The impact of paediatric inflammatory bowel disease. Epidemiology, disease activity and quality of life

Loonen, H.J.

Citation for published version (APA):
Chapter 4.4

Coping Strategies and Quality of Life of Adolescents with Inflammatory Bowel Disease

Hester J Loonen, Martha A Grootenhuis, Bob F Last, and Bert HF Derkx
Abstract

Objective
This study aims to compare generic coping styles adopted by adolescents suffering from inflammatory bowel disease (IBD) to styles used by their healthy peers, and to assess the association between coping styles and health-related quality of life (HRQoL).

Methods
A generic coping style instrument, a disease related coping style instrument and a disease specific HRQoL instrument were administered to 65 adolescents (12-18 years old) with IBD. Normative data from the generic instrument were available. Mean domain scores of IBD patients were compared with normative scores using student t-test. Multivariate linear regression analyses were performed on models with HRQoL domains as dependent, and pre-selected demographic and disease related characteristics and coping styles as independent variables.

Results
Adolescents with IBD use more avoidant coping styles than their healthy peers. HRQoL is strongly associated with coping styles. More use of a predictive coping style (having positive expectations about the disease) is associated with better HRQoL in three out of six HRQoL domains.

Conclusion
The cognitive control strategy of predictive coping is strongly associated with HRQoL: equally strong as disease activity but more strongly than disease course severity. This study suggests that if predictive control strategies can be increased, the HRQoL of adolescents with IBD might also be improved.
Chapter 4.4 Coping and QoL

Introduction

Inflammatory Bowel Disease (IBD) comprises three main disease entities: Crohn’s disease, ulcerative colitis and indeterminate colitis. Its onset is highest in adolescence and young adulthood, but IBD can be diagnosed at as early as 6 months of age. Adolescents with IBD experience considerable stress related to IBD and developmental issues, therefore it is important to examine their coping styles and health-related quality of life (HRQoL) for a number of reasons. First, symptoms show an unpredictable pattern: they can subside for longer periods of time and unexpectedly re-appear with serious consequences. Second, most patients will require surgical removal of part(s) of the bowel at some point in the course of their disease because of intractable disease activity. This is also unpredictable as to when this will happen. Third, most patients will need to take lifelong medication in order to keep symptoms under control, even during long periods of disease remission. Fourth, if the onset of IBD occurs during adolescence, developing feelings of autonomy and gaining personal identity may be complicated. Lastly, symptoms such as frequent (often bloody) diarrhoea, general malaise and severe stomachaches cause severe social impairments. The fact that IBD is incurable and has unexpected flare-ups characterises it as a continuous stressor.

As for psychological functioning, Engström (1992), Burke et al. (1989), Burke, Kocoshis, Chandra, Whiteway and Sauer (1990), and Raymer, Weiniger and Hamilton (1984) found adolescents with IBD to be more depressed compared to children and adolescents with other diseases. Engström (1992) also found children to be more anxious and suffering from lower self-esteem. Studies have reported that children with IBD more frequently denied the existence of their problems. From this, it can be derived that this group is more “at risk” for negative coping.

As for HRQoL, no studies have so far described this outcome of children with IBD because of the absence of a reliable and robust instrument. HRQoL is frequently defined as “the physical, psychological and social domains of health that are influenced by a person’s experiences, beliefs, expectations and perceptions” (Testa & Simonson, 1996). Recently, a disease specific instrument was developed which proved reliable and valid (Loonen et al., 2002). Using a generic instrument, the HRQoL of adolescents with IBD was reported to be impaired compared to that of healthy peers in some (i.e. body complaints, motor functioning, autonomy, and negative emotions), but not all domains assessed (Loonen, Grootenhuis, Last, Koopman & Derkx, 2002). Disease activity appeared to be a strong factor influencing HRQoL scores.

So, although some research is dedicated to the emotional consequences and HRQoL of children with IBD, little attention has been paid to the influence of coping strategies in this population, and only a small number of studies looked into a broader context of stress, appraisal and coping. In relation to common stressors, children with various chronic diseases were
previously found to adopt coping strategies comparable to those adopted by healthy children (Boekaerts & Roder, 1999). However, it is unclear whether this is true for all coping strategies.

Coping is defined as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding a person’s resources” (Lazarus & Folkman, 1984). The primary appraisal of the situation of a chronic illness is threatening and will result in negative emotions (Lazarus & Folkman, 1984). Several other components of the situation will be considered resulting in the secondary coping process. Based on the adaptational outcome of this coping process, and changes in the situation, the child will constantly reappraise the situation and possibly generate other coping strategies. The outcome of the relationship between the child and the stressful situation will therefore be dependent on the characteristics of the specific situation, and the deployment of resources and coping strategies (Frijda, 1986, Lazarus & Folkman, 1984). The effectiveness of coping efforts determine the negative and positive emotions and also the HRQoL, and by that the need for psychosocial interventions (Last & Grootenhuis, 1998).

An important component of the situation that determines the coping process of children with IBD, is the uncontrollability of the situation. Rothbaum, Weisz and Snyder (1982) emphasise the concept of uncontrollability in their two-process model of perceived control. They distinguish primary and secondary control strategies. Primary control is the attempt of a person in a certain stressful situation to alter their environment in order to solve the problem. Secondary control strategies are attempts aimed at modifying oneself, e.g. by changing one’s hopes, expectations or interpretations. This is similar to the classification of problem- and emotion-focused coping strategies (Lazarus & Folkman, 1984). Rothbaum et al. (1982), however, made a further classification into four strategies, i.e. (1) predictive, (2) vicarious, (3) illusory and (4) interpretative control, all possibly used in primary or secondary form. Manifestations of these secondary control strategies in children with a chronic disease are found when they predict a certain (positive or negative) course of the disease in order to avoid disappointments (secondary predictive control), in attributing special power to the doctor on whom all hope is focused (secondary vicarious control), in wishful thinking (secondary illusory control) and in attempts to understand and explain the disease (secondary interpretative control). Children with IBD have few possibilities to change the situation and will therefore be highly dependent on the use of (secondary) cognitive control strategies. The model of Rothbaum et al. (1982) proved to be a useful conceptual framework to better comprehend the cognitive control strategies of children with cancer and their parents (Grootenhuis & Last, 2001; Grootenhuis, Last, de Graaf-Nijkerk & van der Wel, 1996) and was used as a premise in this study among adolescents with IBD.

The aims of this study were to describe coping strategies adolescents with IBD adopt, and to identify predictors of HRQoL. First, we wanted to compare the coping styles adolescents with IBD use to those used by healthy peers. Second, we studied which variables (socio-
demographic, medical and related to coping) most adequately predict the HRQOL of adolescents with IBD.

Methods

Patients

All patients aged between 12 and 18 years old registered in the paediatric IBD databases of two hospitals were contacted by mail and asked to participate. Both centres serve as secondary care hospitals as well as tertiary centres for the middle and western part of the Netherlands. All children with IBD are treated in hospitals, whereas adult patients with IBD are sometimes treated by their general physician. Therefore, these hospitals have a fairly good representation of the paediatric IBD population in this country. Patients were diagnosed with IBD based upon medical guidelines. There were 65 of a total of 104 adolescents who responded (response rate 64%). Mean age was 15.4 years (SD 1.7). Of these 65 adolescents, 45 (54%) were boys, 52% had Crohn’s disease, 45% had ulcerative colitis, and 3% had indeterminate colitis. Median disease duration since diagnosis was 28 months (range 1.5 to 145 months), median disease activity score was 7.0 (range 4 to 16), median disease severity score was 8.5 (range 4 to 17) (all explained below). Responders only differed from non-responders in age: non-responders were on average 1 year older (student t-test, p= 0.043). All other variables were equally distributed among both groups.

From a group of healthy school-attending adolescents (n= 660), normative data for a generic coping style instrument were obtained (Schreurs, Tellegen & van de Willige, 1984). Adolescents attended four high schools in the Netherlands. As for the age distribution, 52% were 13 years old, 32% were 14 years old, and 15% of the adolescents were 15 years old; 53% were girls.

Instruments

The Utrecht Coping List for Adolescents UCL-A (Schreurs et al., 1984) comprises 44 items in seven scales and contains questions about coping behaviour in day-to-day situations. It focuses on seven categories of coping behaviour: active problem handling (directed at clarifying problems and active handling of those problems in order to solve the problem), palliative reaction pattern (diverting one’s attention in order not to think about the problem), avoidance behaviour (avoiding the problem), social support seeking behaviour (looking for comfort and understanding from others), depressive reaction pattern (letting the problem take full control over oneself), expression of emotions (expressing anger and annoyance) and comforting cognitions (having reassuring thoughts). Responses are scored on a 4-point Likert scale, ranging from never/seldom to very often. Internal consistency of the scales in the study
population ranged from 0.45 (expression of emotions) to 0.79 (active problem handling). The expression of emotions scale had a low alpha and was therefore left out of further analyses.

Cognitive Control Strategy Scale for Children (CCSS-c). The model of Rothbaum et al. (1982) served as a framework for the development of a questionnaire assessing four cognitive control strategies. This instrument proved to be useful in earlier research to better understand children’s and parents’ reactions to childhood cancer (Grootenhuis et al., 1996; Grootenhuis & Last, 2001). The CCSS-c consists of 22 items picked from the 36 original items, on four scales. The four cognitive control strategies are: being optimistic about the course of the illness (predictive control), attributing power to medical caregivers (vicarious control), hoping for a miracle or wishful thinking (illusory control) and searching for information in order to better understand emotional reactions and to gain insight into the situation (interpretative control). Children are asked to indicate whether they agree with a given statement on a 4-point scale (totally agree; agree; disagree; totally disagree). Higher scores on all four subscales represent a stronger reliance upon these control strategies. Items composing a subscale were selected after a principal component factor analysis with varimax rotation, and inspection of the psychometric features of the items. Inclusion of items in these subscales was based on (1) factor loadings higher than 0.40, (2) no reduction of the Cronbach’s alpha coefficient of the subscale, and (3) a considerable correlation with the other items of the subscale. After this was carried out, four subscales remained. Internal consistency in our sample occurred in three of the four scales (Cronbach alphas of 0.74; 0.85; 0.45; 0.74 respectively). None of the items on the scales increased the scale’s reliability when deleted. Because of the low internal consistency of the illusory scale (alpha = 0.45), this scale was not included in any further analyses.

HRQoL was assessed with the recently developed, validated disease specific questionnaire, the Impact-II (NL) (Loonen et al., 2002). It has 35 items in six domains (IBD symptoms, systemic symptoms, emotional functioning, social functioning, body image and treatment/intervention related concerns) with a 7 centimetre visual analogue scale as response mode. It contains questions about the child’s HRQoL over the past 2 weeks. Reliability of the six scales was generally good, with Cronbach alphas ranging from 0.57 (treatment/intervention related concerns) to 0.86 (emotional functioning domain). Test-retest reliability gave high intraclass correlation coefficients in all domains (ranging from 0.67 for the treatment/ interventions domain to 0.91 for the emotional functioning domain). Higher scores represent a better HRQoL in the particular domain. For example, a high score in the treatment/ intervention domain implies that the child worries less about the test or treatments that come with the disease; a high score in the IBD symptom domain implies the child worries less about current or future symptoms or sudden flare-ups of the disease.

Disease related variables were collected in the following manner. Adolescents were asked to rate their disease symptoms over the past week on a symptom card assessing five symptoms (stomachaches, blood with bowel movement, fever, weight loss and number of diarrhoeas per
day). Summated scores were calculated, ranging from 5 to 17 points maximally. Higher scores indicate more active disease.

From chart review, the following variables were obtained: *sex, type of disease, time since diagnosis* (assessed in months), and *disease course severity* since diagnosis was scored on seven characteristics (ratio of hospital admissions (in years) since diagnosis, number of exacerbations, duration of corticosteroid use per exacerbation, azathioprine use, cyclosporine use, surgery and height for age). Total severity scores could range between 4 and 21 with higher scores representing a more severe disease course since diagnosis.

**Procedures**

Patients were asked by mail to participate in a larger study assessing the HRQoL of children and adolescents with IBD. All patients and parents provided their written informed consent. The questionnaires were sent to them after the informed consent form was received, together with a pre-stamped envelope asking them to return the questionnaires by mail. Patients were explicitly told that their treating physician did not have access to their data, and that their treatment would not be influenced in any way as a result of participation in the study. The study was approved by the medical ethical committees in both hospitals.

**Statistical analysis**

Comparing the coping styles adolescents with IBD and healthy peers use, we used normative data from the generic coping measure, the UCL-A (Bijstra, Jackson & Bosma, 1994). Student t-test was used to compare mean scale scores between groups.

Multiple regression analysis was performed to assess the association between disease related variables, coping style scales and HRQoL. First, pre-selection of potential associated variables was carried out, calculating correlation matrices of the demographic variables and coping styles per HRQoL domain, accepting an \( r \geq 0.30 \) as criterion for selection of the variable. The disease related variables were: *sex, age in years, type of IBD, disease activity, disease course severity, and time since diagnosis in months*. The coping styles included six generic coping styles, and three disease related cognitive coping styles. One coping style from each instrument was not included in the analyses because of low internal consistency in our patient sample (expression of emotions from the UCL-A, and illusory control from the CCSS-c). Based upon our sample size (n= 65), only six variables were accepted in the regression procedures. The total variance explained by the included variables for each HRQoL domain is presented as the adjusted \( R^2 \) squared.
Table 1.
Generic coping styles of healthy adolescents and adolescents with IBD.

<table>
<thead>
<tr>
<th>Coping style from the UCL-A</th>
<th>Healthy adolescents M(SD)</th>
<th>Adolescents with IBD M(SD)</th>
<th>P value of t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confrontation</td>
<td>15.2 (3.6)</td>
<td>15.2 (3.5)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Palliative reaction pattern</td>
<td>18.7 (4.0)</td>
<td>17.9 (3.6)</td>
<td></td>
</tr>
<tr>
<td>Avoidance</td>
<td>14.9 (3.4)</td>
<td>16.2 (3.8)</td>
<td></td>
</tr>
<tr>
<td>Social support seeking</td>
<td>12.2 (3.6)</td>
<td>12.1 (3.1)</td>
<td></td>
</tr>
<tr>
<td>Depressive reaction pattern</td>
<td>11.7 (2.9)</td>
<td>11.0 (3.2)</td>
<td></td>
</tr>
<tr>
<td>Comforting thoughts</td>
<td>11.3 (2.8)</td>
<td>11.5 (2.7)</td>
<td></td>
</tr>
</tbody>
</table>

Note: Higher coping domain scores represent more reliance upon the strategy.
UCL-A = Utrecht Coping List for Adolescents.

Results

Mean scale scores on the UCL-A for the healthy control group and those of affected adolescents with IBD are listed in Table 1. Adolescents with IBD differ from their healthy peers in one style: they show significantly more avoidance behaviour (for example: brushing aside the problem, reconciling to the situation, wait and see what happens, leaving things the way they are). All other generic coping styles were used equally often by healthy and affected adolescents.

Correlations between the disease-related variables and coping styles and HRQoL domains are listed in Table 2. Disease activity, depressive reaction pattern and predictive coping styles correlate highly with all HRQoL domains, except for the body image domain, where depressive reaction pattern does not correlate as highly (r = 0.22). Sex is negatively associated with HRQOL domains, indicating that girls report a lower HRQoL than boys. Disease activity and disease course severity are also negatively associated with HRQoL domains, representing the validity of the Impact-II questionnaire: more severe disease accounts for a lower HRQoL.

Table 3 depicts the multivariate analyses for these variables. The social functioning domain was best predicted by the included variables, with a high explained variance of 61%. Body image was least explained by the included variables ($R^2$ squared of 13%). Sex was not significantly associated with any HRQoL domain when corrected for all other variables. Disease activity was only associated with worries relating to IBD symptoms (such as: worries about having a flare up, being afraid to undeliberately lose some stool), with social functioning and with body image, when corrected for all other variables in the model. Disease course severity was only associated with concerns over systemic symptoms, such as being tired or not having enough energy, and with social functioning. Depressive reaction pattern, including questions such as often worrying about things in the past and not being able to think about anything else but the problem, was associated with three HRQoL domains (IBD...
symptoms, emotional functioning and social functioning). Having optimistic thoughts about the course of the illness (predictive control) had a strong association with three HRQoL domains, when corrected for other variables. The negative thoughts about treatments/investigations domain was the only domain associated with the cognitive coping style vicarious coping (attributing power to medical caregivers). The association was positive, indicating that adolescents who attribute a lot of power to their doctor worry less about the invasive painful tests and treatments.

**Discussion**

This is the first study to describe the prediction of HRQoL of adolescents with IBD, a chronic gastrointestinal disease with an intermittent course that challenges these children’s coping abilities considerably. Coping proves to be an important predictor of HRQoL, even more than variables more often mentioned, such as gender and disease severity. The results of this study offer insight into the behaviour of adolescents with IBD, as well as into the development of interventions aimed at improving these children’s HRQoL.

Adolescents with IBD use similar coping styles as their healthy peers when dealing with day-to-day stressors, with the exception of one major coping style – avoidant behaviour. This finding is in line with an earlier report of children with various chronic conditions using more submissive behaviour (Meijer, Sinnema, Bijstra, Mellenbergh & Wolters, 2000). Avoidant behaviour could be a result of the unique disease features: frequent stools and associated smells, rumbling stomach noises or peri-anal manifestations of disease are embarrassing and adolescents may prefer avoiding to talk about these features and subsequently avoid other day-to-day problems as well. Also, adolescents want to be part of a group and do not want to be different from their peers. Therefore, avoiding confronting conversations or situations in day-to-day life may be socially very adaptive.

The HRQoL of children with IBD was predicted with variables correlating high with the outcome domains. Predictive cognitive control appeared to be a good predictor of quality of life related to IBD symptoms, systemic symptoms and social functioning. Adolescents who have a more positive view about their future (agreeing with statements such as: I am sure everything will work out right for me, I consider my future on the bright side, when I think about my illness I assume all will go well) are found to have a better HRQoL. This finding stresses the importance of having positive expectations or having a positive outlook in relation to HRQoL. It also shows that children with IBD, even if they experience a severe course of the disease, are able to be resilient (Patterson, 1995). This corresponds with the work of Folkman and Moskowitz (2000) who stress the importance of positive reappraisal (reframing a situation in a positive light) in coping with a chronic illness.
Table 2. Correlation Matrix for the Selection of Relevant Demographic Variables and Coping Styles.

| Correlation Coefficient | 0.30 |
|-------------------------|--|---|
| **HMOD** on life of six HMOD domains. |  |  |
| Type of disease was coded as: Chronic Disease (COD); \( Z \) and intermediate chronic = Z; thus acronyms with chronic disease report a lower |  |  |
| Symptoms and correlation coefficients are presented for continuous variables |  |  |

<table>
<thead>
<tr>
<th>Referred conceptions</th>
<th>Treatment/intervention</th>
<th>Body Image</th>
<th>Functioning (Physical)</th>
<th>Functioning (Social)</th>
<th>Emotion</th>
<th>Symptom</th>
<th>Syndromes</th>
<th>Syndrome</th>
<th>BMI</th>
<th>HBD</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.07</td>
<td>0.14</td>
<td>0.04</td>
<td>0.04</td>
<td>0.06</td>
<td>0.04</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
</tr>
<tr>
<td>0.42</td>
<td>0.27</td>
<td>0.27</td>
<td>0.33</td>
<td>0.32</td>
<td>0.32</td>
<td>0.32</td>
<td>0.32</td>
<td>0.32</td>
<td>0.32</td>
<td>0.32</td>
</tr>
<tr>
<td>0.35</td>
<td>0.33</td>
<td>0.33</td>
<td>0.34</td>
<td>0.34</td>
<td>0.34</td>
<td>0.34</td>
<td>0.34</td>
<td>0.34</td>
<td>0.34</td>
<td>0.34</td>
</tr>
<tr>
<td>0.26</td>
<td>0.12</td>
<td>0.12</td>
<td>0.11</td>
<td>0.11</td>
<td>0.11</td>
<td>0.11</td>
<td>0.11</td>
<td>0.11</td>
<td>0.11</td>
<td>0.11</td>
</tr>
<tr>
<td>0.39</td>
<td>0.22</td>
<td>0.22</td>
<td>0.22</td>
<td>0.22</td>
<td>0.22</td>
<td>0.22</td>
<td>0.22</td>
<td>0.22</td>
<td>0.22</td>
<td>0.22</td>
</tr>
<tr>
<td>0.80</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td>0.28</td>
<td>0.02</td>
<td>0.02</td>
<td>0.02</td>
<td>0.02</td>
<td>0.02</td>
<td>0.02</td>
<td>0.02</td>
<td>0.02</td>
<td>0.02</td>
<td>0.02</td>
</tr>
<tr>
<td>0.10</td>
<td>0.04</td>
<td>0.04</td>
<td>0.04</td>
<td>0.04</td>
<td>0.04</td>
<td>0.04</td>
<td>0.04</td>
<td>0.04</td>
<td>0.04</td>
<td>0.04</td>
</tr>
<tr>
<td>0.27</td>
<td>0.02</td>
<td>0.02</td>
<td>0.02</td>
<td>0.02</td>
<td>0.02</td>
<td>0.02</td>
<td>0.02</td>
<td>0.02</td>
<td>0.02</td>
<td>0.02</td>
</tr>
<tr>
<td>1.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td>0.30</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
<td>0.05</td>
</tr>
</tbody>
</table>
### Table 3.
Multivariate Regression Procedures for the Association between HRQoL, Disease Related Variables and Coping Styles.

<table>
<thead>
<tr>
<th></th>
<th>IBD symptoms</th>
<th>Systemic symptoms</th>
<th>Emotional functioning</th>
<th>Social functioning</th>
<th>Body image</th>
<th>Treatment/intervention related concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>-</td>
<td>- .19</td>
<td>-</td>
<td>- .32 ***</td>
<td>- .26 *</td>
<td>- .25</td>
</tr>
<tr>
<td>Disease activity</td>
<td>-.40 **</td>
<td>-.20</td>
<td>-.11</td>
<td>- .32 ***</td>
<td>- .20 *</td>
<td>- .20</td>
</tr>
<tr>
<td>Disease course severity</td>
<td>-</td>
<td>-.30 *</td>
<td>-.12</td>
<td>- .25 **</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Depressive reaction pattern</td>
<td>-.29 **</td>
<td>-.10</td>
<td>-.31 *</td>
<td>-.20 *</td>
<td>-</td>
<td>- .20</td>
</tr>
<tr>
<td>Comforting cognitions</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>- .25 **</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Predictive coping</td>
<td>-.29 **</td>
<td>.31 *</td>
<td>.27</td>
<td>.34 ***</td>
<td>.22</td>
<td>.19</td>
</tr>
<tr>
<td>Vicarious coping</td>
<td>-.09</td>
<td>.18</td>
<td>-</td>
<td>-</td>
<td>- .33 *</td>
<td>-</td>
</tr>
</tbody>
</table>

The standardised regression coefficient for each variable is presented. P values for the regression coefficient: * p< 0.05, ** p< 0.01, *** p< 0.001.

In relation to our findings, the possible confounding of predictive control with the outcome domains (especially emotional functioning) should be considered. The question whether negative emotions give rise to negative expectations, or negative expectations lead to the report of negative emotions is difficult to answer. The items of the predictive control subscale are formulated without the description of emotional functioning in the items, and are, therefore, not confounded with outcome.

The results of this study may be helpful for professionals, involved in psychosocial care, to be attentive to the control strategies which children with IBD follow. In coping with the stressful situation of living with IBD, adolescents pursue the various cognitive control strategies in their own specific way. Psychosocial intervention is needed if control fails and subsequently, adolescents need support in rebuilding their defences. At such moments, they are no longer able to control their emotions effectively. As health care providers we must try to analyse the control strategies and understand the emotional reactions of the adolescent and use it as a guide for psychosocial interventions. It is important that health care providers understand emotional and behavioural reactions as an outcome of a coping process, because with this knowledge they can respond more appropriately (Last & Grootenhuis, 1998).

Although de Ridder and Schreurs (2001) in their recent review suggest coping is a useful concept for psychosocial interventions for patients with a chronic illness, they emphasise the need for more studies to systematically and explicitly show how individual coping styles can be improved by such interventions. Our results are presented at group level; however, we also feel that individual coping styles should be taken into account. If, for example, a child is very scared about the course of the disease and only uses interpretative control, we should look critically at the amount and content of information he has about his illness. If the child fears a negative outcome of the disease and shows little confidence in his doctor, it may be necessary to enhance his predictive and vicarious control.
There are some limitations to this study. First of all, the incidence and prevalence of IBD in childhood are relatively low, making it difficult to include a large number of patients. The number of patients limited the number of variables that could be included in regression modelling. Only variables with a correlation $\geq 0.30$ could be included, but it may very well be that less highly correlating variables are also highly associated with the outcome when corrected for other confounding variables. Another drawback is our moderate response rate. We do not know how the non-responders cope with their disease, therefore conclusions cannot be generalised to the whole population with absolute certainty. Finally, the cross sectional design of our study restricts definitive conclusions about the causal relation between coping styles and HRQoL.

Medical intervention remains the only way to "treat" this debilitating physical disorder. Disease activity remains an important factor associated with HRQoL. Besides symptom activity, the use of certain coping strategies is also strongly associated with HRQoL. This study suggests that if predictive control strategies can be increased, the HRQoL of adolescents with IBD might also be improved. The effect of medical treatment versus a standard multi-disciplinary approach on the HRQoL of these patients should therefore be evaluated. Psychosocial interventions focusing on coping with stressful situations could improve the HRQoL of these adolescents, and deserve our attention in the near future.

References


