



Self-efficacy in adolescents with inflammatory bowel disease: A pilot study of the “IBD-yourself”, a disease-specific questionnaire

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KEYWORDS

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Abstract

Background and aims: Successful transfer of adolescent IBD patients to an adult gastroenterologist requires anticipation of a changing role for patients and their parents. Self-efficacy has been demonstrated to be important for transfer readiness. We therefore developed an IBD-specific questionnaire (the “IBD-yourself”) to assess self-efficacy in adolescent IBD patients visiting a transition clinic. Our aim was to evaluate the reliability of this questionnaire, and to describe the self-efficacy level of adolescent IBD patients, and the perceived self-efficacy level according to their parents.

Methods: In a cross-sectional design, 50 IBD patients (aged 14–18 years) and 40 parents completed the “IBD-yourself” questionnaire. Internal reliability was assessed by standardised Cronbach's α . Median self-efficacy scores per domain were calculated.

Results: The domains of the questionnaire for adolescents showed good to excellent internal consistency, with Cronbach's α ranging from 0.64 to 0.93. The domains of the parental questionnaire had Cronbach's α ranging from 0.47 to 0.93. Median self-efficacy scores of adolescents varied from 70 to 100%. In comparison with patient's self-assessment, parents thought that their child was more

Abbreviations: IBD-SES, IBD Self-efficacy Scale; IQR, Interquartile range; SD, Standard deviation; SEM, Standard error of the measurement; VAS, Visual analogue scale.

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self-efficacious in knowledge of IBD and diagnostic tests, self-management of medication use, and transfer readiness. Length of time since first visit to the transition clinic was positively correlated with several domains of the questionnaire, such as independent behaviour at the outpatient clinic, and transfer readiness.

Conclusion: The “IBD-yourself” questionnaire is a first step toward evaluating quality and efficacy of IBD transition programmes. Paediatric gastroenterologists should be aware that parents do not always accurately assess the self-efficacy of their child.

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1. Introduction

The incidence of inflammatory bowel disease (IBD) in children is increasing.¹ Most early-onset IBD patients present during adolescence, a critical period for physical and psychosocial development. In a few short years, the growing adolescent must shed the sheltered environment of childhood and achieve self-reliance and independent living.^{2,3} In addition to all these changes, adolescents with IBD have to become independently responsible for their own medical care. At some point, usually around the age of 16–18 years, these patients will move from the paediatric to the adult healthcare system, an important milestone in the life of young IBD patients and their parents.^{4,5}

There are several differences between paediatric and adult IBD health care.^{5–7} Paediatric care tends to be more focused on growth and development, whereas adult gastroenterologists are facing other health issues, such as fertility, pregnancy, and cancer surveillance. There are also significant differences regarding use of sedation during diagnostic procedures, as well as amount of parental involvement. Additionally, the adult gastroenterologist expects his patient to be autonomous and independent. Successful transfer to the adult gastroenterologist requires anticipation of this changing role for the patient and his parents. The transition process should therefore consist of a stepwise programme with age-appropriate checklists of tasks for the patient, as well as for the medical team.^{3,8,9} Currently, there are no tools to evaluate the effect of different IBD transition programmes.⁹

In 2006, a transition clinic for IBD patients between 14 and 18 years was initiated in the Erasmus MC – Sophia Children's Hospital. The transition clinic is located in the adult department, and patients are seen together by both the paediatric and adult gastroenterologist during the first visit and once yearly thereafter. At all other visits, the paediatric gastroenterologist sees the patients alone. The main goal of the transition clinic is to get the adolescent ready for transfer to the adult gastroenterologist by increasing his/her knowledge of disease and treatment, as well as reaching a higher level of self-efficacy. Self-efficacy is a person's belief in his/her capability to organise and execute actions required to deal with prospective situations.¹⁰ Self-efficacy is a prerequisite for self-management, and has been demonstrated to be of key importance in transfer readiness.¹¹

We therefore developed an IBD-specific questionnaire to assess the self-efficacy of adolescents visiting our transition clinic, the “IBD-yourself” questionnaire. The primary aim of this pilot study was to evaluate the reliability of the “IBD-yourself” questionnaire, and to describe the level of self-efficacy of adolescent IBD patients visiting the transition clinic

and the perceived level of self-efficacy according to their parents. In addition, we aimed to compare self-efficacy between disease groups, sexes, and educational levels, and to test for associations between self-efficacy and length of time since first visit to the transition clinic.

2. Materials and methods

2.1. Participants

Patients and their parents/caregivers were recruited from the transition clinic for adolescent IBD patients of the Erasmus MC – Sophia Children's Hospital, Rotterdam, The Netherlands. Adolescent IBD patients, who visited the transition clinic between March and July 2008, were eligible for this study. Exclusion criteria were mental inability to fill out a questionnaire, and not being able to read and understand Dutch. One accompanying parent of the patient and the paediatric gastroenterologist were also asked to participate. Data on patient characteristics, disease history, treatment, date of first visit to the transition clinic, and number of transition clinic visits were retrieved from the medical records after informed consent.

This study was approved by the local ethics committee of the Erasmus MC. Written informed consent was obtained from all patients and their parents/caregivers.

2.2. Measurements

The “IBD-yourself” questionnaire was developed as an instrument to measure self-efficacy of adolescents visiting the transition clinic. Questions of the “IBD-yourself” were generated from the available literature of general and disease-specific self-efficacy measures.^{11–13} A pre-test of the questionnaire was completed by four adolescent IBD patients to determine whether the questionnaire was comprehensible and consistent.

The final version for adolescents contained 12 domains, addressed by at least 59 questions (depending on the patient's treatment; see [Appendix A](#)). The questions on the perceived level of disease burden and independency in general were determined using a 100 mm visual analogue scale (VAS). The VAS on general independency ranged from “not independent” to “very independent”, while the VAS on disease burden ranged from “no disease burden” to “heavy disease burden”. Other domains of the questionnaire were: self-efficacy in knowledge of IBD, diagnostic tests and treatment, self-efficacy in medication use, actual behaviour regarding medication use in the past week, skills for

independent visits to the transition clinic, actual behaviour during visits to the transition clinic, coping with IBD, knowledge of the transition process, and readiness for transfer to the adult gastroenterologist. Most of the questions were rated on a four-point Likert scale, ranging from 1 (“no, definitely not”) to 4 (“yes, definitely”). Higher scores indicated higher levels of self-efficacy. As the total number of questions could differ between patients, it was not possible to generate a total self-efficacy score, only total scores per domain.

The parents of the adolescent IBD patients were invited to fill out an abbreviated version of the “IBD-yourself” questionnaire in order to determine how they perceived the self-efficacy of their child. Patients and parents had to complete the questionnaire in 20 min, separately from each other. The treating paediatric gastroenterologist was only asked to score patient's general independency on a VAS.

2.3. Statistical analysis

Data were collected and analysed in SPSS (version 16.0, SPSS, Inc., Chicago, IL, USA). Descriptive statistics were calculated as percentages for discrete data and medians with interquartile ranges (IQR) for continuous data. VAS scores were obtained by measuring in millimetres the middle of the cross that patients, parents, and paediatric gastroenterologist placed on the VAS. Scale scores were linearly transformed to a 0–100 scale, with higher scores representing higher levels of self-efficacy or heavier disease burden.

Internal consistency of the individual domains was evaluated by calculating the standardised Cronbach's α . Homogeneity was considered to be good if $\alpha > 0.60$, and excellent in case of values >0.90 . In addition, the standard error of the measurement (SEm) was calculated as another measure of reliability of the individual domains. The SEm estimates how repeated measures of the adolescent on the same questionnaire tend to distribute around his or her ‘true’ score. The SEm is calculated by using the Cronbach's α and the standard deviation (SD) of the domains: $SEm = SD * \sqrt{1 - \text{Cronbach's } \alpha}$. A low SEm indicates a reliable test. Reliability of the domain on perceived knowledge of treatment could not be analysed due to the heterogeneity in number of questions per patient (due to variation in medication used).

Demographic and disease-related differences between participants and non-participants were analysed using the Mann–Whitney test or χ^2 -test. The Wilcoxon-signed rank test was used to test for differences in domain scores between adolescents, parents and paediatric gastroenterologist. Differences in total domain scores between gender, disease type, and educational level were assessed by the Mann–Whitney test. Spearman's correlation coefficients were calculated to examine the correlation between total domain scores and length of time since first visit to the transition clinic. All reported *P*-values are two-sided, *P*-values < 0.05 were considered significant.

3. Results

3.1. Patient characteristics

A total of 57 patients was eligible for this study, of whom 50 (88%) were willing to participate. Patient demographics are

Table 1 Patient characteristics of adolescent IBD patients visiting the transition clinic (n = 50).

Gender (male), no. (%)	22 (44%)
Age (year), median (IQR)	16.3 (15.4–17.0)
Disease type	
Crohn's disease	30 (60%)
Ulcerative colitis	18 (36%)
IBD-unclassified	2 (4%)
Duration of disease	
<2 years	34 (68%)
>2 years	16 (32%)
Time since first TC visit	
<1 year	25 (50%)
>1 year	25 (50%)
Number of TC visits	
1–6	38 (76%)
7–12	12 (24%)
Educational level	
Low	30 (60%)
High	20 (30%)
Current medication	
Mesalazine	16 (32%)
Salazopyrine/sulfasalazine	3 (6%)
Mesalazine enema	3 (6%)
Azathioprine	24 (48%)
Methotrexate	4 (8%)
Prednisone	3 (6%)
Infliximab	13 (26%)
Calcium/vitamin D	15 (30%)
Folic acid	5 (10%)
Other medications	4 (8%)

IQR: interquartile range. TC: transition clinic.

presented in Table 1. Non-participants did not differ from participants with respect to age, gender, type of IBD, or disease duration.

As there were adolescents who visited the transition clinic alone, a smaller number of parents (n = 40) filled out the questionnaire: 28 mothers (70%) and 12 fathers (30%), with a median age of 44 years (IQR 42–48).

3.2. Reliability of the “IBD-yourself” questionnaire

Table 2 displays the reliability of the “IBD-yourself” questionnaire for both patients and parents. The internal consistency was good or excellent for all analysed domains of the questionnaire for adolescents (Cronbach's α ranging from 0.64 to 0.93). The Cronbach's α of the domains of the questionnaire of the parents varied from 0.47 to 0.93. In both the questionnaires for adolescents and parents, the SEm was low for most of the domains, confirming the reliability of the questionnaire.

3.3. Outcome of the “IBD-yourself” questionnaire

The median scores for the domains of the “IBD-yourself” questionnaire are listed in Table 3. Adolescents had a median

Table 2 Reliability of the “IBD-yourself” questionnaire for adolescent IBD patients and their parents.

Domains	No. of questions	Questionnaire for adolescents (n = 50)			Questionnaire for parents (n = 40)		
		Cronbach's α^A	SEm	95% CI	Cronbach's α^A	SEm	95% CI
Knowledge of IBD	5	0.76	1.1	14.7–18.9	0.88	0.8	16.2–19.4
Knowledge of diagnostics tests	6	0.76	1.4	17.3–23.0	0.92	0.9	19.4–23.2
Medication use	8	0.89	1.7	22.5–29.3	0.93	1.6	20.9–27.3
Actual behaviour medication use	4	0.68	1.7	11.2–17.8	0.63	1.7	11.1–18.0
Skills for independent outpatient clinic visits	9	0.87	2.2	23.3–32.0	0.89	2.1	20.3–28.6
Actual behaviour outpatient clinic	4	0.64	0.8	4.1–7.3	0.47	0.8	4.1–7.5
Coping with IBD	4	0.93	0.8	12.0–15.3	0.85	1.1	10.8–15.0
Knowledge of transition process (adolescents/parents)	14/15	0.74	3.7	42.8–57.5	0.86	3.2	45.3–58.1
Transfer readiness	2	0.86	0.5	5.2–7.2	0.88	0.5	4.6–6.8

SEm: standard error of the measurement. CI: confidence interval.

^A Standardised, corrected for the number of items within the scale.

VAS score on general independency of 69 (IQR 50–80) by self-assessment. Assessment by their parents resulted in a median score of 75 (IQR 60–89), and by the paediatric gastroenterologist in a median score of 72 (IQR 54–84). There was only a significant difference between the scores of the parents and the paediatric gastroenterologist ($P = 0.04$). The median VAS score on disease burden according to the adolescent was 11 (IQR 4–51), with 13 adolescents (26%) reporting a score ≥ 50 .

In general, adolescents reported high levels of self-efficacy with median scores varying from 70 to 100%. Patients and parents did not always agree on the level of self-efficacy. Parents thought that their child had more knowledge of IBD and diagnostic tests. They also scored significantly higher on self-management of medication use and readiness for transfer

to the adult gastroenterologist. In contrast, adolescents found themselves more capable of independent behaviour at the outpatient clinic.

3.4. Differences between gender, disease groups, and educational level on self-efficacy

Male patients thought they had significantly more knowledge of their disease (median score 90% vs. 80%, $P = 0.03$), were better able to tell friends and teachers about their disease (100% vs. 81%, $P = 0.048$), and were more ready for transfer to the adult gastroenterologist compared with female patients (median score 88% vs. 75%, $P = 0.04$). VAS scores on general independency and disease burden did not differ

Table 3 Median total domain scores of the “IBD-yourself” questionnaire for adolescent IBD patients and their parents.

Domain	Score range	Adolescents (n = 50)		Parents (n = 40)		P-value
		Median score (% of max score)	% with maximal score	Median score (% of max score)	% with maximal score	
VAS on general independency	0–100	69	5	75	7	0.09
VAS on perceived disease burden	0–100	11	2	NA	NA	NA
Knowledge of IBD	0–20	17 (85)	5	19 (95)	12	0.006
Knowledge of diagnostics tests	0–24	20 (83)	14	23 (96)	30	0.02
Medication use	0–32	27 (84)	11	27 (84)	7	0.01
Actual behaviour medication use	0–20	16 (80)	2	16 (80)	2	0.20
Skills for independent outpatient clinic visits	0–36	28 (78)	9	24 (67)	4	0.02
Actual behaviour outpatient clinic	0–8	6 (75)	9	6 (75)	5	0.10
Coping with IBD	0–16	16 (100)	44	13 (81)	18	0.45
Knowledge of transition process (adolescents/parents)	0–70/75	51 (73)	0	52 (69)	0	0.21
Transfer readiness	0–8	6 (75)	19	6 (75)	9	0.05

In both groups, minimal scores of 0 were not observed.

VAS: visual analogue scale. NA: not applicable.

significantly between males and females. Ulcerative colitis (UC) patients had lower median domain scores compared with Crohn's disease (CD) patients, but these differences were not statistically significant, except for independent behaviour during visits to the transition clinic (median score 5 (UC) vs. 6 (CD), $P = 0.04$). There were only two patients with IBD-unclassified, which we did not include in our analysis.

Higher educated adolescents had significantly more knowledge of diagnostic tests than those attending lower educational levels (median score 90% vs. 81%, $P = 0.009$). Additionally, there were significant differences in actual behaviour regarding medication use, with higher scores in the group of higher educated adolescents (median score 80% vs. 75%, $P = 0.050$). In the other domains, there was no significant effect of educational level.

3.5. Self-efficacy and the transition clinic

There was a significant correlation between length of time since first visit to the transition clinic and VAS scores on general independency filled out by the paediatric gastroenterologist ($r = 0.45$, $P = 0.001$) and the parents ($r = 0.35$, $P = 0.03$), but not by the adolescents ($r = 0.23$, $P = 0.11$). Length of time since first visit to the transition clinic was positively correlated with other domains of the questionnaire for adolescents: skills for independent transition clinic visits ($r = 0.29$, $P = 0.04$), actual behaviour at the transition clinic ($r = 0.53$, $P = 0.001$), and transfer readiness ($r = 0.33$, $P = 0.02$).

4. Discussion

In this pilot study, we introduced the "IBD-yourself" questionnaire, the first self-efficacy measure for adolescents with IBD, which proved to be a reliable tool with a high internal consistency. Although additional validation and further domain and question reduction are necessary, this questionnaire is a first step toward evaluating quality and efficacy of IBD transition programmes.

There is a clear need to evaluate and improve transition of adolescent IBD patients, as several studies have identified inadequacies in the preparation of adolescent IBD patients for transfer to the adult gastroenterologist. Deficiencies in knowledge of side effects of medications,^{14,15} disease location, surgical history, date of last colonoscopy, and previous results of small bowel imaging have been reported in adolescent IBD patients.¹⁶ Additionally, adult gastroenterologists frequently report a lack of knowledge of the disease, treatment, and the impact of substance use on health in the young adults transferred to their practice.^{17–19}

Increasing knowledge alone is, however, not sufficient for successful transition.⁶ Self-efficacy in managing self-care has been demonstrated to be of key importance for transfer readiness.¹¹ Self-efficacy has also been associated with improved health behaviour, as was reported in a study on adolescent sickle cell disease patients.²⁰ The patients with higher self-efficacy scores were more likely to attend outpatient clinic appointments after transfer to adult care. In our adolescent IBD population, levels of self-efficacy were high, with scores varying from 70 to 100%. Given the different

disease-related domains, the "IBD-yourself" questionnaire can detect specific areas in which the individual patient needs extra attention. This will facilitate appropriate patient-tailored interventions, which could improve the transition to adult care. Future longitudinal studies in our IBD population will have to investigate the long-term outcomes of assessing and improving self-efficacy during the transition period.

The "IBD-yourself" questionnaire for adolescents proved to be a reliable tool, with good to excellent internal consistency for all domains. The domain on actual behaviour during visits to the transition clinic consisted of four dichotomous questions, which could explain the lower internal consistency compared with the other domains. In a new version of the questionnaire, the response format of this domain will therefore be adapted into a four-point Likert scale (yes, always; yes, often; yes, sometimes; no, never). A current shortcoming of the questionnaire is the limited reproducibility, as it is not possible to generate a total self-efficacy score, emphasising the need for further domain and question reduction in the future. Future studies will also need to investigate test-retest reliability, and further explore concurrent and predictive validity of the questionnaire.

Recently, self-efficacy has been assessed in adult IBD patients.²¹ In an American study, the 29-item IBD Self-efficacy Scale (IBD-SES) proved to be a reliable and valid tool for clinical and research utility. Some of the questions were comparable with the "IBD-yourself" questionnaire regarding management of medical care. The IBD-SES however focused primarily on abilities to cope with stress, symptoms, and maintaining remission, while our questionnaire measured self-efficacy in knowledge of the disease and the transition process, independence in treatment, and independent behaviour during consultations. Although the results were preliminary, adult CD patients reported significantly lower levels of self-efficacy compared with UC patients, and disease duration was not associated with increased self-efficacy scores. Both results are in contrast with data from our study. We found no significant differences in self-efficacy between disease groups. Additionally, length of time since first visit to the transition clinic (which is correlated with disease duration) was positively correlated with several domains of the "IBD-yourself" questionnaire. These different outcomes are probably caused by differences in the questionnaires, as well as age of the study population.

We found several significant differences in self-efficacy scores between males and females, and higher and lower educated adolescents. Remarkably, male patients found themselves better capable of telling friends and teachers about their disease compared with females. In contrast, a study about coping strategies in children demonstrated that girls were more likely to use strategies involving verbal expressions to others, to seek emotional support, and to ruminate about problems.²² Questionnaires on self-efficacy or self-care management in adolescents with other chronic diseases, such as diabetes, sickle cell disease, and cystic fibrosis, did not demonstrate any gender differences.^{23–25} In contrast, a review on the social psychology of self-efficacy reported on a greater sense of self-efficacy in boys.²⁶ Educational level is generally thought to be positively related to self-efficacy,²⁶ but this effect was only demonstrated for two domains in our study. This might be explained by differences in definitions of educational level.

Length of time since first visit to our transition clinic, which is highly correlated with a patient's age, was demonstrated to be positively correlated with several domains of the "IBD-yourself" questionnaire. Due to the cross-sectional design of the study, we do not know whether this positive correlation is a consequence of ageing of the patient or really a beneficial effect of the transition clinic. Other studies on self-efficacy in children with chronic diseases have yielded conflicting results on the effect of age on self-efficacy. Older children with cystic fibrosis and asthma reported higher levels of self-efficacy and self-care management compared with younger children,^{24,27} whereas age had no effect on self-efficacy scores of adolescent sickle cell disease patients.²⁵

The results of the parental questionnaire suggest that parents may not always accurately assess the level of self-efficacy of their child. In general, parents reported higher levels of self-efficacy compared with their children. Discrepancies between adolescent IBD patients and their parents have also been observed in questionnaires on psychosocial and somatic symptoms.²⁸ Eight percent of the adolescents and 13% of the parents reported psychosocial problems, without the counterpart agreeing. Additionally, parents reported more somatic symptoms than their adolescent child. These findings illustrate the importance of gradually establishing an independent relationship between the paediatric gastroenterologist and the patient.

The most effective strategy to successfully transfer adolescent IBD patients to the adult gastroenterologist is yet to be determined. Based on the outcomes of a patient survey,²⁹ the stepwise transition programme in our hospital consists of yearly combined visits with both the paediatric and adult gastroenterologist. A single combined visit before transfer to the adult gastroenterologist has also been reported to be beneficial for subsequent care, and increased confidence in the new gastroenterologist. However, a substantial number of patients (30%) and parents (20%) felt that one visit had not been enough.³⁰ Developing a validated IBD transition tool will enable future studies to investigate the most effective transition strategy.

In conclusion, we have described a novel and valuable tool to assess self-efficacy of adolescents with IBD, which

can be used to further improve IBD transition programmes. Adolescent IBD patients report high-levels of self-efficacy, with several significant differences between male and female patients. Paediatric gastroenterologists should be aware that parents do not always accurately assess the self-efficacy of their child. Additional studies are needed to further improve and validate the "IBD-yourself" questionnaire.

Conflict of interest

None of the authors have a conflict of interest.

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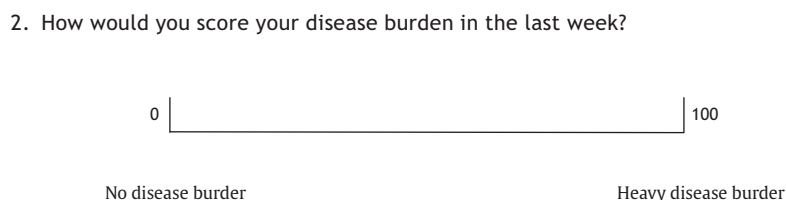
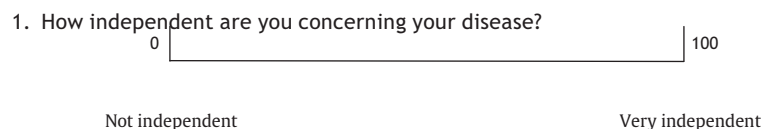
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Statement of authorship:

MZ collected and analysed the data, and drafted the manuscript. CdB assisted in interpretation of the data, and drafted the manuscript. LB collected and analysed the data, and helped to draft the manuscript. MvP collected data, organised the transition clinic, arranged study logistics, and critically revised the manuscript for important intellectual content. AvS assisted in development of the questionnaire, and critically revised the manuscript for important intellectual content. LdR collected data, and critically revised the manuscript for important intellectual content. JvdW was involved in clinical care at the transition clinic, contributed to the development of the questionnaire, and critically revised the manuscript for important intellectual content. JE participated in the conception and design of the study, collected data, and critically revised the manuscript for important intellectual content. All authors read and approved the final manuscript.

Appendix A. The "IBD-yourself" questionnaire

Visual analogue scales



Self-efficacy in knowledge of IBD

I am convinced that...	Yes, definitely	Yes, probably	No, probably not	No, definitely not
I can explain what kind of disease I have.				
I can explain which symptoms my disease can cause.				
I can tell which symptoms I have when my disease worsens.				
I can tell when the symptoms of my disease improve.				
I can clearly describe the future consequences of my disease.				

Self-efficacy in knowledge of diagnostic tests

I am convinced that...	Yes, definitely	Yes, probably	No, probably not	No, definitely not
I can recall the diagnostic tests that I underwent when I was diagnosed with IBD.				
I know the diagnostic tests that I will have to undergo during the course of my disease.				
I can explain why my height and weight are measured during each visit to the outpatient clinic.				
I can explain why I have to undergo blood withdrawals during each visit to the outpatient clinic.				
I can explain what an abdominal ultrasound is.				
I can explain what an endoscopic examination is.				

Self-efficacy in knowledge of treatment

Which medication do you take?

	Which medication do you take to control your IBD symptoms?	Which medication do you take when your symptoms worsen?
Mesalazine, pentasa, salofalk, asacol, salazopyrine, sulfasalazine		
Mesalazine enema		
Azathioprine		
Methotrexate		
Prednisone		
Infliximab		

For each medication taken (also in case of calcium/vitamin D, and/or folic acid), please answer the following questions:

I am convinced that...	Yes, definitely	Yes, probably	No, probably not	No, definitely not
I am able to explain why I am treated with this medication.				
I am able to explain at what time of day I have to take this medication.				
I know the dosage of this medication (in milligrammes).				
I know how often I have to take this medication (in number of pills/enemas/injections/infusions per day/week(s)).				
I am able to explain the side-effects of this medication.				
I am able to explain the consequences when I do not stick to my medication regimen.				

When you have been treated with exclusive enteral nutrition in the past, please answer the following questions:

I am convinced that...	Yes, definitely	Yes, probably	No, probably not	No, definitely not
I am able to explain what exclusive enteral nutrition is.				
I am able to explain why I was treated with exclusive enteral nutrition.				
I know for how long I was treated with exclusive enteral nutrition.				
I know how much nutrition I had to take each day.				

Self-efficacy in medication use

I am convinced that...	Yes, always	Yes, often	Yes, sometimes	No, never
I can manage to set out my medication each day, without help of others.				
I can manage to take my medication at the right time each day.				
I can manage to remember taking my medication, without help of others.				
I am able to ask for a new prescription when my medication runs out.				
I can tell when the medication has no effect on my symptoms.				
I can describe which effect a dosage reduction of my medication has on my symptoms.				
I can manage to take my medication at instructed times even when I am not at home.				
I can manage to bring my medication when I am planning to go out.				

Actual behaviour regarding medication use in the past week

How many days of the past week did you...	Every day	5–6 days	3–4 days	1–2 days	None
remember to take your medication without help of others?					
set out your medication on your own?					
take your medication?					
experience side-effects of your medication?					

Self-efficacy in skills for independent outpatient clinic visits

I am convinced that...	Yes, always	Yes, often	Yes, sometimes	No, never
I can make hospital appointments on my own.				
I can talk to the doctor without my parents being present in the consultation room.				
I am able to discuss my problems with the doctor without help from my parents.				
I dare to ask the doctor any question.				
I dare to confess to the doctor that I did not stick to my medication regimen.				
I dare to tell the doctor if I should disagree with her or him.				
I am able to tell the doctor when my disease worsens/improves, without help of my parents.				
I know how to reach the doctor or nurse, if necessary.				
I can explain to others what was discussed in the consultation room.				

Actual behaviour at the outpatient clinic

	Yes	No	Not applicable
Did you make your own appointment for the most recent visit to the outpatient clinic?			
Did you enter the consultation room alone when you last visited the outpatient clinic?			
Were you able to ask the doctor a lot of questions during your last visit to the outpatient clinic?			
Were you able to influence changes in your medication regimen when you last visited the outpatient clinic?			

Self-efficacy in coping with IBD

I am convinced that...	Yes, always	Yes, often	Yes, sometimes	No, never
I can manage to tell friends about my condition.				
I can manage to explain my condition to friends.				
I can manage to tell my boyfriend/girlfriend about my condition.				
I can manage to explain my condition to my teacher or boss.				

Self-efficacy in knowledge of the transition process

Do you agree on the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
I can explain why the outpatient clinic is located in the adult gastroenterology department instead of the paediatric gastroenterology department.					
I know that this outpatient clinic is called the transition clinic.					
The transition clinic is easy to find.					
I am not able to explain why I have to visit a transition clinic.					
I know what happens when I will transfer to the adult gastroenterologist.					
I know who my adult gastroenterologist is going to be.					
I can explain the differences between paediatric and adult IBD health care.					
I think it is important to know what happens after my transfer to the adult gastroenterologist.					
The transition clinic increases my self-management skills regarding my disease.					
The doctor has given clear information on the transfer to the adult gastroenterologist.					
I am happy to leave the children's hospital.					
I am able to discuss problems regarding sexuality with my doctor.					
Waiting times are short when I visit the transition clinic.					
The doctor and/or research nurse are easily reached, if necessary.					

Self-efficacy in transfer readiness

Do you agree on the following statements?

I am convinced that...	Yes, definitely	Yes, probably	No, probably not	No, definitely not
I am ready to make the transfer to the adult gastroenterologist.				
My parents are ready to make the transfer to the adult gastroenterologist.				

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