of confirmatory factor analysis provide evidence for a satisfactory fit of the total model, the factor loading of the first item 'Take some time off and get away from the situation' on the factor avoidance (see Appendix) was not significant in most of the samples (except for the age sample 18-20 years and the food allergy sample, $p \leq .01$). Therefore, we suggest to exclude this item from the scale 'avoidance' in samples of adolescents and young adults with chronic digestive disorders and in these age groups without chronic digestive disorders. In the so constructed scales, Cronbach's alpha's varied in the different samples from .79 to .86 in task-oriented coping (7 items), .79 to .86 in emotion-oriented coping (7 items) and from .78 to .85 in the avoidance coping scale (6 items).

Discussion

The aim of the present study was to determine whether the theoretically assumed three-factor structure of the CISS-21, a valid and reliable coping measurement instrument in adults, could be reproduced in adolescents and young adults aged 12 to 25 years, with and without various chronic digestive disorders. For this purpose, the fit of the three-factor model was investigated by means of confirmatory factor analysis. Results indicate that the three-factor structure of the CISS-21 has a satisfactory fit, in the younger age samples as well as in the different diagnostic groups and in the control group with healthy peers. In adult samples, the CISS-21 has proven to have good psychometric characteristics; apparently, in younger age samples, generic coping strategies can also be categorized as task-focused, emotion-focused and avoidance coping.

Except a satisfactory fit of the hypothesized three-factor structure of the CISS-21, general support was obtained for factor invariance across age samples and across patient and control samples. For this purpose, 4 models were successively compared in multi group analyses, running up from an equal factor pattern in model 1 to the most restrictive model 4, in which, apart from the factor pattern, the factor loadings and the error terms, the variance also was held invariant. Through the first three models, satisfactory results were obtained. This means that in age groups as well as in patients and controls, the factor pattern, the factor loadings and the error terms appeared to be practically identical in the various samples. These results strongly support the theoretical three-factor structure of the CISS-21 in a younger target group and in adolescents and young adults with chronic digestive disorders. Only the variance - added in the latter model to be held invariant across the samples - did not lead to satisfactory results.

Discrepancies in variance between groups possibly indicate that differences exist in the use of coping strategies between age groups and between patient and controls.

Some comments have to be made upon these results. First, in testing the factor structure, the measures of fit in the sample chronic liver diseases were based on preliminary solutions (the model did not converge). This is probably due to small numbers. However, exploratory factor analyses (data not shown) also demonstrated the theoretical model structure in this sample, supporting the preliminary solutions of the confirmatory factor analyses. In addition, with regard to the factor invariance tests, patients as a whole group were compared with controls first, resulting in evidence for a high extent of invariance across these samples. After that, multi-group analyses were carried out in the five different diagnostic groups. However, the LISREL-model did not converge in these analyses, probably as a consequence of the application of a complex model in relatively small subgroups. Again, results of exploratory factor analyses (data not shown) supported our hypothesis that the theoretical three-factor structure does exist across the separate diagnostic groups as well. Taking these comments into account, it can be concluded that the factor structure of the CISS-21 is being maintained in younger adolescents with and without various chronic digestive disorders.

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Appendix

Shortened version (21-items) Coping Inventory for Stressful Situations (CISS-21)

1. Take some time off and get away from the situation (A) *
2. Focus on the problem and see how I can solve it (T)
3. Blame myself for having gotten into this situation (E)
4. Treat myself to a favorite food or snack (A)
5. Feel anxious about not being able to cope (E)
6. Think about how I solved similar problems (T)
7. Visit a friend (A)
8. Determine a course of action and follow it (T)
9. Buy myself something (A)
10. Blame myself for being too emotional about the situation (E)
11. Work to understand the situation (T)
12. Become very upset (E)
13. Take corrective action immediately (T)
14. Blame myself for not knowing what to do (E)
15. Spend time with a special person (A)
16. Think about the event and learn from my mistakes (T)
17. Wish that I could change what had happened or how I felt (E)
18. Go out for a snack or meal (A)
19. Analyze my problem before reacting (T)
20. Focus on my general inadequacies (E)
21. Phone a friend (A)

T = Task-oriented coping
E = Emotion-oriented coping
A = Avoidance coping

* On the basis of our results it is suggested to exclude this item from the scale 'Avoidance coping' in samples of adolescents and young adults.

6 Coping in adolescents and young adults with chronic digestive disorders: Impact on school and leisure activities

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Abstract

Coping strategies were first compared across adolescents and young adults with several chronic digestive disorders and healthy peers. Subsequently, the impact of coping on performance in school and leisure activities was investigated. Participants were adolescents and young adults (age 12 to 25 years) suffering from inflammatory bowel diseases (IBD), chronic liver diseases, congenital diseases, coeliac disease or food allergy (total n=521) and healthy controls (n=274). Coping was assessed by the shortened version of the Coping Inventory for Stressful Situations (CISS-21), measuring task-oriented, emotion-oriented and avoidance coping strategies. Coping was found to be related to school and leisure activities of adolescents and young adults with chronic digestive disorders. Comparisons between several groups only revealed less use of coping strategies in the youngest adolescents. No differences were found among diagnostic groups, nor between diagnostic groups and control group.

Keywords: coping, adolescent, chronic digestive disorders, school, leisure

Introduction

Having a chronic disease can be considered a major life event regarding the initial shock of the diagnosis, or a sequence of daily hassles if one highlights the problems that a person has to deal with daily [1]. In the literature, major life events and daily hassles have been identified as two types of stressors [2]. In the course of the last decades, the point of view on the impact of these stressors on the individual's functioning have been shifted from the assumption of a greater impact of major life events (e.g. parental divorce) to the insight that daily hassles (e.g. failing at school or feeling ill) can be more stressful [2]. Having a chronic digestive disorder can be easily considered a sequence of daily hassles: physical complaints, use of medication, disability in endurance and the need to diet adherence [3], are aspects most patients have to deal with daily.

Most studies on coping with daily hassles use the transactional model of Lazarus & Folkman [4]as a frame of reference [2]. Central to this model is that people who are confronted with a stressor (e.g. consequences of a chronic disease) evaluate this stressor and the availability of coping resources. Such individual appraisal determines the ability to adapt. The most widely cited and adopted definition of coping is the one derived from this model: constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.

Research on child-adolescent coping, however, is characterized by a lack of clarity and consensus in conceptualizing coping [5]. In addition to recent conceptualizations of coping more explicitly concerning childhood and adolescence, many studies are based on the adult coping model of Lazarus and Folkman [5]. Consistent with this approach, we also adopted their definition of coping.

One could expect that adolescents and young adults with a chronic disease experience more stress than their peers. However, Boekaerts and Röder [2] did not find any empirical study to support this expectation. In the authors' own study [3] it was found that, in comparison with healthy peers, especially adolescents and young adults with inflammatory bowel diseases (IBD), chronic liver diseases or food allergy report more disease burden, including physical complaints, the need to diet adherence, disabilities in endurance and hospitalisation. Moreover, with regard to social position aspects, in particular adolescents and young adults with chronic liver diseases or IBD reported more difficulties in school and leisure activities, compared with healthy peers) [6].

Several studies[2, 7] show that controllable situations provoke more problem-focussed coping than avoidance, whereas less controllable or changeable situations are found to be more often handled with emotion-focussed coping or avoidance. Considering the nature of the daily consequences of several chronic digestive disorders, it can be hypothesized that differences exist in the use of coping strategies. For example, diseases like coeliac disease or food allergy can be considered predominantly controllable as both disorders can be controlled very well by following a diet: in case of coeliac disease a gluten-free diet has to be followed, whereas food allergy patients have to follow a diet in which the product causing the allergic reaction is left out. In general, when the prescribed diets are followed strictly, it is possible for patients to live a normal life. Thus, in particular adolescents and young adults with these chronic digestive disorders can be expected to use task-oriented coping strategies more often than emotion-focussed or avoidance coping. On the other hand, IBD and chronic liver diseases can be considered less controllable by patients. IBD is regarded as a highly unpredictable disease, with unexpected exacerbations and remissions [8]. Also, chronic liver diseases can be considered as very threatening: it is associated with a heavy morbidity, with the prospect or undergoing of a liver transplantation and with a more restrictive life expectation. Adolescents and young adults with IBD or a chronic liver disease can therefore be expected to use more emotion-focussed or avoidance coping strategies.

Furthermore, it is hypothesized that coping processes are responsive to changes in individuals as a result of biological, cognitive and social development [5]. According to Compas et al. [5], developmental changes may contribute to changes in coping responses. It therefore can be assumed that differences regarding the use of coping strategies exist between age groups.

Finally, in the literature on coping it is assumed that coping strategies play a part in the adaptation process of dealing with a chronic disease. In general, problem-focussed coping strategies have been found to be associated to better adjustment, whereas emotion-focussed coping strategies have been found to be related to poor adjustment. Definitions of adjustment in most coping studies, however, mostly concern psychological outcomes, thus neglecting effects on medical and even more frequently on social outcomes [7]. It is beyond question that psychological outcome measures like anxiety or well-being are important for chronically ill patients. Nevertheless, taking practical consequences into consideration, assessment of everyday life measures may be more relevant [7].

Elaborating on the present research, we first wished to compare coping strategies in adolescents and young adults with several chronic digestive disorders and controls without chronic digestive disorders, and in various age groups. The second objective of this study was to determine whether performance in school and leisure activities of adolescents and young adults with chronic digestive disorders is (partly) dependent on the use of coping strategies.

Methods

Study population

Participants of research were adolescents and young adults between the ages of 12 and 25, suffering from chronic digestive diseases, categorized as IBD, chronic liver diseases, congenital disorders, food allergy and coeliac disease. Patients were recruited via 18 medical specialists in 9 academic and specialized hospitals using the following criteria: being diagnosed within one of the five diagnostic categories stated by a certified medical specialist, illness duration of at least six months, age from 12 to 25, being non-institutionalized, being aware of diagnosis, not being terminally ill, being mentally capable to participate and mastering the Dutch language sufficiently. Extra patients with coeliac disease were recruited through a patient organization, using the same criteria (diagnosis had to be confirmed by at least one small-bowel biopsy). There was no selection on illness activity or severity of complaints and disability.

Controls were randomly recruited from the patient files of 173 general practitioners, all being general practitioners of participating patients. In The Netherlands (almost) every inhabitant is registered with a general practitioner. In recruiting controls, the same criteria were used as for the recruitment of patients, except being diagnosed within one of the five diagnostic categories. General practitioners were provided with a random set of three different letters of the alphabet on the basis of which they were requested to select three controls with surnames starting with the indicated letters and fitting the specified criteria.

Informed consent

The study was approved by all participating hospitals' ethical committees. All participants gave written informed consent (if younger than 18 years, one of the parents or carers had to sign as well). Only after informed consent was received, a written questionnaire was sent to the respondents.

Measurement

Data were collected by a mailed questionnaire. Four *background variables* were measured: gender, age, socio-economic status and puberty status. Socio-economic status was operationalized by the highest education of one of the parents or carers on a 7-point-scale, from (1) no education or only primary school to (7) a completed university training. Puberty status was assessed by physical characteristics: having had the first menstruation in case of female participants and the presence of a heavy voice in combination with axillary hair in male participants. Puberty status was taken into account because of the assumption that chronic disorders can be accompanied with a delayed puberty [9], a factor that could play a role in school and leisure activities.

Furthermore, eight *burden of disease* measures were assessed: physical complaints, anxiety, depression, disability in endurance, hospitalisation, use of medication, the need to diet adherence and toilet use. Physical complaints were measured by a set of 23 complaints, based on literature and brochures of physicians and patients' associations. All items were scored on a 3-point-scale from (0) no trouble - (2) much trouble during the last four weeks. Anxiety and depression were measured by the Hospital Anxiety and Depression Scale (HADS) [10,11], both consisting of 7 items (Cronbach's alphas respectively .79 and .72), and scored on a 4-point scale. Disability in endurance was assessed by a scale derived from the Children Quality Of Life questionnaire (TACQOL) [12], consisting of 3 items (Cronbach's alpha .86). Hospitalisation was measured by a scale existing of two items: 'number of times hospital admission' and 'number of times undergoing surgery' (Cronbach's alpha .75). Daily use of medication was assessed by the number of times of medicine intake a day, at the moment of this study. The need to diet adherence was measured on a 4-point-scale, from (0) no diet at all ("I can eat and drink what I want") - (3) strict diet adherence. Finally, toilet use refers to going to the toilet at night because of bowel movement/defecation or stoma care. This item was assessed on a 5-point-scale, ranging from (0) never - (4) always.

Coping was assessed by the shortened version of the Coping Inventory for Stressful Situations (CISS-21) [13, 14]. The CISS is a theoretically derived, generic measuring instrument. Assessing meta coping strategies facilitates comparison between several diagnostic groups and allows general conclusions on coping strategies and coping effectiveness [7]. The CISS consists of 21 items (see Appendix) measuring three coping strategies: emotion oriented coping (e.g. "Become very upset"), task oriented coping (e.g. “Work to understand the situation”) and avoidance coping (e.g. “Visit a friend”). Each scale consists of 7 items, randomly distributed within the form to control for order effects.

The CISS has been frequently used in chronically ill patients with various diseases and has proven to have good psychometric characteristics in adult samples (as from 16 years) [15]. Furthermore, confirmatory factor analyses provided evidence for a satisfactory fit and the invariance of the theoretically assumed three-factor structure of the CISS in adolescents and young adults in a younger target group (as from 12 years), with and without various chronic digestive disorders [16]. As the factor loading of one item relating to avoidance coping ”Take some time off and get away from the situation” (see Appendix) appeared not to be significant in most of the samples, it was suggested to exclude this item [16], leaving the avoidance coping scale with 6 items instead of 7. In the so constructed scales, Cronbach's alphas were found to be .78 or higher, in diagnostic groups as well as in controls and in several age groups.

Respondents were asked to rate each item on a five point scale ranging from (1) “not at all” to (5) “very much”. Scale scores were transposed to the same format as the item scores (1-5).

Five aspects of *school and leisure activities* of adolescents and young adults were assessed [6]: school-absenteeism due to illness, educational level, going out, undertaking cultural activities and friendship. Firstly, school-absenteeism was measured by whole weeks absence during the total school period. Educational level was assessed by the highest educational level at the moment of this study, on a 7-point-scale from (1) no education or only primary school to (7) university level. Going out and undertaking cultural activities were assessed by two scales derived from the Netherlands Health Interview Survey [17]. The scale 'going out' consisted of 3 items: going to the movies, going to a disco- or house party and visiting a pub (Cronbach's alpha .63). Undertaking cultural activities was assessed by 4 items: visiting a library, going to a play or concert, visiting a museum and reading books (Cronbach's alpha .62). These items were scored on a four point scale. In order to facilitate interpretation the scale scores were transposed to the same format (1-4). Finally, friendship was assessed by two items derived from the national survey Youth and Sex [18]: ‘having friends’ and 'undertaking activities with friends' (Cronbach's alpha .62). Again, as both items were scored on a five point scale, the scale score was transposed to the same format to facilitate interpretation.

Statistics

To describe the sample, socio-demographic descriptives were computed, followed by analyses of variance or Chi-square tests to test differences between groups. In analysis of variance, Scheffé- (homogeneous groups) or Tamhane's T2- (non-homogeneous groups) procedure was used.

In order to compare the use of coping strategies between adolescents and young adults with various chronic digestive disorders and controls (first research question), analysis of variance was applied. In this procedure age, gender, puberty status and socio-economic status were added as covariates to control for their effects. These background variables appeared to differ significantly between groups (see results section), while being associated with most of the outcome measures. The same procedure was followed in comparing the use of coping strategies in different age groups (12-14, 15-17, 18-20 and 21-24 years), except that in these analyses type of diagnosis was introduced as a covariate (instead of age).

To investigate the relationship between coping and school and leisure activities in patients (second research question), two statistical procedures were performed. First, Pearson correlation coefficients were computed between coping strategies and aspects of school and leisure activities in the patients group. Second, multiple regression analyses were performed on each aspect of school and leisure activities. These regression analyses were carried out in three steps. In the first step, background variables were entered into the regression equation (age, gender and socio-economic status), inclusive of type of diagnosis (four diagnostic groups as dummy’s, with one diagnostic group as reference group); in the second step eight disease burden indices were entered, and in the final step, the three coping strategies were entered into the model.

Results

Sample

521 Adolescents and young adults suffering either from IBD (n=190), chronic liver diseases (n=51), congenital digestive disorders (n=122), coeliac disease (n=61) or food allergy (n=97) adequately completed the

questionnaire. Mean response was 50.3% varying from 38.6% in adolescents and young adults with chronic liver diseases to 58.8% in participants with IBD. The sample included also 274 controls, response rate 49,0%. In Table 1 the characteristics of the sample are summarized. The mean age in the different groups varied from 18.4 years to 22.1 years, the IBD and chronic liver disease groups being significantly older than the control group and the other three diagnostic groups. The *percentage female participants* varied from 45.9% to 70.1% in the various groups, the food allergy group consisted of significantly more female respondents than the control group. In addition, differences were found among the diagnostic groups as well. The mean score on *socio-economic status* varied from 3.8 to 4.7. Although analysis of variance showed an overall statistic indicating significant differences between groups, the posthoc test (Scheffe) did not reveal any differences, probably due to small numbers in subgroups. Finally, the percentage participants that had not reached *puberty status* varied from 5.4% to 16.8%, being significantly lower in the IBD group than in the control group and in the congenital disorders group.

Table 1 Characteristics of the sample, patients and controls

	I	II	III	IV	V	
	Inflammatory bowel disease	Chronic liver disease	Congenital digestive disorders	Coeliac disease	Food allergy	Control group
	n=190	n=51	n=122	n=61	n=97	n=274
Age (Mean,SD)	22.1 (2.3)*$^{\#}$ III,IV,V	22.0 (2.7)*$^{\#}$ III,IV,V	18.4 (3.7)$^{\#}$ I,II	18.4 (3.7)$^{\#}$ I,II	18.4 (3.8)$^{\#}$ I,II	18.5 (3.8) F(5)=38.21, p-.000
% 12-14	0.5	2.0	21.3	18.0	21.6	17.9
% 15-17	4.2	3.9	18.0	21.3	17.5	26.6
% 18-20	17.4	23.5	24.6	23.0	27.8	19.0
% 21-24	77.9	70.6	36.1	37.7	33.0	36.5
Gender (% women)	58.9$^{\#}$ III	51.0$^{\#}$ V	45.9$^{\#}$ I,IV,V	67.2$^{\#}$ III	70.1*$^{\#}$ II,III	55.5 Chi^{2}(5)=16.84, p=.005
Socio-economic status (Mean, SD)	4.2 (1.7)	3.8 (2.0)	4.3 (1.7)	4.7 (1.6)	4.6 (1.6)	4.5 (1.6) F(5)=2.78, p=.017
Puberty (% reached)	94.6*$^{\#}$ III	91.8	83.2$^{\#}$ I	93.3	90.7	89.0 Chi^{2}(5)=11.98, p=.035

*p < .05 in comparison with control group
$^{\#}$ p < .05 in comparison with indicated diagnostic group

Use of coping strategies

Table 2a presents mean scores on the three coping strategies in diagnostic groups and control group. Results show highest scores on task oriented coping and lowest scores on emotion oriented coping. No significant differences were found between adolescents and young adults with various chronic digestive disorders and healthy controls, nor among the diagnostic groups. Apparently, adolescents and young adults in the different diagnostic groups and healthy peers use task-oriented coping strategies, emotion-oriented coping strategies and avoidance coping to the same extent.

When several age groups are distinguished, differences in the use of coping strategies come into sight. In Table 2b mean scores on the coping strategies are given for 4 age groups. Analyses of variance showed significant differences between age groups. In the youngest group (12-14 years) significantly lower scores were found compared with the older groups on all dimensions of coping. Furthermore, adolescents in the age of 15-17 years scored significantly lower on task-oriented coping than older age groups. Adolescents in the two oldest categories were found to use coping strategies to the same extent.

Table 2a Mean scores (standard deviation) on 3 coping scales of the CISS in diagnostic groups and control group[1]

	Inflammatory bowel disease n=190	Chronic liver disease n=51	Congenital digestive disorders n=122	Coeliac disease n=61	Food allergy n=97	Controls n=274	
Emotion oriented coping (1-5)	2.6 (0.9)	2.9 (1.0)	2.5 (0.8)	2.7 (0.9)	2.6 (0.9)	2.5 (0.8)	F(5)=1.33, p=.250; between diagnostic groups: F(4)=1.43, p=.224
Task oriented coping (1-5)	3.5 (0.7)	3.3 (0.7)	3.1 (0.8)	3.2 (0.9)	3.2 (0.8)	3.3 (0.8)	F(5)=1.52, p=.183; between diagnostic groups: F(4)=1.33, p=.259
Avoidance (1-5)	3.2 (1.0)	3.1 (0.9)	3.0 (1.0)	3.0 (0.9)	3.1 (1.0)	3.0 (0.9)	F(5)=0.52, p=.763; between diagnostic groups: F(4)=0.25, p=.913

[1] Differences in age, gender, socio-economic status and puberty status were being controlled in analyses of variance

Table 2b Mean scores (standard deviation) on 3 coping scales of the CISS in four age groups

	I 12-14 (n=109)	II 15-17 (n=135)	III 18-20 (n=168)	IV 21-24 (n=383)	
Emotion oriented coping (1-5)	2.2 (0.8)*II,III,IV	2.5 (0.8)*I	2.7 (0.9)*I	2.7 (0.9)*I	F(3)= 6.47, p=.000
Task oriented coping (1-5)	2.8 (0.8)*II,III,IV	3.1 (0.8)*I,III,IV	3.4 (0.7)*I,II	3.4 (0.7)*I,II	F(3)=16.06, p=.000
Avoidance (1-5)	2.6 (1.0)*III,IV	3.0 (0.9)	3.1 (0.9)*I	3.1 (0.9)*I	F(3)= 3.19, p=.023

* p < .01 in comparison with indicated age group (after controlling for differences in gender, diagnosis, socio-economic status and puberty)

Relation between coping and school and leisure activities

First, correlation coefficients were computed to investigate the relation between coping and school and leisure activities of patients. In Table 3 Pearson correlation coefficients are presented. In general, weak but significant correlations were found between all school and leisure aspects on the one hand and one or two coping strategies on the other hand. School absenteeism, educational level and going out correlated positively with task oriented coping. Furthermore, going out appeared to be positively correlated with avoidance coping. Avoidance coping was also positively associated with both cultural activities and friendship. Only one negative association was found: between friendship and emotion oriented coping.

Table 3 Correlation between coping scales and school and leisure measures, in patients with chronic digestive disorders (n=521)

	school-absenteeism	educational level	going out	cultural activities	friendship
Emotion oriented coping	-.003	.015	-.038	.014	-.220**
Task oriented coping	.120**	.232**	.115**	.027	.087
Avoidance coping	.014	.057	.286**	.091*	.186**

Note: Pearson correlation coefficients
*= p≤.05 **= p≤.01

Secondly, hierarchic regression analyses of the five school and leisure aspects were performed on coping strategies, with background characteristics and burden of disease measures also being part of the regression model, entered in separate steps. Results of these analyses are shown in Table 4. Coping contributed significantly to the regression model on educational level, going out and friendship, but not on school absenteeism en leisure activities.

Regarding educational level, the model explained 20% of the variance, of which coping provided the smallest (but significant) contribution. Task oriented coping was related significantly to a higher educational level. With respect to going out, the final model explained 13% of the variance, the largest part being explained by coping. Avoidance coping appeared to be a positive predictor of going out. Finally, with regard to friendship, 17% was explained by the regression model, again with the largest part being explained by coping. Two coping strategies were identified as significant contributors: avoidance coping in a positive way and emotion oriented coping in a negative way.

Table 4 Parameters of regression analyses of school and leisure aspects on coping, in patients with chronic digestive disorders (n=521)

	School-absenteeism			Educational level			Going out			Cultural acitivities			Friendship		
	β	AR^2	Δp	β	AR^2	Δp	β	AR^2	Δp	β	AR^2	Δp	β	AR^2	Δp
Background variables:		.047	**		.133	**		.032	**		.131	**		-.005	ns
Age	-.043			.153*			.178**			-.112			-.066		
Gender	.063			.033			-.086			.244**			-.065		
Socio-economic status	.052			.288**			.053			.243**			.050		
Puberty status	.105*			.125*			.051			-.034			.070		
IBD[1]	.141			.017			.107			-.040			.128		
Chronic liver disease[1]	.064			.062			.046			.068			.117		
Congenital digestive disorder[1]	-.060			.012			.099			.097			.078		
Food allergy[1]	-.006			.059			-.055			.063			-.046		
Burden of disease measures:		.217	**		.186	**		.053	*		.147	ns		.077	**
Physical complaints	.096			.129*			.079			.145*			.037		
Anxiety	.010			-.104			.070			-.035			.060		
Depression	-.111			-.122			-.094			-.171**			-.102		
Disability in endurance	.151**			-.054			-.135*			.003			-.157**		
Medical treatment	.329**			-.079			-.013			.007			-.088		
Medicine use	.136*			-.094			-.031			.078			-.039		
Diet	.104			.003			.110			-.053			.086		
Toilet use	-.077			-.129*			-.034			-.033			-.102*		
Coping scales:		.216	ns		.202	*		.133	**		.143	ns		.174	**
emotion oriented	-.042			.060			-.070			.058			-.215**		
task oriented	.077			.147**			-.085			.027			-.023		
avoidance	-.010			-.009			.331**			-.005			.319		

[1] coeliac disease is reference group * p≤.05 ** p≤.01

Discussion

The first objective of this study was to compare coping strategies between different diagnostic and age samples: between adolescents and young adults with various chronic digestive disorders and healthy peers, among diagnostic groups, and among several age groups. In contrast with our hypotheses no differences were found between the several diagnostic groups nor between the diagnostic groups and the control group. Therefore, it can be stated that adolescents and young adults with several chronic digestive disorders and healthy peers handle general problems or stressful situations in the same way. These findings support previous results of studies in adolescents with other chronic diseases, such as diabetes, rheumatic diseases and asthma [2]. There may be a difference, however, between generic coping (as measured in our study) and disease-specific coping, i.e. coping specifically aimed at the disease and disease burden. Whereas, apparently, no differences exist among diagnostic groups as far as generic coping is concerned, adolescents and young adults with various chronic digestive disorders possibly differ in the use of disease-specific coping strategies.

Making a distinction between age groups, our results indicate that adolescents in the age of 12 to 14 years, generally make less use of coping strategies than older adolescents. Compared with older age groups, these youngsters were found to report lower scores on each coping strategy. Moreover, on the coping scale task oriented coping, adolescents in the age of 15 to 17 years also appeared to report lower scores compared with older age groups. These findings suggest that, although task oriented coping strategies were found to be the most frequently reported strategies in handling stressful situations, this way of coping requires certain skills which need to be developed. In addition, it is likely that skills in order to use strategies relating to avoidance coping and emotion oriented coping are developed in an earlier stage. It is assumed [5] that more complex methods of coping efforts emerge in early to middle childhood, with the development of more language and metacognitive capacities such as cognitive reframing or restructuring a problem situation. Greater diversity and flexibility in the range of coping responses available to the individual is expected to develop during middle childhood and adolescence. Results of our study can be considered consistent with this expectation.

With regard to the second research question, to determine whether performance in school and leisure activities of young patients with chronic digestive disorders is dependent on coping, results indicate that coping can be considered a predictor for some aspects. Even when background characteristics, type of diagnosis and disease burden measures are taken into consideration, some coping strategies were identified as predictors, especially with regard to educational level, going out and friendship.

Regarding educational level, task-oriented coping was found to relate significantly with a higher educational level. This coping strategy is aimed at solving the problem, cognitively restructuring the problem or attempts to alter the situation. Obviously, using this kind of coping efforts is positively related to educational level.

Going out on the other hand appeared to be positively associated with avoidance coping. Making use of in particular this kind of coping reactions, apparently is related with more going out in adolescents and young adults with chronic digestive diseases. Also, avoidance coping was found to be a positive predictor on friendship as well. In other words, handling problems and stressful situations by activities and cognitive changes aimed at avoiding the stressful situation via distracting oneself with other situations or tasks or via social diversion can be considered a positive predictor for the number of friends, undertaking activities with friends and going out. It must be noted that the scale avoidance includes two sub-dimensions, namely person-oriented (social diversion) and task-oriented (distraction) coping strategies [20]. The items which relate to person oriented coping strategies (items 7 Visit a friend", 15 "Spend time with a special person" and 21 "Phone a friend", see Appendix) involve behaviour directed to a friend or a special person. However, repeated analyses without these items, thus only including items 4, 9 and 18 relating to distraction (alpha .84), did not change the relationships with going out and friendship (data not shown).

Thirdly, emotion-oriented coping appeared to be negatively related to friendship. Emotion-oriented coping refers to emotional reactions that are self-oriented and aims to reduce stress. Reactions include emotional responses, self-preoccupation and fantasizing [13]. Probably, self-oriented coping efforts leave less room for sharing problems with friends. In the present study, however, a cross-sectional design was used, so that no statements on the direction of an association can be made. As a consequence, it is also thinkable that having no friends or only a few friends results in using predominantly self-oriented coping strategies in handling stressful situations.

Finally, school absenteeism and undertaking cultural activities did not appear to be (partly) dependent on the use of coping strategies. Regression analyses revealed that, in case of school absenteeism, burden of disease explained the largest part of the variance, in particular disability in endurance, medical treatment and medicine use. Regarding cultural activities, background characteristics, especially gender and socio-economic status, appeared to explain the largest part of the variance. Apparently, school absenteeism and undertaking cultural activities are not so much dependent on the use of coping strategies as on burden of disease measures or background characteristics.

According to Compas et al. [5], there is evidence from more than 60 studies suggesting that coping matters in the psychological adjustment of adolescents exposed to stressors. In general, problem-focussed and active coping (i.e. task-focussed coping) have been found to be associated with better adjustment, whereas emotion-focussed coping and passive coping (avoidance, emotion-focussed coping strategies) have been found to be related to poorer adjustment [5,7,21]. However, most studies operationalize adjustment in terms of psychological outcomes. Positive effects on psychological adjustment are not necessarily parallel to beneficial effects concerning medical and social outcomes like compliance, the use of medical resources or work absenteeism.[7]. With regard to task-focussed and emotion-focussed coping strategies, our results - relating to social outcomes - are consistent with previously found associations. With regard to avoidance coping, our results suggest a positive association with social outcomes as going out and friendship.

In general, in addition to our research questions, highest scores were found on task oriented coping and lowest scores on emotion oriented coping. In other words, coping reactions referring to solving the problem, cognitively restructuring the problem or attempts to alter the situation were the most frequently reported coping efforts in our study. In the literature on adolescent coping, due to various coping measurement techniques, a rich variety of coping responses have been reported. This makes it difficult to compare results [19]. In studies on adult coping, similar outcomes have been reported [22].

In interpreting these findings, it should be noted that using a generic measuring instrument, the assumption is being made that there is some consistency in adolescent use of coping strategies across stressful situations. According to Ayers, Sandler and Twohey [23], several studies have provided evidence that this assumption is quite reasonable for adolescents.

In addition, we used a coping measuring instrument, the CISS, which was originally developed for use in adults. Although the underlying factor structure was the same when used in a younger target group [3], the possibility exists that such an instrument may not adequately cover the full range of coping efforts used by adolescents and young adults [23]. Although individual items of the CISS refer to coping behaviour, the underlying structure of the CISS assesses meta coping strategies which makes it improbable that coping efforts of adolescents stay out of reach.

Furthermore, due to the cross-sectional design of our study, no statements can be made on the (causal) role of coping; findings only concern associations between coping and the social position of adolescents and young adults with chronic digestive disorders.

A final point of attention involves the response of the research group, 50.3% in patients and 49.0% in controls. It appeared that in patients, respondents were on the average a half year younger than non-respondents (respectively 19.6 and 20.1 years), and a higher percentage was female (respectively 57% en 49% females). The same pattern existed in the control group: the mean age in the respondents group was 18,5 years, compared with 20 years in non-respondents and 56% of the respondents was female in relation to 42% in the non-respondents group. In addition, to verify whether the control group was representative for the Dutch population between the ages of 12 and 25, data regarding educational level, failing classes and relationships were compared with national statistics (data not shown). With regard to these aspects, our controls were practically similar to the national statistics. In consequence, given a small deviation with regard to age and gender, the findings in our study can be considered rather representative.

Taking these considerations into account, it can be concluded that coping is related to school and leisure activities of adolescents and young adults with chronic digestive disorders. Comparisons between several diagnostic and age groups only revealed differences between age groups, showing less use of all measured coping strategies in the youngest adolescents, in particular with regard to task-focussed coping. Positive contributions of task-oriented coping were found on educational level, and of avoidance coping on going out and friendship, while emotion-oriented coping related negatively to friendship.

Further research is needed to investigate the mechanisms through which coping is related to social outcome measures (mediating role) in adolescents and young adults with chronic digestive disorders. More detailed insight in such mechanisms can be helpful in preventing adolescents and young adults with chronic digestive disorders from difficulties in school and leisure activities.

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Appendix A

Shortened version (21-items) Coping Inventory for Stressful Situations (CISS):

(1. Take some time off and get away from the situation (A))
2. Focus on the problem and see how I can solve it (T)
3. Blame myself for having gotten into this situation (E)
4. Treat myself to a favourite food or snack (A)
5. Feel anxious about not being able to cope (E)
6. Think about how I solved similar problems (T)
7. Visit a friend (A)
8. Determine a course of action and follow it (T)
9. Buy myself something (A)
10. Blame myself for being too emotional about the situation (E)
11. Work to understand the situation (T)
12. Become very upset (E)
13. Take corrective action immediately (T)
14. Blame myself for not knowing what to do (E)
15. Spend time with a special person (A)
16. Think about the event and learn from my mistakes (T)
17. Wish that I could change what had happened or how I felt (E)
18. Go out for a snack or meal (A)
19. Analyse my problem before reacting (T)
20. Focus on my general inadequacies (E)
21. Phone a friend (A)

T = Task-oriented coping
E = Emotion-oriented coping
A = Avoidance coping

7 General discussion

In this chapter first the main results are presented and discussed following the research questions that were formulated in chapter 1. Subsequently, a strength and weakness analysis of this study is given, followed by a summary of the most significant conclusions. The chapter closes with recommendations for patients and their parents, for physicians, as well as for future research.

Main results

The first aim of this study was to gain more insight into the social position of adolescents and young adults with various chronic digestive disorders, such as IBD, chronic liver diseases, congenital digestive disorders, celiac disease and food allergy. There are indications that the social position of adolescents and young adults is adversely affected by the fact that they have a chronic digestive disorder; previous research of young patients with IBD [1,2] had pointed out that these patients are at risk to experience difficulties in practising sports, attending school and difficulties with long distance (school) trips or to staying over in friends houses. Results of our study support these findings: several aspects of social position, e.g. school attendance, going out, labour participation, appeared to be negatively affected by a chronic digestive disorder, especially in adolescents and young adults with chronic liver diseases and IBD. On the other hand, results of this study indicate that adolescents and young adults with chronic digestive disorders generally reach the same educational level and have friends and relationships to the same extent as their healthy peers. In discussion groups (not reported in this thesis, [3]), most adolescents and young adults with various chronic digestive disorders were confident that finally everything will work out all right: their educational level, a job, relationships and a partner. They realised, however, that it might take them more effort and energy to reach a situation comparable with that of their healthy peers. In addition, they pointed out that they use their limited energy for commitments such as school and work in the first place, so that only little or no energy is left for leisure activities in the evening or in the weekend. Apparently, in general, they do all they can to keep up with their healthy peers at school or in their jobs, at the expense of other activities.

After a description of the social position of adolescents and young adults with different chronic digestive disorders in relation to population controls, it was aimed to investigate whether disease burden characteristics necessarily mean that difficulties in the social position will occur. According to the main path in our conceptual framework, disease burden was considered to have a significant impact on the social position. Disease burden in this context was interpreted as daily consequences, more or less, of the disease, such as physical complaints, the need to adhere to a diet and the need to take medication, hospital admission and dependency on toilet facilities. Before the relationships with social position aspects was discussed, a description was given of the burden of disease of adolescents and young adults in the different diagnostic groups, in relation to population controls. Especially young patients with a chronic liver disease, IBD or food allergy were found to experience daily consequences of their disease, such as physical complaints, disability in endurance, hospitalisation, and medication intake and diet concerns. In the food allergy group, a remarkably high number of physical complaints was found, probably caused by other allergies which often accompany food allergy. As pointed out above, it was hypothesized that an important part of the explanation of dealing with possible difficulties in the social position could be attributed to the disease burden. Results from our study indeed revealed significant associations between several burden of disease indices on the one hand, and school performance, leisure activities and labour participation on the other hand. However, these relationships were rather weak, which may be (partly) due to the distal character of the outcome measures. Social position aspects as measured in this study, i.e. school performance, labour participation or going out, are, to a certain extent, also dependent on environmental factors and conditions. This is in contrast with psychological or physical outcomes, often referred to as quality of life or well-being aspects, which are more closely related to a person, and, therefore, are more likely to be susceptible to person-related characteristics, such as burden of disease. Taking this into account, and in combination with the consistent character of the associations, the following disease burden indices can be considered to be risk factors for experiencing difficulties in school performance and leisure activities for adolescents and young adults with chronic digestive disorders: depression, disability in endurance, hospitalisation, need to adhere to a diet and toilet use. In addition, the extent of being dependent on toilet facilities and medication intake can be considered as determinants of limited chances on the labour market.

Next to the impact of disease burden, this study aimed to investigate the role of coping in relation to the social position. According to our conceptual framework, several intra- and extra-individual factors are suggested to exert influence on the main pathway. Apart from disease and disease burden characteristics, these factors are supposed to have an additional and mediating impact on the social position of adolescents and young adults with a chronic digestive disorder. Acknowledging the possible impact of the other introduced factors, coping was selected for further investigation in the present study, as it was considered to be a key concept in explaining difficulties in the social position.

Because of the heterogeneity of the study population and large age ranges from young adolescence to young adulthood, we wished to compare first the use of coping strategies between the different diagnostic groups, between diagnostic groups and the control group, and between several age categories. For this purpose, the Coping Inventory for Stressful Situations-21 (CISS-21) [4,5] was chosen. The CISS-21 is a theoretically derived, generic measuring instrument, known for its good psychometric characteristics when applied to adult populations of the chronically ill. As the CISS primarily has been developed to be used for adult populations, and validated in age groups from the age of 16 years, confirmatory factor analysis was applied to determine whether the theoretically assumed three-factor structure could be reproduced for younger adolescents, from the age of 12 years. Results provide evidence for the same factor structure in younger age groups, as well as in the different diagnostic groups and the control group. Apparently, in younger age samples generic coping strategies can also be categorized as task-focused, emotion-focused and avoidance coping. It should be noted, however, that an instrument originally developed for use in adult samples may not adequately cover the full range of coping efforts used by adolescents [6]. Although the separate items of the CISS-21 refer to coping behaviour, for example ‘visit a friend’ or ‘determine a course of action and follow it’ (see Appendix 2), the underlying structure of the CISS-21 assesses three meta coping strategies. Therefore, it is possible that we have missed certain coping efforts of adolescents. However, with the available items of the CISS-21, the three meta coping strategies could be adequately assessed. In conclusion, the CISS-21 was found to be applicable in comparative studies of adolescents and young adults of different ages, with and without chronic digestive disorders. Subsequently, comparisons of the scores on the three scales between the different samples showed no differences between the several diagnostic groups nor between patients and controls. This means that adolescents and young adults with several chronic digestive disorders handle problems or stressful situations generally in the same way as their healthy peers. These results are consistent with the findings in other cohorts with chronic diseases [7,8]. Next, the use of coping strategies was compared between several age categories. Results from these comparisons indicated that the youngest adolescents generally make less use of coping strategies than older adolescents, in particular with regard to task-focussed coping. Probably, this way of coping requires certain skills that are developed in a later phase. According to Compas et al. [9], more complex methods of coping efforts emerge with the development of more language skills and meta-cognitive capacities, such as restructuring stressful situations.

After comparison of the use generic coping strategies in the various diagnostic and age samples, it was investigated whether coping contributes to school performance and leisure activities. Scientific literature provides evidence that coping is important in the psychological adjustment of adolescents exposed to stressors [9]. In general, task-focussed coping has been found to be associated with better adjustment, whereas emotion-focussed and avoidance coping have been found to be related to poorer adjustment [9-12]. Our results showed positive contributions of task-oriented coping on educational level, and of avoidance coping on going out and friendships, while emotion-oriented coping related negatively to friendships. In contrast with the general opinion on the use of avoidance coping strategies, these results suggest a positive effect of avoidance coping. However, the study design does not allow to make statements on the direction of these relationships. As a consequence, causality in this context cannot be proven. Again, these associations were rather weak, possibly due to the distal character of our outcome measures. As outlined above, social position aspects, such as going out, are dependent on environmental factors as well. It might be that, in the case of school performance and leisure activities, these environmental factors (such as impact of parents and friends, quality of the school) are more closely related to these outcome measures than psychological concepts, such as coping. It must be mentioned that in most studies on the impact of coping, adjustment is operationalized in terms of psychological outcomes [11]. According to Schreurs and De Ridder [13], research shows that, although coping has an independent impact on the well-being of chronically ill patients, effects also are generally found to be small.

In addition, the traditional view on coping has been changed in the past few years, at instigation of Aspinwall and Taylor in 1997 [14] to propose a new concept of proactive coping. According to Greenglass et al. [15], this view on coping harmonizes with a relatively recent shift in approaches to psychology, from a focus on helplessness and pathology to a more positive, optimistic approach that emphasizes health and the promotion of well-being [16]. In contrast with traditional approaches to coping, which can be seen as reactive - something which occurs temporarily after a stressful event-, the proactive coping is more future-oriented in the sense that the individual is seen as someone who is able to take preparatory or preventive steps in coping with anticipated stress [15]. A proactive person is considered to realise improvements in life and environment instead of mainly react to a past or anticipated adversity [17], and, therefore, will need several social skills. According to Aspinwall and Taylor [14], the skills associated with proactive behaviour include planning, goal setting, organization and mental stimulation. These skills will probably need to be (further) developed by adolescents and young adults. So far, research is directed at adult populations, and it is, therefore, not known whether or to what extent proactive coping is an adequate approach for younger adolescents. Nevertheless, in relation to social position aspects as measured in our study, proactive coping might be a promising concept, possibly providing concrete points for social skill training.

Methodological reflection

This study has several important strengths. First, a controlled research design with a population based control group was used to give a solid image of several social position aspects of young patients with chronic digestive disorders in relation to the social position of their healthy peers. In addition, by including a control group, it was possible to gain insight into disease burden aspects and the use of generic coping strategies, before we started studying the proposed relationships of the research model. Second, this is the first comparative study in which a considerable number of patients with several chronic digestive disorders participated. As a consequence, diagnostic groups could be mutually compared, as well as separately with a control group.

Nevertheless, this study also has its limitations which have to be discussed. First, although the included diagnostic groups represent the majority of chronic digestive disorders, not all chronic digestive disorders are covered in this thesis. As a consequence, no statements have been made on patients with chronic digestive disorders in general; the statements in this thesis only concern the included diagnostic groups. Young patients with chronic digestive disorders in cystic fibrosis (CF) were excluded: a study on medical, psychological and social consequences of CF was carried out in The Netherlands in the same period [18]. With regard to the social consequences, generally similar results were found. Although CF patients feel more often inhibited by their illness, they have as many relationships and social contacts as on their average peers in The Netherlands. They go less frequently to a disco or a pub, but visit a cinema more often. Furthermore, CF patients reach the same educational level as is the average in The Netherlands. However, choices regarding school and secondary education are often influenced by CF.

A second point of attention involves the response of the research group: 57% of the patients and 54% of the controls. Compared to the proportions in the non-respondents group, IBD-patients responded more frequently, with a difference of 13%. Young patients with a chronic liver disease, congenital digestive disorder or food allergy responded less frequently with differences of around 5%. With regard to celiac disease, the percentage of patients in the respondents group was equal to the percentage in the non-respondents group. Comparisons between respondents and non-respondents on age and gender characteristics showed that patient respondents were on average one year younger than patient non-respondents. Furthermore, a higher percentage was female. We do not have information about the reasons for non-response. The same pattern concerning age and gender existed in responding and non-responding controls. To verify whether the control group was representative for the Dutch population between the ages of 12 and 25, data regarding some specific social position aspects were compared with national statistics, resulting in almost similar outcomes. Given some deviation regarding background characteristics, the findings in our study can be considered to be largely representative for the different diagnostic groups.

Third, the recruitment of most patients by physicians in academic and specialized centres might create the impression that more seriously ill patients were selected. However, as the Dutch health care system is organized in such a manner that most young patients, and especially children, with chronic digestive diseases are treated and controlled in specialized centres, it is not likely that we have missed less seriously ill patients. Moreover, there is strong evidence that adolescents and young adults with chronic digestive disorders who have not been treated there, have been seen at least once in an academic or specialized centre, serving as a secondary or tertiary hospital and, as a result, have been enclosed in the hospitals' registration, which was used to select the patients for this study. As for IBD, it is more likely that many patients are seen in peripheral hospitals. To test our assumption that a recruitment procedure via academic hospitals does not necessarily has to result in a selection of more seriously ill patients, IBD patients recruited by physicians in academic hospitals and participating patients recruited via the IBD Registry South Limburg were compared on disease characteristics. In this IBD Registry patients participate via all (six) hospitals in the region, including one university hospital, two general district hospitals and three minor associated hospitals [19]. Regarding co-morbidity and illness duration, no differences were found between these two groups (data not shown in this thesis). In addition, patients selected from the academic hospitals did not appear to be more seriously ill, as indicated by reported burden of disease characteristics, such as physical complaints, medication intake or hospitalization (taking gender, age and socio-economic status into account). Although the IBD Registry South Limburg partly includes patients who are seen in an university hospital, results from this comparison support our assumption that we did not select the more seriously ill patients.

Finally, the cross sectional design of this study can also be considered to be a limitation, because no statements could be made on the direction of associations. Therefore, conclusions on the causality of relationships could not be drawn.

Conclusions

- From this study it can be concluded that in particular adolescents and young adults with chronic liver diseases and IBD are at risk to suffer from social restrictions. These restrictions relate to school attendance, leisure time activities, labour participation and the financial situation.
- As far as educational level, friendships and initiating and maintaining relationships is concerned, young patients with different chronic digestive disorders have the same opportunities as population controls.
- In comparison with controls, especially young patients with chronic liver disease, IBD and food allergy daily experience consequences of their disease, such as physical complaints, disability in endurance, hospitalization, medication intake and diet concerns.
- Depression, disability in endurance, hospitalization, the need to adhere to a diet and toilet use can be considered risk factors for experiencing difficulties in school performance and leisure activities.
- In addition, the extent of medication intake and toilet use are determinants of being able to participate on the labour market.
- Furthermore, we conclude that younger adolescents (12-14 years) generally make less use of task oriented, emotion oriented, as well as avoidance coping strategies, compared with older age groups.
- Adolescents and young adults with various chronic digestive disorders use generic coping strategies to the same extent as those without.
- Coping was found to be associated with school performance and leisure activities. Positive associations were found between task-oriented coping strategies and educational level. In addition, avoidance coping was positively associated with more contacts with friends and going out, whereas emotion-oriented coping strategies appeared to be negatively associated with friendships.
- Reviewing the research model, it can be stated that, apart from the diagnosis, both burden of disease and coping partially account for differences in the social position of adolescents and young adults with chronic digestive disorders. These findings are useful starting-

points for optimalising education and clinical practice as well as for further research.

Recommendations

Several practical implications of this study are worth mentioning. First, in the direction of physicians, it is considered important to recognize, apart from physical functioning, the possible impact of a chronic digestive disorder on the social position of adolescents and young adults. In treating these patients, more attention is requested for the social aspects, so that potential restrictions can be identified early. In addition, it is recommended to provide young patients with a chronic digestive disorder and their parents with information on the possible impact on social position aspects, e.g. with a brochure developed during the present study. This brochure, entitled "Jong zijn & omgaan met een chronische spijsverteringsaandoening … soms moeilijk te verteren" [Being young & dealing with a chronic digestive disorder … sometimes hard to digest], was especially developed for patients and their parents, commissioned by the Foundation for Children's Welfare Stamps Netherlands. Patients and parents also are encouraged to obtain optimal information from their physicians and from patient organizations in order to be better prepared and to be able to take measures, if necessary, in time.

Apart from these practical implications, this study has generated several recommendations for future research. The research model, as outlined in the introductory chapter, presents several hypothesized relationships on explanatory concepts. For the present study, coping was selected as it was expected to be an important factor. Further analyses is needed to investigate the mechanisms through which coping is related to social outcome measures (mediating role) in adolescents and young adults with chronic digestive disorders. More detailed insight in such mechanisms can be helpful for preventive actions. In addition, as another approach of coping has been proposed in the literature, it is recommended to explore the effects of proactive coping on social position aspects. So far, proactive coping has hardly been subject of empirical research, especially younger study populations need further research.

Except for coping, more knowledge is required on the influence of the other intra- and extra-individual factors, as introduced in the research model. Our survey covered all concepts of this model and we intend to continue this study and also investigate the hypothesized relationships concerning optimism, self-esteem, social support and parental protection. A complete understanding of the introduced relationships provides concrete points of application for prevention and support so that preventive guidelines can be developed. In addition, we suggest to study these relationships within specific target groups, such as young IBD patients and patients with chronic liver diseases. Our findings pointed out that these patients run a higher risk to experience difficulties in their social position.

Furthermore, it would be worthwhile to conduct a follow-up study on the social position in the same IBD and chronic liver disease patients in order to obtain information on the long-term effects. For this purpose, we are preparing a follow-up study and we will repeat the survey next year, as by then it is five years since the data for the present study were collected.

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8 Summary

A chronic digestive disorder can be accompanied by -sometimes embarrassing- symptoms and complaints, such as pain, lack of energy, flatulency or incontinence, which can affect the social position of patients. In addition, diet commitments, or worries about toilet facilities can have a serious impact on social activities. Available studies in young patients with IBD indicate that several aspects of the social position can be adversely affected, resulting in, for instance, experiencing difficulties in active sports, such as swimming or running, a relatively high score in school absenteeism, not going on long distance trips or not spending the night with friends. So far, the impact of different chronic digestive disorders on the social position of adolescents and young adults has hardly been subject of research. The present study was conducted to provide a basis for preventive interventions in order to support young patients in their development with a maximum of equal possibilities in society.

Central to this thesis is the impact of being diagnosed with a chronic digestive disorder, such as an inflammatory bowel disease (IBD), chronic liver disease, congenital digestive disorder, coeliac disease or food allergy, on the social position of adolescents and young adults. Secondly, it was aimed to investigate whether the type of disease and disease burden characteristics imply risk factors for possible difficulties in the social position. In addition, the contribution of coping was studied. The study was conducted within a theoretical framework, which is presented in chapter one. On the basis of this model, the following research questions formed the starting-point of this thesis:

1. Do various chronic digestive disorders, i.e. IBD, chronic liver diseases, congenital digestive disorders, coeliac disease and food allergy, have a negative impact on the social position of adolescents and young adults? Which specific aspects of the social position are negatively affected by a chronic digestive disorder?
2. How can the burden of a chronic digestive disorder in adolescents and young adults be described, in terms of daily manifestations, compared to population controls?

3. Does burden of disease constitutes a risk factor for school performance and leisure activities of adolescents and young adults with chronic digestive disorders?
4. Does burden of disease constitutes a risk factor for the labour market position of young adult patients with chronic digestive disorders
5. Do coping strategies differ between several diagnostic groups and population controls? Do they differ between various age groups?
6. Does the use of coping strategies contribute to school performance and leisure activities of adolescents and young adults with chronic digestive disorders?

In total 758 patients, categorized in five diagnostic groups, and 306 population-based controls in the age of 12 to 24 years participated in this study. The mean age in the different groups varied from 17.5 to 20 years. More details on the background of this study, on the recruitment procedures for patients and controls and on the measurement methods can be found in chapter one. The research questions are successively studied in the following chapters. In addition, one chapter pays attention to the factor structure of the Coping Inventory for Stressful Situations (CISS) because, in this study, it is used in a younger target group than it originally was developed for.

In chapter two, the first research question - whether having a chronic digestive disorder has a negative impact on the social position of adolescents and young adults - is investigated. For this purpose, five diagnostic groups were each compared with a population-based control group. Several social position aspects, such as school absenteeism, going out, having a paid job, needing re-education in order to get a job, getting benefits as main income source, encountering bottlenecks in establishing financial commitments, dating and making love, appeared to be negatively divergent from population controls. In particular adolescents and young adults with chronic liver diseases and IBD were found to be at risk to suffer from several social restrictions. Also, apart from a relatively high score in school absenteeism, young patients with food allergy were found to have less self-confidence in dating, and adolescents and young adults with congenital digestive disorders reported more restrictions in the domain of sexuality. Young patients with coeliac disease appeared to be similar to population controls with regard to all measured aspects of the social position. It was concluded that suffering from a chronic liver disease or IBD can have a serious impact on the social position of young patients.

Chapter three deals with the impact of burden of disease on school performance and leisure activities of adolescents and young adults with various digestive disorders. In this chapter, a description of burden of disease in the several diagnostic groups in comparison with the control group is given as well. Results showed that, in comparison with healthy peers, young liver and IBD patients have to cope with more physical complaints, disability in endurance, hospitalization, medication intake and diet concerns. In addition, patients with a chronic liver disease reported to experience more anxiety and depression, whereas IBD patients need to use the toilet more often. Furthermore, young patients with food allergy were found to report higher scores on most of the measured indices. Apart from diet adherence, which obviously was found to be an important consequence of food allergy, results indicated that food allergy patients use medication more often, are hospitalized more frequently and experience more disability in endurance compared with healthy peers. A salient finding is that the highest mean score on physical complaints was found in this diagnostic group. This can probably be explained by other allergies which often accompany food allergy, causing additional physical complaints. The consequences of coeliac disease and congenital digestive disorders appeared to be limited to a few disease burden indices. Several burden of disease indices can be identified as risk factors for experiencing difficulties in school performance and leisure activities. These include depression, disability in endurance, hospitalization, need to diet adherence and toilet use. The conclusion of this chapter is that especially adolescents and young adults with a chronic liver disease, IBD and food allergy experience daily consequences of their disease. Several indices can be considered risk factors regarding school performance and leisure activities.

In chapter four the labour participation of adolescents and young adults with various chronic digestive disorders is studied in more detail. First, a comparison was made between young patients in the several diagnostic groups and population controls. Labour participation was studied in non-students, approximately 40% of our study population. Being unemployed or having a limited part-time job (up till 19 hours) can be considered to have a more severe impact on the quality of life in this group. According to national classifications, the number of working hours were divided in four categories: 0-11 hours, 12-19 hours, 20-34 hours and 35 hours or more. Following the common definition of labour participation, a working week of less than 12 hours was considered as not participating on the labour market. Also, a working week of 35 hours or more was interpreted as having a full-time job, and both categories of 12-19 hours and 20-34 hours as having a part-time job. Controlling for age, gender and socio-economic status, patients with IBD and chronic liver diseases were found to differ negatively from the control group, in all categories of labour participation. Subsequently, it was investigated whether labour participation depends on disease characteristics, such as burden of disease. In the regression models, socio-economic status and gender appeared to be the most important factors. In addition, toilet use and medication intake were found to be significant contributors as well. Being employed as from 12 hours per week, as well as being employed as from 20 hours a week, were found to be negatively associated with socio-economic status; with more highly educated parents, patients are less likely to find a job or to be employed as from 20 hours per week. Similarly, a more frequent toilet use (at night) was found to relate negatively to both employment measures. Male patients appeared to be more likely to have a full-time job than females, whereas medication intake was found to relate negatively to a full-time position. It was concluded that young patients with IBD or chronic liver diseases are less likely to participate on the labour market or to participate to the same extent compared with population controls. Except for socio-economic status and gender, the extent of medication intake and toilet use were identified as determinants of a limited labour market position.

Chapter five investigates the factor structure of the Coping Inventory for Stressful Situations-21 (CISS-21). The CISS-21 is known as a valid and reliable measure of generic coping strategies in adult samples with various chronic diseases. Little was known about application to a younger target group. In this chapter confirmatory factor analysis on the CISS-21 was performed in adolescents and young adults with and without various chronic digestive disorders. The CISS-21 assesses three coping strategies: task-oriented, emotion-oriented and avoidance coping. First, the fit of this three-factor structure was tested in several sub-samples: in age groups, in diagnostic groups and in the control group. After that, the invariance of the factor structure was examined across these sub-samples. Results provided evidence that the three-factor structure of the CISS-21 was adequate, in the younger age samples as well as in the different diagnostic groups and in the control group with healthy peers. In addition, general support was obtained for factor invariance across age samples and across patient and control samples. As a result, it was concluded that the factor structure of the CISS-21 is being maintained in younger adolescents with and without various chronic digestive disorders. Therefore, the use of coping strategies in adolescents and young adults of different ages can be compared, and, additionally, a comparison can be made between healthy and chronically ill adolescents and young adults.

Chapter six reports on the employment of the CISS-21 to compare the use of generic coping strategies between adolescents and young adults with different chronic digestive disorders and healthy peers, as well as between several age groups. Subsequently, the impact of coping on school performance and leisure activities was investigated. With regard to the use of coping strategies, our results indicated that the youngest adolescents, in the age of 12 to 14 years, make less use of coping strategies than older adolescents. Furthermore, on task-oriented coping, adolescents in the age of 15 to 17 years also were found to report lower scores compared with older age groups. It was suggested that, although task oriented coping strategies were found to be the most frequently reported strategies in handling stressful situations, this way of coping requires certain skills which need to be developed. Between adolescents and young adults with various chronic disorders, no differences were found in the extent of using generic coping strategies. Between patients and their healthy peers no differences were found either. Although not that strong, coping appeared to be associated with school performance and leisure activities. Task-oriented coping strategies related to a higher educational level. Also, avoidance coping was positively associated with friendship and going out. Emotion-oriented coping strategies appeared to be negatively associated with friendship. It was concluded that young adolescents generally make less use of coping strategies than older adolescents, especially with regard to task-focussed coping. Adolescents and young adults with different chronic digestive disorders and healthy peers handle general problems or stressful situations in the same way. To a limited extent, coping was found to be associated with school performance and leisure activities.

Finally, chapter seven discusses the main results. In this chapter, a strength and weakness analysis of this study is given as well, followed by a summary of the most significant conclusions. The chapter closes with recommendations for physicians, for patients and their parents, as well as for future research.

Samenvatting

Jongeren met een chronische spijsverteringsaandoening kunnen te maken hebben met verschillende klachten, zoals pijn, gebrek aan energie, incontinentie of flatulentie, die van invloed kunnen zijn op het sociaal-maatschappelijk functioneren. Ook zelfzorgactiviteiten zoals een dieet moeten volgen of het gebruiken van medicatie kunnen op het sociaal-maatschappelijk functioneren van invloed zijn. Beschikbare studies onder jongeren laten zien dat verscheidene aspecten van het sociaal-maatschappelijk functioneren in negatieve zin kunnen worden beïnvloed door het hebben van een chronische darmontstekingsziekte (IBD). Hetgeen kan resulteren in het niet of minder goed beoefenen van actieve sporten, zoals zwemmen of rennen, een hoog ziekteverzuim op school, niet op reis kunnen of logeren bij vrienden. Tot dusver was er slechts weinig wetenschappelijke aandacht voor een dergelijke impact van chronische spijsverteringsaandoeningen, terwijl juist gedurende de adolescentie belangrijke keuzes worden gemaakt die veelal bepalend zijn voor de toekomst. Met de resultaten van dit onderzoek is een basis gelegd voor informatievoorziening en preventieve interventies om jonge patiënten zoveel mogelijk dezelfde kansen te laten hebben als hun gezonde leeftijdgenoten.

Het doel van dit onderzoek was in de eerste plaats om inzicht te krijgen in het sociaal-maatschappelijk functioneren van jongeren met een chronische spijsverteringsaandoening, zoals IBD, bijvoorbeeld de ziekte van Crohn of colitis ulcerosa, chronische leveraandoeningen, zoals hepatitis B of C of een auto-immuun hepatitis, aangeboren aandoeningen van het spijsverteringskanaal, zoals anusatresie of de ziekte van Hirschsprung, coeliakie en voedselallergie. Ten tweede is gekeken in hoeverre de ziektelast, zoals de mate van fysieke klachten, medicatiegebruik, het hebben van een dieet en opnames in het ziekenhuis, een rol speelt in het sociaal-maatschappelijk functioneren. Met andere woorden, zijn er bepaalde ziektelastindicatoren die als risicofactor kunnen worden opgevat wanneer het gaat om de sociaal-maatschappelijke positie. Behalve ziektelast is onderzocht in hoeverre copingstrategieën, manieren van omgaan met problemen en stress, gerelateerd zijn aan sociaal-maatschappelijk functioneren. Het onderzoek is uitgevoerd binnen een theoretisch kader, zoals uiteengezet in hoofdstuk één.

Op basis van dit model werden onderstaande vraagstellingen geformuleerd. Deze vragen vormden de basis van dit onderzoek:

1. Hebben verschillende chronische spijsverteringsaandoeningen, zoals IBD, chronische leveraandoeningen, aangeboren aandoeningen van het spijsverteringskanaal, coeliakie en voedselallergie, een negatieve impact op het sociaal-maatschappelijk functioneren van jongeren? Ten aanzien van welke sociaal-maatschappelijke aspecten worden knelpunten ervaren door jongeren met bovengenoemde chronische spijsverteringsaandoeningen?
2. Hoe ziet de ziektelast, in termen van min of meer dagelijkse consequenties, van jongeren met verschillende chronische spijsverteringsaandoeningen eruit in vergelijking met gezonde leeftijdgenoten?
3. In hoeverre houdt de ziektelast een risicofactor in voor het functioneren op school en de vrijetijdsbesteding van jongeren met een chronische spijsverteringsaandoening?
4. In hoeverre houdt de ziektelast een risicofactor in voor de arbeidsparticipatie van jongeren met een chronische spijsverteringsaandoening?
5. Zijn er verschillen in het gebruik van generieke copingstrategieën tussen jongeren met verschillende chronische spijsverteringsaandoeningen en gezonde leeftijdgenoten? Zijn er verschillen tussen leeftijdsgroepen?
6. In hoeverre houdt het gebruik van copingstrategieën verband met het functioneren op school en de vrijetijdsbesteding van jongeren met een chronische spijsverteringsaandoening?

In totaal participeerden 758 patiënten, verdeeld over eerdergenoemde vijf diagnosegroepen, en 306 controlepersonen uit de algemene bevolking in het onderzoek, allen in de leeftijd van 12 tot en met 24 jaar. De gemiddelde leeftijd in de verschillende groepen varieerde van 17,5 tot 20 jaar. Gedetailleerde informatie over de achtergrond van deze studie, de wervingsprocedures voor patiënten en controlepersonen en de vragenlijst, is opgenomen in hoofdstuk één. De vraagstellingen van dit onderzoek worden achtereenvolgens behandeld in de hoofdstukken twee tot en met zes. Hierbij is ook een hoofdstuk gewijd aan de factorstructuur van de vragenlijst over coping (CISS-21) vanwege de toepassing in een jongere doelgroep dan waarvoor deze oorspronkelijk was ontwikkeld en getest.

In hoofdstuk twee is de eerste vraagstelling – of het hebben van een chronische spijsverteringsaandoening een negatieve impact heeft op het sociaal-maatschappelijk functioneren van jongeren – uitgewerkt. Hiertoe werden de vijf diagnosegroepen vergeleken met de controlegroep. Verscheidene aspecten van de sociaal-maatschappelijke positie bleken in negatieve zin af te wijken van die van de jongeren in de controlegroep, zoals het ziekteverzuim op school, uitgaan, arbeidsparticipatie, de noodzaak voor omscholing om werk te vinden, het hebben van een uitkering als belangrijkste inkomstenbron, problemen bij het aangaan van financiële verplichtingen, uitgaan en tevredenheid over het seksleven. Met name jongeren met een chronische leveraandoening en jongeren met IBD rapporteerden knelpunten ten aanzien van diverse sociaal-maatschappelijke aspecten. Ook jongeren met voedselallergie en aangeboren aandoeningen van het spijsverteringskanaal bleken knelpunten te ervaren, zij het in mindere mate dan jongeren met chronische leveraandoeningen en IBD. De sociaal-maatschappelijke positie van jongeren met coeliakie bleek ten aanzien van de gemeten aspecten vergelijkbaar met die van gezonde jongeren. Voor wat betreft het opleidingsniveau, activiteiten met vrienden en het aangaan en onderhouden van relaties kan geconcludeerd worden dat jongeren met chronische spijsverteringsaandoeningen dezelfde mogelijkheden en kansen hebben als hun gezonde leeftijdgenoten. In discussiegroepen met jongeren met verschillende chronische spijsverteringsaandoeningen (niet beschreven in dit proefschrift) kwam naar voren dat men uiteindelijk wel vertrouwen heeft in het goed afronden van de opleiding, het vinden van werk en het aangaan van relaties. Wel kost dat volgens hen vaak meer moeite en energie, en moeten keuzes worden gemaakt waarbij meestal de school- en werkverplichtingen voorop staan, ten koste van andere activiteiten.
Op basis van dit hoofdstuk werd geconcludeerd dat met name chronische leveraandoeningen en IBD een negatieve impact kunnen hebben op het sociaal-maatschappelijk functioneren van jongeren.

Hoofdstuk drie gaat in op de impact van ziektelast op het functioneren op school en in de vrije tijd van jongeren met een chronische spijsverterings-

aandoening. Bovendien wordt een beschrijving van de ziektelast van jongeren met verschillende spijsverteringsaandoeningen gegeven (vraagstellingen twee en drie). De resultaten lieten zien dat, in vergelijking met hun gezonde leeftijdgenoten, jongeren met een chronische leveraandoening en IBD vaker te maken hebben met fysieke klachten, een beperkte conditie, een verblijf in het ziekenhuis, medicatiegebruik en een dieet. Daarnaast rapporteerden jongeren met een chronische leveraandoening meer gevoelens van angst en depressie, en jongeren met IBD een frequenter toiletgebruik. Ook jongeren met voedselallergie gaven aan veel last van hun aandoening te hebben, in de zin van het vaker moeten volgen van een dieet, een frequenter medicatiegebruik, vaker een opname in het ziekenhuis en het hebben van een slechtere conditie vergeleken met gezonde leeftijdgenoten. Opmerkelijk was dat in deze groep de hoogste score werd aangetroffen op fysieke klachten. Een mogelijke verklaring hiervoor is dat voedselallergie vaak gepaard gaat met andere allergieën die extra klachten kunnen veroorzaken. De ziektelast zoals gerapporteerd door jongeren met coeliakie en jongeren met aangeboren aandoeningen van het spijsverteringskanaal bleek beperkt tot een aantal ziektelastindicatoren. Los van het type diagnose kunnen depressieve gevoelens, een beperkte conditie, ziekenhuisopnames, het moeten volgen van een dieet en het extra afhankelijk zijn van toiletfaciliteiten over het algemeen opgevat worden als risicofactoren voor school en vrijetijdsbesteding. Met andere woorden, hoe meer 'last' van deze factoren, hoe meer kans op bijvoorbeeld verzuim van school of minder vaak uitgaan dan gezonde leeftijdgenoten.
Geconcludeerd werd dat met name jongeren met een chronische leveraandoening, IBD en voedselallergie min of meer dagelijkse consequenties van hun aandoening ervaren. Verschillende ziektelastindicatoren kunnen worden beschouwd als risicofactor voor het functioneren op school en in de vrije tijd.

In hoofdstuk vier is de arbeidsparticipatie van jongeren met chronische spijsverteringsaandoeningen en de invloed van ziektelast nader bestudeerd (vraagstelling vier). Allereerst werden de jongeren in de verschillende diagnosegroepen vergeleken met de jongeren in de controlegroep. Alleen de jongeren die aangaven geen dagopleiding (meer) te volgen werden in deze analyses betrokken: de achterliggende gedachte hierbij was dat werkeloos zijn, of het hebben van een kleine parttime-baan (tot 19 uren per week) in

deze groep over het algemeen meer impact heeft op de kwaliteit van leven dan bij jongeren die een dagopleiding volgen. Naar een landelijk gehanteerde indeling werd het aantal werkende uren per week ingedeeld in vier categorieën: 0-11 uren, 12-19 uren, 20-34 uren en 35 uren of meer. Hierbij werd volgens de gangbare definitie van arbeidsparticipatie een werkweek van 11 uren of minder opgevat als niet participerend op de arbeidsmarkt, een werkweek van 35 uren of meer als een fulltime-baan, en beide categorieën van 12-19 en 20-34 uren als parttime-banen. Rekening houdend met de invloed van leeftijd, geslacht en sociaal-economische status (opleidingsniveau van de ouders), bleken jongeren met chronische leveraandoeningen en IBD in negatieve zin te verschillen van jongeren in de controlegroep. Met andere woorden, in vergelijking met hun gezonde leeftijdgenoten, hebben jongeren met een chronische leveraandoening en jongeren met IBD minder kansen op de arbeidsmarkt. Vervolgens werd met behulp van regressie-analyse gekeken in hoeverre de ziektelast gerelateerd is aan arbeidsparticipatie. De resultaten lieten zien dat achtergrondkenmerken als sociaal-economische status en het geslacht belangrijke verklarende factoren zijn voor de mate van arbeidsparticipatie. Daarnaast bleken de mate van toiletgebruik en dagelijks medicatiegebruik samen te hangen met arbeidsparticipatie. De volgende relaties werden aangetoond: werkzaam zijn, dus vanaf 12 uren per week, evenals het hebben van een flinke parttime-baan of fulltime werk (vanaf 20 uren per week), bleken in negatieve zin samen te hangen met sociaal-economische status. Met andere woorden, jonge patiënten met hoger opgeleide ouders bleken minder vaak een (flinke) baan te hebben. Eenzelfde negatief verband werd gevonden tussen frequent toiletgebruik en het hebben van een (flinke) baan. Ook medicatiegebruik bleek negatief samen te hangen met een fulltime baan. Tenslotte bleken mannelijke jongeren vaker een fulltime baan te hebben dan vrouwen.
Geconcludeerd werd dat jongeren met een chronische leveraandoening of IBD minder kansen hebben op de arbeidsmarkt in vergelijking met hun gezonde leeftijdgenoten. Los van de rol van achtergrondkenmerken, zoals de sociaal-economische status en het geslacht, kunnen de mate van medicatiegebruik en toiletgebruik opgevat worden als risicofactoren voor een beperktere positie op de arbeidsmarkt.

In hoofdstuk vijf is verslag gedaan van het toetsen van de factorstructuur van de vragenlijst over coping, de CISS-21. De CISS-21 staat bekend als een

valide en betrouwbaar meetinstrument voor het meten van het gebruik van generieke copingstrategieën onder volwassenen met diverse chronische aandoeningen. Er was nog maar weinig bekend over het gebruik van de CISS-21 bij jongere patiënten. Voor dit hoofdstuk werd confirmatieve factoranalyse op de CISS-21 toegepast om te onderzoeken of de factorstructuur van het instrument bij toepassing onder jongeren dezelfde is als bij toepassing onder volwassenen. De CISS-21 meet drie verschillende copingstrategieën: taakgericht, emotiegericht en vermijdingsgericht. Eerst werd deze factorstructuur getoetst in verschillende groepen: in de vijf diagnosegroepen, in de controlegroep en in vier leeftijdsgroepen. Vervolgens werd de invariantie van de factorstructuur getoetst in verschillende groepen. De resultaten leverden voldoende bewijs voor een stabiele factorstructuur bij toepassing in een jongere doelgroep, met of zonder een chronische spijsverteringsaandoening.
Geconcludeerd werd dat het mogelijk is om met dit instrument het gebruik van generieke copingstrategieën door jongeren met of zonder verschillende spijsverteringsaandoeningen, en jongeren van verschillende leeftijden, met elkaar te vergelijken.

In hoofdstuk zes is de CISS-21 toegepast om het gebruik van generieke copingstrategieën te vergelijken tussen jongeren met verschillende chronische spijsverteringsaandoeningen en hun gezonde leeftijdgenoten, alsook tussen verscheidene leeftijdsgroepen. Vervolgens is gekeken in hoeverre er een relatie bestaat tussen coping en het functioneren op school en in de vrije tijd (vraagstellingen vijf en zes). Voor wat betreft het gebruik van copingstrategieën lieten de resultaten zien dat de jongste groep, van 12 tot 14 jaar, minder vaak gebruikmaakt van de generieke copingstrategieën dan de oudere leeftijdsgroepen. Bovendien bleken jongeren van 15 tot 17 jaar minder vaak gebruik te maken van taakgerichte copingstrategieën dan de oudere leeftijdsgroepen. Een mogelijke verklaring hiervoor is dat taakgerichte copingstrategieën specifieke vaardigheden vereisen die pas in een later stadium volledig ontwikkeld zijn. Tussen de verschillende diagnosegroepen werden geen verschillen in het gebruik van copingstrategieën aangetroffen, noch tussen de jongeren met chronische spijsverteringsaandoeningen en jongeren uit de controlegroep. Dit betekent dat jongeren met verschillende chronische spijsverteringsaandoeningen niet anders omgaan met problemen en stress dan hun gezonde leeftijdgenoten. In

relatie tot het sociaal-maatschappelijk functioneren bleken taakgerichte copingstrategieën positief samen te hangen met het opleidingsniveau, vermijdingsgerichte copingstrategieën bleken positief gerelateerd aan vriendschap en uitgaan en emotiegerichte copingstrategieën bleken negatief samen te hangen met vriendschap.
Geconcludeerd werd dat jongere adolescenten over het algemeen minder gebruik maken van generieke copingstrategieën dan oudere adolescenten, met name voor wat betreft taakgerichte copingstrategieën. Jongeren met verschillende chronische spijsverteringsaandoeningen en hun gezonde leeftijdgenoten hanteren stressvolle situaties op dezelfde manier. Los van het type diagnose en de ziektelast, speelt de wijze van omgaan met problemen en stress een rol in het sociaal-maatschappelijk functioneren. Hoe deze rol er precies uitziet en in hoeverre coping zich verhoudt tot de relatie tussen ziektelast en het sociaal-maatschappelijk functioneren, vergt nader onderzoek.

In hoofdstuk zeven tenslotte zijn de belangrijkste resultaten besproken en wordt een sterkte-zwakte analyse van het onderzoek gegeven. Ook zijn in dit hoofdstuk de belangrijkste conclusies nog eens op een rij gezet. Het hoofdstuk is afgesloten met enkele aanbevelingen voor zowel artsen, patiënten en hun ouders, als voor toekomstig onderzoek. In de richting van artsen, wordt gepleit voor erkenning van de mogelijke impact van een chronische spijsverteringsaandoening op het sociaal-maatschappelijk functioneren van jongeren. Het is van belang dat er meer aandacht komt voor de mogelijke gevolgen voor het dagelijks leven, zodat eventuele keuzes en mogelijkheden tijdig met de patiënt en de ouders kunnen worden besproken. De brochure 'Jong zijn & omgaan met een chronische spijsverteringsaandoening … soms moeilijk te verteren' – tijdens het onderzoek speciaal ontwikkeld voor patiënten en hun ouders - kan een goed hulpmiddel zijn om jongeren te informeren over de mogelijke sociaal-maatschappelijke gevolgen. Ook patiënten zelf en hun ouders worden aangemoedigd om informatie te vragen, via hun arts, huisarts of patiëntenorganisatie, zodat tijdig keuzes kunnen worden gemaakt of maatregelen getroffen. Ook in de richting van toekomstig onderzoek zijn verscheidene aanbevelingen gedaan. Eén van de aanbevelingen betreft de uitvoering van een vervolgonderzoek naar de sociaal-maatschappelijke positie van jongeren met chronische leveraandoeningen en IBD die in het huidige onderzoek participeerden. Een dergelijke herhaling zal belangrijke informatie opleveren over effecten op de lange termijn. Op dit moment worden voorbereidingen getroffen om deze vervolgstudie volgend jaar uit te voeren: dan zijn er vijf jaar verstreken sinds de dataverzameling voor het huidige onderzoek.

Appendices

Appendix 1: Overview of participating hospitals and the recruitment of patients
Appendix 2: Questionnaire

Appendix 1 Overview of participating hospitals and the recruitment of patients

Overzicht werving van patiënten per diagnosegroep naar deelnemende ziekenhuizen (%, verticaal)

	Diagnosegroep[1]					Totaal
	I	II	III	IV	V	
AZN / Radboud	12,6	1,0	87,1	1,9	-	22,6
AZR / Dijkzigt / Sophia	15,9	44,0	10,7	-	46,9	20,9
UMC Utrecht / WKZ	8,6	21,8	1,5	29,3	32,0	15,8
AMC / Emma kinderziekenhuis	24,7	18,1	0,7	-	46,9	11,2
AZG	18,9	13,5	-	1,4	16,5	11,1
Coeliakievereniging	-	-	-	43,7	-	7,1
IBD studiecentrum Zuid-Limburg	17,8	-	-	-	-	6,1
LUMC	-	-	-	11,2	-	1,8
Rijnstate	-	-	-	10,7	-	1,7
Zuiderziekenhuis	-	-	-	-	4,6	0,7
Juliana Kinderziekenhuis	0,7	-	-	1,9	-	0,5
Bosch Medicentrum	0,9	1,6	-	-	-	0,5
Totaal (n=100%)	454	193	272	215	194	1.328

[1] I = IBD II = chronische leveraandoeningen III = aangeboren aandoeningen
IV = coeliakie V = voedselallergie

Appendix 2 Questionnaire

A. GEZONDHEID

1. Heb je behalve een spijsverteringsaandoening(en) één of meer andere aandoeningen?
(Het maakt niet uit of deze wel of niet met je spijsverteringsaandoening te maken hebben)
☐ nee
☐ ja, namelijk...

2. Hieronder worden enkele gezondheidsklachten genoemd. Wil je per klacht aankruisen in welke mate je ***de afgelopen 4 weken*** last van deze klachten hebt gehad? Als je last hebt van andere klachten, kun je die onder aan het rijtje invullen.

	geen last	een beetje last	veel last
* Buikpijn (darmkrampen/pijn in leverstreek)	☐	☐	☐
* Gewrichtspijn	☐	☐	☐
* Boeren	☐	☐	☐
* Misselijkheid	☐	☐	☐
* Overgeven	☐	☐	☐
* Koorts	☐	☐	☐
* Schilferende huid	☐	☐	☐
* Jeuk in mondholte	☐	☐	☐
* Jeuk op een andere plaats	☐	☐	☐
* Huiduitslag	☐	☐	☐
* Zwelling in mondholte	☐	☐	☐
* Zwelling op een andere plaats	☐	☐	☐
* Kortademigheid	☐	☐	☐
* Niezen/'loopneus'	☐	☐	☐
* Ontlasting niet op kunnen houden	☐	☐	☐
* Diarree	☐	☐	☐
* Obstipatie (verstopping, ontlasting moeilijk kwijt kunnen)	☐	☐	☐
* Winderigheid	☐	☐	☐

* Bloed/slijmverlies bij ontlasting	☐	☐	☐
* Moeheid	☐	☐	☐
* Geen eetlust	☐	☐	☐
* Een andere klacht, namelijk:	☐	☐	☐
* Een andere klacht, namelijk:	☐	☐	☐

3. De volgende uitspraken gaan over hoe je je ***de afgelopen week*** voelde. Wil je per uitspraak aangeven welk antwoord het beste bij jou past? Denk niet te lang na. Er zijn geen foute antwoorden, elk antwoord is goed, zolang het je eigen indruk weergeeft. Het gaat dus alleen om de afgelopen week.

Bronnen vraag 3: Spinhoven P, Ormel J, Sloekers PPH, *et al*. A validation study of the Hospital Anxiety and Depression Scale (HADS) in different groups of Dutch subjects. *Psychol Med* 1997; **27**:363-70. Zigmund AS, Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* 1983; **67**:361-70.

3a. Ik voel me gespannen

- ☐ meestal
- ☐ vaak
- ☐ af en toe, soms
- ☐ helemaal niet

3b. Ik geniet nog steeds van de dingen waar ik vroeger van genoot

- ☐ zeker zoveel
- ☐ wel wat minder
- ☐ duidelijk minder
- ☐ eigenlijk nauwelijks nog

3c. Ik heb een soort angstgevoel alsof er iets vreselijks zal gebeuren

- ☐ ja zeker en vrij erg
- ☐ ja, maar niet zo erg
- ☐ een beetje, maar het hindert me niet
- ☐ helemaal niet

3d. Ik kan best lachen en de dingen van de vrolijke kant zien

- ☐ net zoveel als vroeger
- ☐ nu wel wat minder
- ☐ duidelijk minder
- ☐ helemaal niet

3e.Ik maak me ongerust
- ☐ heel erg vaak
- ☐ vaak
- ☐ af en toe, maar niet zo vaak
- ☐ heel soms

3f. Ik voel me opgewekt
- ☐ helemaal niet
- ☐ heel af en toe
- ☐ soms
- ☐ meestal

3g.Ik kan best rustig zitten en me ontspannen
- ☐ jazeker
- ☐ meestal
- ☐ af en toe
- ☐ helemaal niet

3h.Ik heb het gevoel dat alles moeizamer gaat
- ☐ bijna altijd
- ☐ heel vaak
- ☐ soms
- ☐ helemaal niet

3i. Ik heb een soort angstig, gespannen gevoel in mijn buik
- ☐ helemaal niet
- ☐ soms
- ☐ vrij vaak
- ☐ heel vaak

3j. Het interesseert me niet meer hoe ik er uitzie
- ☐ inderdaad, helemaal niet meer
- ☐ niet meer zoveel als eigenlijk zou moeten
- ☐ het interesseert me wel, maar iets minder dan vroeger
- ☐ het interesseert me nog net zoveel (of net zo weinig) als vroeger

3k. Ik ben onrustig en voel dat ik iets te doen moet hebben
- ☐ inderdaad, heel duidelijk
- ☐ duidelijk
- ☐ enigszins
- ☐ helemaal niet

3l. Ik verheug me van tevoren op dingen die komen gaan
- ☐ net zoveel (of net zo weinig) als vroeger
- ☐ een beetje minder dan vroeger
- ☐ veel minder dan vroeger
- ☐ bijna nooit

3m. Ik raak plotseling in paniek
- ☐ inderdaad, zeer vaak
- ☐ tamelijk vaak
- ☐ soms
- ☐ helemaal nooit

3n. Ik kan van een goed boek genieten, of van zoiets als een radio- of televisieprogramma
- ☐ vaak
- ☐ tamelijk vaak
- ☐ af en toe
- ☐ heel zelden

4. Ben je wel eens opgenomen geweest in het ziekenhuis (met minstens één overnachting) en zo ja, hoe vaak en waarvoor?
(als je niet meer precies weet hoe vaak, wil je dan schatten, hoe vaak ongeveer?)
- ☐ nee
- ☐ ja: .... keer, voor
....

5. Ben je wel eens geopereerd en zo ja, hoe vaak en waarvoor?
- ☐ nee
- ☐ ja: .... keer, voor ....

6a. Gebruik je op dit moment medicijnen?

- ☐ nee → ***ga nu door met vraag 7***
- ☐ ja, soort/naam medicijn:

  ....
  ....
  ....

6b. Hoe vaak per dag of per week gebruik je medicijnen?

(als je meerdere soorten medicijnen gebruikt op hetzelfde tijdstip dan geldt dat als één keer)

.... keer per dag / per week ***(graag omcirkelen)***

7. Moet je letten op *wat* je eet of drinkt?

- ☐ nee, ik kan eten en drinken wat ik wil → ***ga nu door met vraag 8***
- ☐ ja, ik moet er wel een beetje op letten wat ik eet of drink
- ☐ ja, ik moet toch wel oppassen met wat ik eet of drink
- ☐ ja, ik volg een echt dieet

8. Moet je 's nachts je bed uit vanwege ontlasting?

(ook het verzorgen van een stoma of darmen spoelen, e.d.)

- ☐ ja, altijd
- ☐ ja, meestal wel
- ☐ even vaak wel als niet
- ☐ nee, meestal niet
- ☐ nee, nooit

9. Hieronder volgen enkele activiteiten. Wil je per activiteit aangeven in hoeverre je er ***de afgelopen 4 weken*** moeite mee hebt gehad?

Bron vraag 9: Verrips GH, Vogels AGC, Verloove-Vanhorick SP, *et al*. Health-Related Quality of Life Measure for Children - the TACQOL. *J Applied Therapeutics* 1998;**1/4**:357-60.

	geen moeite mee	soms moeite mee	vaak moeite mee
* Rennen	☐	☐	☐
* Lopen	☐	☐	☐
* Staan	☐	☐	☐
* De trap aflopen	☐	☐	☐
* Spelen/sporten	☐	☐	☐
* Lang hollen of lopen, met je uithoudingsvermogen	☐	☐	☐
* Het bewaren van je evenwicht	☐	☐	☐
* Dingen handig en vlug doen	☐	☐	☐

B. HET DAGELIJKS LEVEN

In dit deel komen verschillende onderwerpen aan bod. We hebben ze verdeeld in blokken. Je hoeft niet alle blokken te beantwoorden. Bovenaan ieder blok staat aangegeven of ze voor jou bedoeld zijn. Het wijst zich vanzelf.

1. Welke van de volgende omschrijvingen is op dit moment op jou van toepassing? *(je kunt meerdere antwoorden aankruisen)*
   - ☐ ik ben scholier of student
   - ☐ ik ben werkzaam in loondienst, voor .... uur per week *(geen vakantiewerk)*
   - ☐ ik ben werkzaam in een eigen bedrijf (zelfstandige)
   - ☐ ik ben werkloos / werkzoekend (geregistreerd bij het arbeidsbureau)
   - ☐ ik ben arbeidsongeschikt verklaard, voor .... procent
   - ☐ ik ben huisvrouw/huisman
   - ☐ ik doe vrijwilligerswerk (of werk met behoud van uitkering), voor .... uur per week
   - ☐ ik zit in de ziektewet

De volgende vragen, vraag 2 t/m 10 gaan over school en opleiding

2. Wat is de <u>hoogste</u> opleiding die je hebt afgerond?
   - ☐ (nog) geen
   - ☐ lagere school / basisonderwijs
   - ☐ speciaal onderwijs (SO)
   - ☐ voortgezet speciaal onderwijs (VSO)
   - ☐ lager beroepsonderwijs (huishoudschool, LTS, LEAO, enz.)
   - ☐ MAVO
   - ☐ HAVO, VWO/GYM
   - ☐ middelbaar beroepsonderwijs (MTS, MEAO, enz.)
   - ☐ hoger beroepsonderwijs (HTS, HEAO, Sociale Academie, enz.)
   - ☐ universiteit
   - ☐ een andere opleiding, namelijk: ....

3. Volg je op dit moment een opleiding? Zo ja, welke opleiding en in welk jaar zit je? *(ook als je op dit moment door ziekte niet naar school kunt maar anders wel was gegaan, volg je een opleiding)*
   ☐ nee, ik volg op dit moment geen opleiding
   ☐ lagere school
   ☐ speciaal onderwijs (SO)
   ☐ voortgezet speciaal onderwijs (VSO)
   ☐ lager beroepsonderwijs (huishoudschool, LTS, LEAO, enz.)
   ☐ MAVO
   ☐ HAVO, VWO/GYM
   ☐ middelbaar beroepsonderwijs (MTS, MEAO, enz.)
   ☐ hoger beroepsonderwijs (HTS, HEAO, Sociale Academie, enz.)
   ☐ universiteit
   ☐ een andere opleiding, namelijk: ....

4. Ben je wel eens in verband met ziekte (*algemeen, dus ook griep enz.*) ***langer dan een week*** afwezig geweest van school/opleiding? Zo ja, hoe vaak is dat gebeurd en tijdens welke school/opleiding was dat?
   ☐ nee
   ☐ ja, tijdens:
   ....(school/opleiding) ... keer, in totaal ongeveer ..... weken
   .... (school/opleiding) ... keer, in totaal ongeveer ..... weken
   .... (school/opleiding) ... keer, in totaal ongeveer ..... weken

5. Heb je wel eens een jaar over moeten doen? Zo ja, hoe vaak is dat gebeurd en op welke school/opleiding was dat?
   ☐ nee
   ☐ ja, op de: .... (school/opleiding)
   .... (school/opleiding)
   .... (school/opleiding)

De vragen 6 en 7 gaan over ***toekomstig betaald*** werk. Hiermee wordt 'echt' werk bedoeld, dus bijbaantjes of vakantiewerk tellen niet mee. Deze vragen ***alleen invullen als je (nog) niet hebt gewerkt***. Anders doorgaan met het volgende blok (vraag 8).

6. Heb je wel eens gesolliciteerd naar een betaalde baan?
Met een betaalde baan wordt 'echt' werk bedoeld, dus bijbaantjes of vakantiewerk tellen niet mee. Het maakt verder niet uit of het tijdelijk of vast werk is, of part-time of full-time.
   ☐ nee
   ☐ ja

7. Ben je op dit moment op zoek naar een betaalde baan?
   ☐ nee
   ☐ ja

De vragen 8 t/m 12 gaan over ***huidig*** werk. Deze vragen ***alleen invullen als je werkt of hebt gewerkt in een betaalde baan of eigen bedrijf***. Studenten en zij die (nog) geen betaald werk hebben gehad, kunnen doorgaan met het volgende blok (vraag 13).

8. Hoeveel tijd zat er tussen het afronden van je opleiding en het vinden van een betaalde baan (je eerste baan)? *(Bijbaantjes of vakantiewerk tellen <u>niet</u> mee. Tijdelijk of vast werk, part-time of full-time, werk in loondienst of als zelfstandige maakt niet uit)*.
   .... maanden / jaren ***(graag omcirkelen)***

9. Ben je op dit moment op zoek naar een betaalde baan of op zoek naar ander betaald werk?
   ☐ nee
   ☐ ja

10. Heb je op dit moment betaald werk?
   ☐ ja, een vaste baan
   ☐ ja, tijdelijke baan, namelijk voor .... jaar
   ☐ ja, in een eigen bedrijf
   ☐ nee, op dit moment geen betaald werk

11. Is je werk op tenminste jouw opleidingsniveau?
(als je op dit moment niet werkzaam bent, bedoelen we je laatste baan)
☐ ja, mijn werk is tenminste op mijn opleidingsniveau
☐ nee, mijn werk is onder mijn opleidingsniveau

12. Was (of is) *omscholing* nodig omdat je met je opleiding niet voldoende uit de voeten kon (kunt)?
☐ nee, omscholing was (is) niet nodig
☐ ja, ik heb mij omgeschoold / ik ben juist bezig met omscholing

De vragen 13 t/m 36 gaan over financiële verplichtingen.

13. Wat is jouw bron van inkomen? *(je kunt meerdere antwoorden aankruisen)*
☐ studiefinanciering
☐ loon/salaris
☐ inkomsten als zelfstandig ondernemer
☐ inkomsten via partner
☐ bijstandsuitkering (ABW)
☐ werkloosheidsuitkering (WW, RWW, wachtgeld)
☐ uitkering bij ziekte (WULBZ, ziektewet)
☐ arbeidsongeschiktheidsuitkering (WAO, AAW, WAZ, WAJONG)
☐ nabestaandenuitkering (ANW, AWW)

14a. Heb je wel eens een verzekering anders dan voor ziektekosten afgesloten of geprobeerd af te sluiten?
(Denk bijvoorbeeld aan een levensverzekering voor een hypotheek, arbeidsongeschiktheidsverzekering voor zelfstandige ondernemers, autoverzekering)
☐ nee → ***ga nu door met vraag 15***
☐ ja

14b. Is het wel eens voorgekomen dat jou een verzekering is geweigerd?

☐ nee
☐ ja, nl: .... *(graag invullen welke soort verzekering)*

14c. Is het wel eens voorgekomen dat je je voor sommige risico's <u>niet</u> kon verzekeren?

☐ nee
☐ ja, nl: .... *(graag invullen welke soort verzekering)*

14d. Is het wel eens voorgekomen dat je voor een verzekering een <u>hogere</u> premie moest betalen?

☐ nee
☐ ja, nl: .... *(graag invullen welke soort verzekering)*

15a. Heb je wel eens een hypotheek afgesloten of geprobeerd af te sluiten?

☐ nee → ***ga nu door met vraag 16***
☐ ja

15b. Is jou wel eens een hypotheek geweigerd?

☐ nee
☐ ja

16a. Heb je wel eens een andere lening dan een hypotheek afgesloten of geprobeerd af te sluiten?

☐ nee → ***ga nu door met vraag 17***
☐ ja

16b. Is jou wel eens een lening geweigerd?

☐ nee
☐ ja

Vraag 17 gaat over het besteden van vrije tijd.

17. Hieronder staan verschillende activiteiten. Wil je per activiteit aankruisen hoe vaak je dat doet?

Bron vraag 17: Statistics Netherlands (CBS).
Statistical yearbook of The Netherlands.
Voorburg/Heerlen: CBS; 1999

Activiteit:	eigenlijk nooit	af en toe	regel-matig	erg vaak
* TV kijken	☐	☐	☐	☐
* Radio luisteren	☐	☐	☐	☐
* CD's/cassettebandjes/LP's luisteren	☐	☐	☐	☐
* Computerspelletjes	☐	☐	☐	☐
* Internetten	☐	☐	☐	☐
* bezoek bibliotheek	☐	☐	☐	☐
* Winkelen	☐	☐	☐	☐
* Zelf aan muziek/foto/film/toneel doen	☐	☐	☐	☐
* Lezen van boeken	☐	☐	☐	☐
* Op je kamer zijn en (n)iets doen	☐	☐	☐	☐
* Spelletjes doen, ook dammen of schaken	☐	☐	☐	☐
* Bezoek sociaal cultureel centrum	☐	☐	☐	☐
* Bezoek disco/house	☐	☐	☐	☐
* Bezoek café/kroeg	☐	☐	☐	☐
* Naar toneel/concert gaan	☐	☐	☐	☐
* Naar museum gaan	☐	☐	☐	☐
* Naar bioscoop gaan	☐	☐	☐	☐
* Naar dierentuin/recreatiepark gaan	☐	☐	☐	☐
* Naar sportwedstrijd gaan	☐	☐	☐	☐
* Zwemmen of andere watersport beoefenen	☐	☐	☐	☐
* Fietsen of wandelen	☐	☐	☐	☐
* Andere sporten beoefenen	☐	☐	☐	☐
* Naar het strand gaan	☐	☐	☐	☐
* Naar bos/heide, stadspark of een meer gaan	☐	☐	☐	☐
* Verzamelen van dingen	☐	☐	☐	☐
* Schilderen, handwerken	☐	☐	☐	☐
* Doe het zelven/klussen	☐	☐	☐	☐
* Zorgen voor een huisdier	☐	☐	☐	☐

Hieronder volgen enkele vragen over relaties en seksualiteit. Deze vragen zijn onderverdeeld in drie blokken. Je hoeft ze niet alle drie te beantwoorden. Het eerste blok, vraag 18 t/m 23 is bedoeld voor ***iedereen***, de andere twee wijzen zich vanzelf.

18. Hoeveel vrienden/vriendinnen heb je?
   ☐ eigenlijk niemand
   ☐ 1-2
   ☐ 3-5
   ☐ 6-10
   ☐ meer dan 10

Bron vraag 18 t/m 23: Vogels T, van der Vliet R. *Jeugd en seks. Gedrag en gezondheidsrisico's bij scholieren.* [Youth and sex. Behaviour and health risks in pupils.] Den Haag: SDU; 1990.

19. Hoe vaak ga jij met vrienden/vriendinnen op stap (bijv. naar een feest of de stad ingaan)?
   ☐ bijna elke dag
   ☐ minstens 1 keer per week
   ☐ minstens 1 keer per maand
   ☐ minder dan 1 keer per maand
   ☐ nooit

20. Hoe vaak heb jij de laatste tijd geprobeerd iemand te versieren?
   ☐ nooit
   ☐ soms
   ☐ regelmatig
   ☐ vaak

21. Als ik iemand wil versieren, dan ....

	dat past helemaal niet bij mij	dat past een beetje bij mij	dat past bij mij	dat past helemaal bij mij
* Voel ik me zeker van mezelf	☐	☐	☐	☐
* Ben ik verlegen	☐	☐	☐	☐
* Weet ik niet goed wat ik moet zeggen	☐	☐	☐	☐
* Laat ik duidelijk merken wat ik wel en niet wil	☐	☐	☐	☐
* Ben ik bang om af te gaan	☐	☐	☐	☐
* Wil ik zo snel mogelijk met die ander vrijen	☐	☐	☐	☐

22. Welke situatie is ***op dit moment*** op jou van toepassing?
   ☐ vaste verkering
   ☐ los-vaste verkering
   ☐ geen verkering

23. Als je jouw ervaring met seks vergelijkt met de ervaring van je vrienden/vriendinnen, dan is jouw ervaring .....
   ☐ veel groter
   ☐ groter
   ☐ hetzelfde
   ☐ kleiner
   ☐ veel kleiner

De vragen vraag 24 en 25 ***alleen invullen als je <u>wel eens</u> met iemand hebt gevreeën***. Anders doorgaan met vraag 1 van deel C.

Bron vraag 24 en 25: Vogels T, van der Vliet R. *Jeugd en seks. Gedrag en gezondheidsrisico's bij scholieren.* [Youth and sex. Behaviour and health risks in pupils.] Den Haag: SDU; 1990.

24. Heb jij je wel eens belemmerd gevoeld bij het vrijen (bijvoorbeeld door schaamte)?
   ☐ nooit
   ☐ soms
   ☐ regelmatig

25. Hoe tevreden ben jij over je huidige seksleven?
Omcirkel een rapportcijfer van 1 (heel erg ontevreden) tot en met 10 (heel erg tevreden):
Rapportcijfer: 1 2 3 4 5 6 7 8 9 10

C. ALGEMENE GEGEVENS

1. Wat is je leeftijd?
   .... jaar

2. Ben je jongen/man of meisje/vrouw?
   ☐ jongen/man
   ☐ meisje/vrouw

3. Met onderstaande kenmerken willen we nagaan of je wel of niet (meer) in de puberteit zit. Wil je per kenmerk aankruisen of deze wel of niet op jou van toepassing is?

	ja	nee
* Haargroei onder de oksels	☐	☐
* Jongens/mannen: een lagere stem krijgen of hebben (baard in de keel)	☐	☐
* Meisjes/vrouwen: de eerste menstruatie gehad	☐	☐

4. Hoe is je woon- en leefsituatie? *(let op: je kunt hier meer dan één antwoord aankruisen!)*
   ☐ ik woon bij (één van) mijn ouders
   ☐ ik woon met nog .... broers / zussen
   ☐ ik woon alleen en heb geen duurzame relatie
   ☐ ik heb een duurzame relatie maar woon niet samen met mijn partner
   ☐ ik woon samen met mijn partner/echtgenoot of echtgenote
   ☐ ik woon met mijn kind(eren); aantal kinderen: ....
   ☐ op mij is een andere situatie van toepassing,
   namelijk: ....

5. Wat is de hoogste opleiding die je ***moeder*** heeft afgerond?
   - ☐ geen / lagere school / basisonderwijs
   - ☐ lager beroepsonderwijs
   - ☐ (M)ULO, MAVO, drie jaar HBS
   - ☐ middelbaar beroepsonderwijs
   - ☐ HBS, HAVO, VWO/GYM, MMS
   - ☐ hoger beroepsonderwijs
   - ☐ universitair onderwijs

6. Wat is de hoogste opleiding die je ***vader*** heeft afgerond?
   - ☐ geen / lagere school / basisonderwijs
   - ☐ lager beroepsonderwijs
   - ☐ (M)ULO, MAVO, drie jaar HBS
   - ☐ middelbaar beroepsonderwijs
   - ☐ HBS, HAVO, VWO/GYM, MMS
   - ☐ hoger beroepsonderwijs
   - ☐ universitair onderwijs

7. Zou je het leuk vinden en ben je bereid om tegen het einde van dit jaar mee te doen aan een groepsdiscussie? Dan worden de resultaten besproken en overlegd wat mogelijke oplossingen zijn voor bestaande knelpunten. De groep zal uit ongeveer 10 personen bestaan.
   (Als je 'ja' aankruist, krijg je vanzelf een uitnodiging en kun je alsnog bedenken of je wel of niet mee wilt doen.)
   ☐ ja, ik wil graag een uitnodiging ontvangen
   ☐ nee, ik wil liever niet meedoen aan een groepsdiscussie

8. Zou je bereid zijn en stem je ermee in om na enkele jaren nog eens een dergelijke vragenlijst te ontvangen en in te vullen? Dit betekent dat we dan je naam- en adresgegevens bewaren. Voor dit onderzoek maakt het geen verschil: de bewerking en de rapportage blijft in alle gevallen geheel anoniem.
   ☐ ja
   ☐ nee

CISS-21 uit de ‘extra vragenlijst’

Hieronder staan enkele manieren opgesomd die mensen gebruiken om op moeilijke of stressvolle situaties te reageren. Wil je bij elke uitspraak aankruisen in hoeverre je die manier gebruikt als je zo'n situatie meemaakt? Van 'helemaal niet' tot 'heel erg sterk'.

Met andere woorden: wat past ***het beste bij jou?***

		helemaal niet				heel erg sterk
*	Een tijdje er tussenuit gaan om afstand te nemen van de situatie	☐	☐	☐	☐	☐
*	Me concentreren op het probleem en kijken hoe ik het kan oplossen	☐	☐	☐	☐	☐
*	Mezelf verwijten dat ik in zo'n situatie terecht gekomen ben	☐	☐	☐	☐	☐
*	Mezelf trakteren op iets heel lekkers (om mezelf te verwennen)	☐	☐	☐	☐	☐
*	Me zorgen maken over dat ik het allemaal niet aankan	☐	☐	☐	☐	☐
*	Nadenken over hoe ik vergelijkbare problemen heb opgelost	☐	☐	☐	☐	☐
*	Een vriend(in) opzoeken	☐	☐	☐	☐	☐
*	Een koers bepalen en die volgen	☐	☐	☐	☐	☐
*	Iets voor mezelf gaan kopen	☐	☐	☐	☐	☐
*	Mezelf verwijten dat ik te emotioneel ben over wat er gebeurd is	☐	☐	☐	☐	☐
*	Mijn best doen om de situatie te begrijpen	☐	☐	☐	☐	☐
*	Me verward voelen	☐	☐	☐	☐	☐
*	Onmiddellijk ingrijpen om de situatie te redden	☐	☐	☐	☐	☐
*	Mezelf verwijten dat ik niet weet wat ik moet doen	☐	☐	☐	☐	☐
*	De tijd doorbrengen met een bijzonder persoon	☐	☐	☐	☐	☐
*	Nadenken over de gebeurtenis en leren van mijn fouten	☐	☐	☐	☐	☐
*	Wensen dat ik kon veranderen wat er gebeurd was en hoe ik me voelde	☐	☐	☐	☐	☐
*	Iets lekkers gaan halen buiten de deur	☐	☐	☐	☐	☐
*	Het probleem goed analyseren alvorens aktie te ondernemen	☐	☐	☐	☐	☐
*	Me richten op mijn tekortkomingen	☐	☐	☐	☐	☐
*	Een vriend(in) opbellen	☐	☐	☐	☐	☐

Zijn er nog andere manieren waarop je omgaat
met moeilijke situaties dan hierboven genoemd?

Ja, namelijk:

*	....	☐	☐	☐	☐	☐
*	....	☐	☐	☐	☐	☐

Bronnen: Endler NS, Parker DA. *Coping Inventory for Stressful Situations (CISS): Manual (2nd ed.).* Toronto: Multi Health Systems;1999.
De Ridder DTD & Maes S. *Dutch translation of the CISS-21.* Lisse: Swets & Zeitlinger (Swets Test Publishers); in press.

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Curriculum vitae

Hiske (Hilly) Calsbeek is geboren op 21 januari 1969 in Uithuizen. Na het behalen van het vwo-diploma in Warffum studeerde zij Gezondheidswetenschappen aan de Universiteit Maastricht (destijds Rijksuniversiteit Limburg). In 1991 studeerde zij af in de richting verplegingswetenschap. Daarna behaalde zij in 1993 het diploma HBO-verpleegkunde aan de Hogeschool Sittard. Hierna volgden enkele aanstellingen in beleids- en projectfuncties in achtereenvolgens het Canisius-Wilhelmina Ziekenhuis in Nijmegen, de Sint Maartenskliniek in Nijmegen en bij NU'91 in Utrecht. Sinds 1996 werkt zij bij het NIVEL en heeft zij (mee)gewerkt aan diverse studies, waaronder het onderzoek dat ten grondslag ligt aan dit proefschrift.