Illness perceptions of adolescents with inflammatory bowel disease and the association with distress and well-being

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Summary
Inflammatory Bowel Disease is one of the most common chronic diseases affecting children and adolescents. It requires a lifelong medical treatment, as well as the adoption of a healthy lifestyle. However, little is known about illness perceptions of adolescents suffering from IBD and how they relate to well-being measures. Aims were 1) to describe illness perceptions, distress and well-being of adolescents with IBD; and 2) to associate illness perceptions with distress and well-being of adolescents with IBD.

Thirty-six adolescents aged 12 to 18, diagnosed with IBD, answered the Brief Illness Perception Questionnaire and distress and well-being items from the Health Behaviour in School-aged Children questionnaire.

Overall the disease is perceived as benign. The majority of adolescents show some concerns about the disease but they feel a reasonable self-control over their illness and strongly believe in the benefits of treatment. Globally, adolescents showed positive perceptions of their health status and of their life. However, tiredness, exhaustion and nervousness were referred as frequent symptoms. Significant correlations showed that higher threatening perception of illness was associated with an increased frequency of physical symptoms, of tiredness and exhaustion, of depression and nervousness and with less satisfaction with life (rs ranging from .331 to .587). All descriptive and correlational results were significantly stronger in adolescents with active disease compared to those in remission.

Negative illness perceptions will likely trigger distress and malaise in adolescents with IBD. From the evaluation/comprehension of illness perceptions, it is possible to plan interventions to change negative perceptions and illness outcomes.

KEYWORDS: INFLAMMATORY BOWEL DISEASE; ADOLESCENTS; ILLNESS BELIEFS; DISTRESS; WELL-BEING.

Introduction
Inflammatory Bowel Disease (IBD) is one of the most common chronic diseases that affect children and adolescents[1]. It is an autoimmune disease of the digestive tract, which can be diagnosed during childhood, but more often in adolescence[1]. IBD can be classified into two distinct pathologies, which are ulcerative colitis (UC) and Crohn's disease (CD) according to the affected location in the digestive tract and the type of injury presented[1,2]. It is also common to find extraintestinal manifestations of the disease, meaning that IBD is more than a bowel issue that causes abdominal pain, diarrhoea, blood and weight losses and fatigue[1]. The assessment of the severity of symptoms is useful to determine the activity of the disease, that could range between asymptomatic (remission), mild, moderate and severe. As a recurrent disease, the main objective of treatments is to achieve and maintain the disease remission, heal the intestinal mucosa and relieve all symptoms, preventing future relapses, since the course of IBD is usually unpredictable[3-5].

Evidence shows that living with a chronic illness during adolescence is a challenging experience[6]. Controlling IBD requires a lifelong regimen management, even in remission periods. This will necessarily include medical treatment, with constant surveillance, as well as the adoption of a healthy lifestyle, with a balanced diet, physical activity, mental well-being and avoidance of risk-taking behaviours, such as substance use. Furthermore, the chronic condition itself and all of the requirements associated with[1,7] the therapeutic regimen may compromise the adolescent's psychosocial adaptation and lead to psychological disturbances, such as depressive symptoms that, alongside with pain, malaise and fatigue, are likely to disrupt daily life activities[8,9]. Thus, when compared with their healthy peers, adolescents who suffer from IBD present a slightly higher risk of suffering from anxiety and depressive symptoms, and this symptomatology may be aggravated during periods of active disease[9,10]. A meta-analysis about depressive symptoms in children and adolescents with different chronic physical illness, such as infection/AIDS, and sickle cell disease, found that the distress level does not differ between adolescents, regardless of their disease[9].

The psychosocial impact of chronic illnesses on adolescents can be analysed through a biomedical or a psychosocial framework. The biomedical perspective is associated with a categorical or condition-specific approach that focus on the disease specificity, duration and treatment[11]. On the other hand, the psychosocial perspective suggests a non-categorical or generic approach that argues that children with chronic conditions face common life experiences and problems based on generic dimensions of their conditions, rather than on specific characteristics of any particular disease entity. However, and considering the limitations of both approaches, a biopsychosocial or a modified categorical approach was developed that combines aspects from biomedical and psychosocial dimensions, taking into account the adolescent's subjective experience of illness and treatment[11].

The association between illness perceptions and a range of physical and mental health outcomes have been demonstrated in a number of conditions[12], therefore, it is important to comprehend how young people make sense of and manage their illness. For example, negative illness perceptions are associated with higher future disability and to the need of healthcare services, and to a slower and poorer recovery[13], whereas positive illness perceptions are associated with an earlier return to normal daily activities[14]. Illness perceptions can be defined as a cognitive construct that each patient develops about his own disease and that can be described into five components: identity, causal beliefs, timeline, control or cure, and consequences[13,15]. Illness perceptions are influenced by self-experience, others experience, knowledge, culture and personality traits[13,16] and they change over time and according to the disease course[16]. As an individual construct, it is possible to find very different perceptions about the same condition[13,16], which in some cases are even medically incorrect[15] and these perceptions will trigger emotional responses and coping behaviours adapted to the disease demands [16]. This is the Common Sense Model of Illness Representations, developed by Leventhal and colleagues, in 1980[17].

Hagger and Orbell (2003) conducted a meta-analytic review of 45 studies about illness perceptions and concluded that worse illness perceptions in consequences, timeline and identity dimensions were related to a poorer physical and social functioning, increased distress and lower levels of well-being and vitality. Moreover, higher perceptions of illness control were related to better outcomes in those variables [12]. The assessment of illness perceptions is also useful to understand the psychological impact of the disease on the individual and to estimate treatment adherence patterns[16]. From the evaluation/comprehension of illness perceptions, it is possible to plan interventions to change negative perceptions and illness outcomes[12, 16].

There are also qualitative studies on illness perceptions, using interviews and narratives. As an example, in a study conducted by Woodgate (1998) adolescents described their experience of having IBD as restrictive, painful, annoying and time-consuming, especially when the disease was out of control, causing severe symptoms[18]. In addition, when IBD was active, adolescents perceived less benefits from treatment and less self-control over their life, since IBD disrupted daily life activities, school attendance and family routines[1,7,8]. Lynch and Spence (2008) also questioned adolescents about their perceptions of IBD's cause and found that stress and unknown causes were the most reported[19].

Despite the numerous studies about illness perceptions on different pathologies, little is known about illness perceptions of adolescents suffering from IBD. As such, the aims of this study were:

- To describe illness perceptions, distress and well-being of adolescents with IBD.
- To associate illness perceptions with distress and well-being of adolescents with IBD.

Research methods

Participants

This study sample comprised 36 adolescents (22 male and 14 female) aged between 12 and 18 years (M = 14.75; SD = 1.90), diagnosed with IBD (21 suffered from Crohn Disease and 15 suffered from Ulcerative Colitis). In relation to disease activity, 12 were symptomatic and 24 were in remission.

A convenience sample was used with the following inclusion criteria: being an adolescent aged between 12 and 18 years, suffering from IBD diagnosed at least 6 months earlier, without any other chronic condition

or cognitive or sensorial impairment, who was willing to participate in the study.

Data were collected between March and June of 2015, in paediatric gastrology outpatient services and at non-oncologic paediatric day-hospital service.

Instruments

• *Portuguese version of The Brief Illness Perception Questionnaire (Brief IPQ),* translated and adapted by McIntyre, Araújo-Soares and Trovisqueira, in 2004[20]. The Brief IPQ is composed by eight items, to assess the five dimensions of illness perceptions, using a 5-point Likert-scale ranging between 0 and 4. One qualitative open question about the perception of the three main causes of the disease was also added to the questionnaire. According to the scoring instructions of the instrument, for items related to consequences [1], timeline [2], identity [5], concern [6] and emotional impact [8], higher scores mean more negative illness perceptions. For items about personal control [3], treatment [4] and coherence [7], higher scores mean more positive illness perceptions. It is also possible to create a new variable about the global perception of illness as being more or less threatening. To calculate the total score of this variable, a sum must be computed with the initially reversed scores of items 3, 4, and 7. This score ranges between 0 and 32. A higher score indicates a more threatening perception of the illness. In relation to the qualitative item about the causal perception of the illness, answers must be analysed through content analysis and they are usually labelled as stress, lifestyle, and heredity (Broadbent, Petrie, Main, & Weinman, 2006). The internal consistency was calculated for each item and for the total score. Results of the analysis of the internal consistency using Cronbach's Alpha suggested the elimination of the item related to the illness dimension "timeline". This elimination seemed logical, since the IBD is a chronic condition and the factor timeline is usually considered not relevant by respondents. The Cronbach's Alpha value for the IBD sample was $\alpha = .644$.

• *Health and well-being scale – Adapted version of the Health Behaviour in School-aged Children (HBSC) questionnaire.* HBSC assesses health and health-related behaviours, in the format of multiple-choice questions and was designed for school-aged children. It was developed within an international collaboration project from World Health Organization and it is applied every four years, at selected schools[21]. For this study only a few items about distress and well-being were selected, in a total of 15 items. These items measured self-rated health; the presence of physical and psychological symptoms, as for example stomach ache and dizziness; life satisfaction; illness as an impairment; and self-rated happiness.

Procedure

The study was approved by the hospital Ethics Committee. At first, adolescents were contacted by a nurse, and were then informed about the study, together with their parents, and invited to participate. Parents were also asked to sign an informed consent form.

MEAN VALUES, STANDARD DEVIATION AND RANGE OF B-IPQ, AND MANN-WHITNEY U TEST, BY DISEASE ACTIVITY **1**

.Brief-IPQ Items	IBD			Disease Activity
		SD	Range	M-W U test
1. How much does your illness affect your life?	1.11	0.820	2	U = 110.000 *p* = .225
2. How long do you think your illness will continue?	3.78	0.485	2	U = 137.000 *p* = .733
3. How much control do you feel you have over your illness?	2.53	1.320	4	U = 83.000 *p* = .035
4. How much do you think your treatment can help your illness?	3.47	0.736	2	U = 143.000 *p* = .985
5. How much do you experience symptoms from your illness?	1.53	1.055	4	U = 114.000 *p* = .294
6. How concerned are you about your illness?	2.22	1.149	4	U = 78.000 *p* = .022
7. How well do you feel you understand your illness?	2.81	1.117	4	U = 114.500 *p* = .300
8. How much does your illness affects you emotionally? (e.g. does it make you angry, scared, upset or depressed?)	1.42	1.1139	4	U = 57,000 *p* = .003
How much do you perceive your illness as threatening or benign?*	9.4722	4.27943	17	U = 58.000 *p* = .004

NOTE: * computed without item 2

Findings

Description of illness perceptions, distress and well-being of adolescents with IBD

In order to describe illness perceptions, distress and well-being of adolescents with IBD, mean values, standard deviation and range scores were calculated.

Results evidenced that IBD was perceived as benign by the majority of the adolescents, indicative of the perceived small impact on their lives and on their emotional responses (table 1). The majority of the adolescents showed a reasonable perceived control over their illness and felt that treatment could be highly beneficial. A small number of adolescents perceived a significant impact from their illness' symptomatology, which is probably related to the cyclic nature of the disease. In terms of illness-related concerns, most adolescents reported being worried. Despite the levels of concern, the majority believed that they understood their disease relatively well.

Findings related to the perceived causes of illness were analysed through content analysis, which resulted in a set of 28 possible causes of IBD, grouped into 12 categories, namely: physical efforts, sedentary lifestyle, excessive care of others, fate, self-care, congenital, diet, pathogenic causes, genetics and heredity, emotions, organic causes and unknown causes. The most cited cause was diet (38.9%) associated with poor diet or the intake of a specific food that may have caused injury to the bowel (e.g. cow's milk); followed by unknown causes (27.8%) and genetics and heredity (22.2%). More than half of the adolescents were only able to report a single cause for their illness.

In relation to distress and well-being variables (table 2), the values obtained evidenced that the majority of the adolescents had positive perceptions about their health status and about their life, in terms of satisfaction and happiness. The frequency of physical symptoms and psychological distress was globally low. However, the frequency of symptoms of tiredness, exhaustion and

MEAN VALUES, STANDARD DEVIATION AND RANGE OF HBSC VARIABLES, AND MANN-WHITNEY U TEST, BY DISEASE ACTIVITY **2**

Distress and well-being	IBD			Disease Activity
		SD	Range	M-W U test
How is your health? (poor to excellent)	2.25	0.604	2	U = 127.500 *p* = .527
How often do you feel headaches?	1.31	0.525	2	U = 129.000 *p* = .519
How often do you feel stomach ache?	1.36	0.683	2	U = 109.000 *p* = .121
How often do you feel back pain?	1.50	0.697	2	U = 111.000 *p* = .201
How often do you feel neck and shoulder pain?	1.39	0.549	2	U = 110.500 *p* = .180
How often do you feel tired and exhausted?	1.75	0.692	2	U = 97.000 *p* = .084
How often do you feel dizzy?	1.11	0.398	2	U = 143.,000 *p* = .944
How often do you feel sad and depressed?	1.25	0.439	1	U = 108.000 *p* = .107
How often do you feel difficulties in getting to sleep?	1.50	0.775	2	U = 129.000 *p* = .546
How often do you feel irritable?	1.42	0.500	1	U = 126.000 *p* = .480
How often do you feel nervous?	1.61	0.599	2	U = 125.000 *p* = .472
How often do you feel afraid?	1.22	0.485	2	U = 130.000 *p* = .495
How much do you think your illness is a barrier to do things you would like?	1.59	0.666	2	U = 29.000 *p* = .040
How satisfied are you with your life? (scored in a 10-point scale)	8.00	1.656	5	U = 96.000 *p* = .053
How do you feel? (unhappy to very happy)	1.86	0.487	2	U = 137.500 *p* = .773

nervousness were the most reported by adolescents. They also perceived the disease as little intrusive, as a barrier to accomplish some of their goals.

The adolescents were grouped into two sub-samples according to the disease activity (active or in remission), and statistically significant differences were found in illness perceptions referring to self-control, concern, emotional impact, threat perception, and self-perception of illness as a barrier to do things (table 2). These findings suggest that adolescents with active disease held more negative illness perceptions and felt a stronger negative impact of IBD on daily life. No statistically significant differences were found when adolescents were grouped into IBD subtype.

Association of illness perceptions with distress and well-being

Bivariate Pearson's correlations were performed between illness perceptions and distress and well-being. Only statistical significant correlations at the 0.05 and 0.01 levels were considered. The B-IPQ total score was associated with HBSC variables.

Positive statistically significant correlations were found, indicating that a more threatening perception of illness was correlated with an increased frequency of headache ($r = .379$, $p < .05$); of stomach ache ($r = .419$, $p < .05$); of tiredness and exhaustion ($r = .331$, $p < .05$); of sadness and depression ($r = .376$, $p < .05$); of nervousness ($r = .408$, $p < .05$); with a higher self-perception of illness as a barrier to doing things ($r = .458$, $p < .05$); less satisfaction with life ($r = .587$, $p < .01$); and increased feeling of unhappiness ($r = .498$, $p < .01$). In relation to the disease activity, results showed that active disease was correlated with a more threatening perception of illness ($r = .479$, $p < .01$); an increased frequency of tiredness and exhaustion ($r = .346$, $p < .05$); and with an increased self-perception of illness as a barrier to do things ($r = .475$, $p < .05$).

Discussion

The aims of this study were to describe illness perceptions, distress and well-being of adolescents who suffer from IBD, and to study the association of illness perceptions with distress and well-being.

In this study, IBD was perceived as little intrusive on adolescent's lives and on their emotional responses. They perceived satisfactory levels of self-control, benefits of treatment and reported few symptoms. Participants also reported that their disease was not experienced as a great concern, also mentioning a relatively good understanding of the disease, and were even conscious of their life-long disease. All these perceptions summed up into an overall positive illness perception, in which IBD was perceived as benign. Nevertheless, aspects such as the ability to do things, satisfaction with life and happiness, and the presence of physical symptoms and emotional distress are likely to negatively influence illness perceptions. Our findings provide evidence of the influence of negative illness perceptions on distress and well-being. Although no previous studies have analysed illness perceptions of adolescents with IBD using the B-IPQ, our findings are supported by several qualitative studies. In fact, negative illness perceptions, distress and malaise are associated with disease activity, in which IBD is perceived as a more restrictive disease[18]. This was also found by Nicholas and colleagues (2007), that demonstrated that adolescents have different perspectives of the impact of IBD on their lives, according to the disease activity, and that feelings of tiredness and exhaustion are frequent and interfering[8]. Lindfred and colleagues (2012), stated that adolescents with a severe disease course perceived less satisfaction with health and life, while those with inactive disease were able to integrate disease into their lives and expressed an overall well-being[7].

The causes of IBD were mainly perceived as related to modifiable causes, such as diet, and to unmodifiable ones, such as genetics. For some, the cause was unknown. These findings are similar to previous studies on IBD[19] and are common to the causal beliefs of other chronic conditions, whose causes are attributed to psychosocial stress, genetics and illness behaviours[12].

According to Broadbent et al. (2015), the B-IPQ was previously used in studies with children who suffered from cerebral palsy[22], and cancer survivors[23] and with adolescents who suffered from chronic rheumatic disease[24], and asthma[25]. Similarly, these findings also showed negative illness perceptions were present when disease caused more suffering, restrictions and symptoms. Globally, for these patients, the disease had little impact on life and on emotions, the treatments were viewed as strongly helpful to control the disease, while self-control perception was low. They demonstrated a good understanding of their disease and showed little concern. The patients thought their disease would last for a long time, except for the group of children who had a history of cancer. This similarity among different conditions seems to support a non-categorical view of the psychosocial impact of chronic illnesses on adolescents.

The generalisability of these results is subject to certain limitations. For instance, the sample size, which is relatively small and does not allow a true representation of all adolescents with IBD. In addition, adolescents with Intermediate IBD were not included in this study. On the other hand, the majority of the adolescents were in a remission phase, although it was still possible to identify differences according to disease activity.

Conclusion

In sum, findings suggest that intervention with adolescents with IBD

should focus on their subjective experience of illness, rather than screening for clinical features, Interventions should be implemented to empower adolescents with more coping skills strategies as a way to improve their perception of self-control over the disease. Importantly, clinicians should also carefully approach illness perceptions of their patients, in order to better understand and change disease-related outcomes, because negative illness perceptions will likely trigger distress and malaise in adolescents with IBD.

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