MICI-MINOTS: linguistic and metric validation of a pediatric questionnaire on knowledge about inflammatory bowel disease Short title: MICI-MINOTS

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Short title: MICI-MINOTS

C. Cousin [§, 1], C. Bevilacqua [§, 2], C. Roman[1], B. Roquelaure[1], A. Loundou[3], K. Baumstarck[3], A. Fabre[1,4, *].

§: Both authors contributed equally to this work

1: Service de pédiatrie multidisciplinaire, Timone Pediatric Hospital, 13385 Marseille, France.

2: Pédiatrie maladies des enfants. Centre Hospitalier Sainte-Musse, 83100 Toulon, France.

3: EA 3279, Self-perceived Health Assessment Research Unit, School of Medicine, Aix Marseille University, 13385 Marseille, France.

4: Aix-Marseille University, INSERM, GMGF, 13385 Marseille, France.

*corresponding author: alexandre.fabre@ap-hm.fr

Abstract

Background: Therapeutic education is an essential part of the treatment of chronic diseases, such as inflammatory bowel disease (IBD). The IBD-KID, developed in Canada in English, assesses children's and adolescents' acquired knowledge about their condition and has been validated in Canadian and Australian populations. However, there is no pediatric questionnaire in French to assess patients' knowledge about IBD.

Objective: To report the linguistic validation process and metric validity of the MICI-MINOTS, the French version of the IBD-KID.

Method: The translation process consisted of three consecutive steps: forward–backward translation, acceptability testing, and cognitive interviews. The IBD-KID consists of 23 questions, but a 24th question about immunomodulatory therapy was added in the MICI-MINOTS. Psychometric testing was conducted with five groups: children with IBD, their parents, children in a control group, their parents, and health workers recruited from the Timone Pediatric Hospital and the Saint Sebastien Maternal and Child Protection Center, Marseille, France. A total of 15 individuals completed the tool twice, with a 15-day interval. Internal consistency, reliability, external validity, reproducibility, and sensitivity to change were tested.

Results: A total of 38 children with IBD (sex: 20 boys, 18 girls; age: 13.90 [±2.88] years; 25 with Crohn's disease), 20 children in the control group, 58 parents (every child was included with one parent), and 62 health workers were included in the analysis. Intraclass correlation was 0.94 (95% confidence interval 0.83–0.98) for test–retest assessment. Readability using

the Scolarius score corresponded to elementary school level. Among the children with IBD, 89.5% answered all 24 questions. For 23 questions, the mean score of children with IBD was higher than among children in the control group: 9.58 (± 3.01) versus 5.47 (± 3.56), respectively ($p < 0.01$). Parents of children with IBD scored higher than parents of children in the control group: 10.63 (± 3.16) versus 8.4 (± 3.07), respectively ($p = 0.012$). In the health workers' group, pediatric residents (17.82 ± 3.46) scored higher than nurses 11.75 (± 3.4) and ward clerks (8.67 ± 2.40; $p < 0.01$). Patients' knowledge score was significantly related to their parents' knowledge score ($r = 0.402$, $p = 0.012$) for 23 questions.

Conclusion: The French version of the IBD-KID showed satisfactory psychometric properties to assess knowledge about the disease in French-speaking children.

Keywords: Inflammatory bowel disease; ulcerative colitis; Crohn's disease; pediatric; knowledge; assessment; questionnaire.

1. INTRODUCTION

The global prevalence of pediatric inflammatory bowel disease (IBD) is on the rise in developed and developing nations alike [1–3]. The highest annual pediatric incidence of IBD in the world was 23/100,000 person-years in Europe in 2018 [4]. The prevalence of both ulcerative colitis (UC) and Crohn's disease (CD) are highest in Europe (505 and 322 per 100,000 person-years, respectively) [5,6]. According to the most recent EPIMAD data from 2015, there were 250,000 people with IBD in France and 8,000 new diagnoses per year (www.observatoire-crohn-rch.fr). As reported by the recent Gower-Rousseau[3] study, the French incidence of pediatric IBDs is 4.4/105 inhabitants of the same age and sex.

IBD is a chronic disease potentially requiring long-term treatment, necessitating therapeutic

adherence. Therapeutic education, associated with improved adaption strategies for IBD, has proved efficient [7]. There is evidence that the provision of disease-related information reduces patients' anxiety levels [8].

Knowledge assessment usually involves the use of standardized questionnaire-type tools that cover different aspects of the disease and of the therapeutic management. A review of the literature presents numerous validated questionnaires concerning IBD-related knowledge in adult patients: Crohn's and Colitis Knowledge Score [9], Jones Questionnaire [10], Keegan's Short Knowledge Questionnaire [11], Crohn's and Colitis Pregnancy Knowledge Score (CCP-Know)[12], MyHealth Passport for IBD [13], IBD-INFO Questionnaire [14], and the Inflammatory Bowel Disease Knowledge (IBD-KNOW) [15].

However, only one questionnaire, the IBD-KID designed by Haaland et al. [16], involves an assessment of children's and adolescents' IBD-related knowledge. This questionnaire was developed in English and validated in a Canadian population [16], and further validated in an Australian population [17].

Currently, there is no validated French version of this survey for pediatric patients. An unvalidated French survey concluded that adolescents' level of knowledge about their disease, both in terms of general information and treatment, needs improvement [18]. A validated questionnaire for French-speaking pediatric patients with IBD would, therefore, be useful. After agreement with the creators of the English version, we proposed a linguistic validation based on current standard methods, and followed the methodology used for the original in 2014 [16].

The main objective was to validate a French adaptation of the IBD-KID: the MICI-MINOTS. The secondary objective was to assess the IBD-related knowledge of patients, their parents, and health workers.

2. METHODS

The IBD-KID [16] includes 23 questions on general knowledge about IBD across domains such as anatomy, physiology, and treatment. Each multiple-choice question has only one right answer. A correct answer corresponds to 1 point, for a total score of 23 points. If the participant provides more than one answer, does not answer the question, or chooses the "don't know" option, he/she is awarded 0 points. The MICI-MINOTS questionnaire followed the same scoring pattern.

2.1. Development of questionnaire

Questionnaire development involved two main steps: (1) translation and cultural adaptation and (2) psychometric testing [19]. The two steps were coordinated by a team that included gastroenterologists, nurses, patients, and experts in the metric validation of tools (EA3279 Self-Perceived Health Assessment Research Unit, Aix-Marseille University, Marseille, France).

2.1.1. Linguistic validation

Linguistic validation was conducted according to current standard methods in two steps. First was the backward/forward translation, conducted by two professional translators (one native English speaker and one native French speaker). Second was cognitive debriefing; acceptability testing of the questionnaire was performed on a small sample (n = 10) including three senior pediatric gastroenterologists at Timone Pediatric Hospital. Understandability, potential for misinterpretation, and acceptability were checked, and some terms were revised. We included a 24th item about immunomodulatory treatment. This French version was available for metric validation.

2.1.2. Metric validation

Validation was conducted with a larger sample of individuals in order to assess the questionnaire's reliability, validity, and sensitivity. The sample included five categories of individuals: children with IBD, their parents, IBD-free children, their parents, and health workers.

2.2. Study design

2.2.1 Study population

Pediatric patients being followed up for IBD (CD or UC) in the pediatric gastroenterology department of Timone Pediatric Hospital, who could speak and read French, and who were hospitalized in the pediatric gastroenterology unit or visited the hospital for consultations were asked to participate with a parent (IBD group). Pediatric patients without IBD hospitalized in the pediatric orthopedic surgery department of Timone Pediatric Hospital, who could speak and read French, were asked to participate with one of their parents (control group).

Health workers, including pediatricians, medical residents (pediatric or other specialties), general nurses, childcare nurses, childcare auxiliaries, and ward clerks, were recruited from Timone Pediatric Hospital and the Saint Sebastien Maternal and Child Protection Centre in Marseille.

We excluded children younger than 7 years, people who did not speak or read French, and people included in another survey with an exclusion period still going on at the time of pre-inclusion. All participants provided informed consent.

2.2.2. Data collection and questionnaire completion

Under the same experimental conditions, parents and children completed a booklet including the MICI-MINOTS questionnaire, sociodemographic data, medical data, activity score of IBD

(Pediatric CD Activity Index [20] and Pediatric UC Activity Index) [21], and an anxiety questionnaire. Children completed the State-Trait Anxiety Inventory for Children (STAIC) [22] while their parents completed the STAI – YB [23]. The whole booklet was collected on the day it was completed.

The health workers filled a booklet including the MICI-MINOTS questionnaire, sociodemographic data, and professional data.

2.3. Testing of the MICI-MINOTS questionnaire

2.3.1. Validity testing

Using a method similar to that of Haaland et al. [16], we assessed the relationship between the mean MICI-MINOTS scores of children with IBD and their parents, and presumed surrogate markers of IBD-related knowledge (age, educational level, type of IBD, disease duration, disease activity, anxiety level, parents' socio-professional level, patient association membership, family history). We also evaluated the relationships and correlations between dimensional scores and other quantitative parameters in the different groups. We used backward multiple linear regression analyses, one with patient MICI-MINOTS score as the dependent variable, and one with parent knowledge score as the dependent variable. We followed the same process that Haaland et al. [16] and Eaden et al. [9] used to illustrate the discriminatory value of their knowledge questionnaires. They identified different mean scores among three groups that were expected to have different levels of IBD-related knowledge. In this survey, we compared five subgroups within the health workers' group (senior doctors, junior doctors, childcare nurses, general nurses, and secretaries).

The hypothesis tested was that the MICI-MINOTS scores obtained by patients with IBD and their parents would be higher than the scores obtained by patients in the control group and their parents. Therefore, to assess the discriminatory ability of the MICI-MINOTS, we compared the scores of children with IBD with those of their parents (using a matched *t* test,

intraclass correlation coefficient). We also compared the mean MICI-MINOTS score of parents of children with IBD with those of parents in the control group. Scores of children with IBD were compared with those of children in the control group, and then with those of health workers, using Student's *t* test.

2.3.2. Reliability testing: reproducibility

The reproducibility study was carried out with a subgroup of 15 medical staff at the Maternal and Child Protection Center whose knowledge of IBD remained unchanged between the two evaluations (without new research or teaching about IBD between T0 and T1). This separate "test–retest" group of 15 people was given a second identical questionnaire, 2 weeks (± 3 days) after they completed the first questionnaire. The intraclass correlation coefficients for each dimension were documented (scores at both evaluation times). The reliability of the test was also assessed by evaluating the internal consistency using Cronbach's α, a second method of reliability, as Haaland et al. did with the IBD-KID [16,24].

2.3.3. Acceptability and feasibility

Acceptability was assessed using the questionnaires with all 24 questions completely answered. The readability of the MICI-MINOTS was assessed with Scolarius (www.scolarius.com). Data quality was assessed by determining the percentage of questions left blank, not answered properly (more than one option circled for a question), or answered as "don't know" [25].

2.3.4. Statistical analysis

Data analysis was performed using IBM SPSS Statistics 20.0.0 on Windows by statisticians of the Clinical Research Methodology Unity in Marseille. Only questionnaires with fewer than 25% missing values were considered reliable and analyzed in the metric validation study. Quantitative parameters are presented as mean and standard deviation, or median and

minimum–maximum. Qualitative parameters are presented as sample size and proportion. The same process was used in the different groups of the survey. The significance level was set at $p < 0.05$. Associations between both patient and parent MICI-MINOTS scores and independent variables were evaluated in bivariate analyses. Pearson's or Spearman's correlation coefficients and *t* tests were used for comparisons using dichotomous and continuous independent variables, respectively. Means were compared using a one-way analysis of variance (Tukey test).

This process had been validated and authorized according to the General Data Protection Regulation. This study was approved by the local committee of Aix Marseille University (reference 2015-09-30-01).

3. RESULTS

3.1. Sample characteristics

During the inclusion period from February 2, 2015 to February 5, 2019, a total of 68 pairs of questionnaires (child and parent) were administered to patients with and without IBD. Finally, 58 of the 68 pairs of questionnaires were more than 75% complete and were included for the analysis (response rate of 85%). Among the 10 pairs of questionnaires that were less than 75% complete, six belonged to patients with IBD (three with UC and three with CD) and four to patients in the control group; because of the importance of the lacking data and the small sample, statistic testing could not be performed for these 10 pairs of questionnaires.

A total of 38 children with IBD were included with a parent. Five patients with IBD were aged between 7 and 10 years old (three with CD and two with UC); two patients were 7 eleven years old and three were between 8 and 9 years old. Because our patient population

was more restricted, we chose to include patients from the moment that reading was acquired, i.e., for an age of more than 7 years.

The median duration of IBD was 2.25 years (minimum 0.25 years, maximum 8.0) and 25 of the 38 (65%) patients had had IBD for 2 years or longer. Children with CD and UC were not significantly different except with regard to sex: Children with CD were mostly boys while children with UC were mostly girls. Table 1 describes the characteristics of children with IBD. A total of 20 children without IBD hospitalized in the pediatric orthopedic surgery department were included in the control group with one parent. The demographic and social data of children with and without IBD were not significantly different (Table 2). The characteristics of the parents are presented in Table 3. Parents of children with and without IBD were not significantly different except regarding school grade achieved and Internet research about IBD. The health workers' group included 62 participants: 11 senior doctors, 17 junior pediatric doctors, five junior non-pediatric doctors, 13 childcare nurses, seven general nurses, and nine ward clerks. Every member of this group filled the questionnaire completely, yielding a response rate of 100%. The health workers' characteristics are shown in Table 4. Health workers were significantly different from both groups of parents in terms of age, school grade, IBD association membership, and Internet research about IBD.

3.2. Validity testing: discriminatory validity and external validity

Since we included a question that was not part of the IBD-KID, we assessed a double score: first out of 23 points for the 23-item questionnaire and then out of 24 points with the final item about immunotherapy added.

The MICI-MINOTS score was significantly different across the respondent groups. Children with IBD scored higher than children in the control group: The mean scores for the 23-question MICI-MINOTS among children with and without IBD were 9.58 ± 3.01 and 5.47 ± 3.56, respectively ($p < 0.01$); the mean scores for the 24-question MICI-MINOTS among

children with and without IBD were 9.71 ± 3.10 and 5.52 ± 3.44, respectively ($p < 0.01$). Parents of children with IBD scored higher than parents of children in the control group for both the 23- and 24-question MICI-MINOTS: 10.63 ± 3.16 vs. 8.4 ± 3.07, respectively ($p = 0.012$) and 10.97 ± 3.33 vs. 8.4 ± 3.07, respectively ($p= 0.006$). Children with CD scored higher than children with UC, but the difference was not significant: 9.96 ± 3.08 and 8.85 ± 2.82, respectively ($p = 0.27$), for the 23-question MICI-MINOTS and 10.12 ± 3.16 and 8.93, respectively ($p = 0.26$), for the 24-question MICI-MINOTS.

In the health workers' group, MICI-MINOTS mean scores displayed the expected decreasing trend and the difference between the subgroups of health workers was significant ($p < 0.01$) (Table 5): Physicians scored the highest, followed by childcare nurses, general nurses, and ward clerks ($p < 0.01$ inter-group).

There was a positive correlation between children's and parents' scores ($r = 0.402$, $p = 0.012$ for score out of 23 points; $r = 0.379$ $p = 0.019$ for score out of 24 points). There was no significant correlation between children's MICI-MINOTS scores and disease type, children's or parents' ages, children's anxiety level, IBD patient association membership (however, only one patient was a member of an IBD association), activity score of the disease, having a relative with IBD, school level achieved by children and parents, or perceived knowledge. There was no significant correlation between parents' and health workers' school level achieved and their own MICI-MINOTS scores.

3.3. Reliability testing: reproducibility

The test–retest group involved 15 people: four doctors, four childcare nurses, four general nurses, and three childcare auxiliaries. Their mean age was 46.8 years (± 13.1), and all 15 professionals were women. Five of them had a relative with IBD (in the case of a relative, they were at least second-degree relatives), and one was a member of an IBD patient

association. This group completed two sets of MICI-MINOTS questionnaires with an interval of 2 weeks (± 3 days) to assess the test–retest reliability. The intraclass correlation was 0.940 (95% confidence interval: 0.83–0.98, $p < 0.001$). The internal consistency, assessed with Cronbach's α, was 0.936 (95% confidence interval: 0.82–0.98).

3.4. Acceptability and feasibility

We assessed the readability of the MICI-MINOTS questionnaire in French using the website Scolarius (www.scolarius.com); the questionnaire scored 70, corresponding to elementary school level. Among the children with IBD, 89.5% answered all 24 questions. Children with IBD versus children in the control group circled more than one answer for 0.40 (± 0.56) and 0.50 (± 0.89) questions, respectively ($p = 0.63$). Children with IBD versus children in the control group left 0.03 (± 0.16) and 0.0 (± 0.0) questions blanks, respectively ($p = 0.32$). Children in the control group answered "don't know" significantly more often than did children with IBD (8.45 [± 5.22] vs. 5.95 [± 3.11], respectively, $p = 0.06$).

The performance of children with IBD and their parents on select MICI-MINOTS items is presented in Table 6. A copy of the MICI-MINOTS questionnaire is available online (supplementary data).

4. DISCUSSION

The MICI-MINOTS is a valid French tool for assessing the IBD-specific knowledge of pediatric patients. After the validated Polish version of the IBD-KID, which was presented at the ESPGHAN Congress in 2018 by Banaszkiewicz et al. [26] (Conference paper), this is the second adaptation of the IBD-KID in a language other than English. However, the MICI-MINOTS is the first French adaptation of the IBD-KID.

The MICI-MINOTS demonstrated capability to assess pediatric patients' IBD-related knowledge. We evaluated the questionnaire's reproducibility only with control adults because Haaland and colleagues' study [16] already demonstrated good internal consistency among patients with IBD. We chose Scolarius (www.scolarius.com) because it is a validated tool for assessing readability of texts in French that has been used in other studies as well [27].

The size of our sample was smaller than that used by Haaland et al. [16], but the mean age of patients with IBD was similar to that in the Haaland et al. study: 13.90 ± 2.88 versus 14.6 ± 0.2, respectively. However, the current study was intended to validate the transcription of an already existing and validated scale. The small number of children with IBD in our study led to a lack of power, which could explain the statistical insignificance of some results, for example, the comparison between patients with UC and CD regarding MICI-MINOTS scores. In our study, the number of children with CD was higher than the number of children with UC, as in Day and colleagues' study [17], whereas they were equivalent in the Haaland et al. survey. This could explain why we could not identify a positive correlation between IBD knowledge and CD.

We did not identify a correlation between anxiety and IBD-specific knowledge. However, numerous studies have indicated that anxiety seems to have an unclear effect [8,28,29], with contradictory results of education programs on anxiety levels. We observed that higher MICI-MINOTS scores among children were associated with higher parental knowledge of IBD; therefore, education programs should target parental knowledge as a means to improve children's knowledge.

We did not find a correlation between IBD knowledge and membership to a patient association. In our study, there was only one patient, representing 2.6% of our study sample, who was a member of an association, whereas 23 of 99 IBD patients (23.2% of this study sample) were members of an IBD association in the Haaland et al. study [16]. In 2015, out of

about 250,000 patients with IBD in France, the Association Francois-Aupetit had 8,684 members, which represents 3.4% of the French population with IBD (www.observatoire-crohn-rch.fr; www.afa.asso.fr). Our study sample seems to be representative of the French population with IBD, and this low membership appears to be a French characteristic.

Our second objective was to assess the IBD-related knowledge of the study population, and to this end we compared the scores of the 23-question MICI-MINOTS with other populations assessed with the IBD-KID. The scores of these groups in different study populations are presented in Table 7. In this study, children with IBD and their parents, as well as nurses (pool of childcare nurses and general nurses), reported a significantly lower level of disease-specific knowledge assessed with the 23-question MICI-MINOTS than the populations of Canada [16], Sydney [17], and Australia [30] assessed with the IBD-KID. Pediatric residents and ward clerks did not show significantly different results from the other studies [16,17,30]. These lower results in our study could be explained by a younger age of inclusion for children, although age was not identified as a factor correlated with the final score for MICI-MINOTS.

These differences in scores between populations in different countries could be due not only to a true lack of specific knowledge about IBD, but also to different information about the disease given to the patient in different countries. Multicentric studies should be performed to explain this difference; however, a specific study with a representative sample of French children with IBD would be useful to assess the true level of knowledge in these patients.

High-scoring areas of children's knowledge in this study were questions about the spread of IBD, stress as a trigger of relapse, life expectancy of patients with IBD, and order of digestive tract (Table 6). The same observation was made in Canadian [16] and Australian children with IBD [17].

Low-scoring areas of knowledge were questions about herbal remedies and the role of surgery

in IBD, as was the case with Canadian and Australian children with IBD [16,17]. The role of salicylates and azathioprine in maintenance therapy was a high-scoring area in Australian children [17], whereas Canadian children with IBD [16] and those in our study did not score well in this regard. Canadian children with IBD and French children with IBD in the present study scored poorly on the role of enteral nutrition and osteoporosis related to IBD, steroids, and poor nutrition [16]. Overall, the children with IBD included in our study had low scores on therapeutics (including questions about tumor necrosis factor [TNF]-alpha inhibitors) and disease management.

Our questionnaire added to the IBD-KID a new question about immunotherapies, specifically TNF-alpha inhibitors, because of the developments in therapies for IBD since the IBD-KID was initially designed. In the same way, this questionnaire will have to be updated with new research results in the coming years.

As the MICI-MINOTS is a validated questionnaire for the assessment of knowledge related to IBD for pediatric patients, we will make it available to the scientific community. The MICI-MINOTS questionnaire could be useful for the assessment of pediatric patient knowledge in France, and could be used after the questionnaire has been culturally adapted for other French-speaking populations. A digital version could make the questionnaire more attractive and entertaining for patients, and it could also be used in association with other questionnaires concerning mood and quality of life and integrated into education programs.

5. CONCLUSION

The psychometric properties of the MICI-MINOTS were satisfactory for its use in the assessment of knowledge of the disease in French-speaking children with IBD. It was demonstrated to be a valid, reliable, and readable self-administrated questionnaire. This study

revealed that French pediatric patients with IBD lack knowledge about their own disease. The questionnaire could help these patients obtain more information to achieve better self-management and control of IBD. The MICI-MINOTS could help identify the specific areas in which patients lack knowledge, which could be tackled in future medical consultations. This could be the first step toward the development of a focused and appropriate education program to improve patient knowledge.

Conflict of interest: None

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www.scolarius.com

www.observatoire-crohn-rch.fr

www.afa.asso.fr

TABLES

Table 1. Characteristics of children with inflammatory bowel disease

	CD (*N* = 25)	UC (*N* = 13)	*p*
Sex (boy/girl)	18/7	2/11	**0.01**
Age (mean ± SD), years	14.07 ± 2.87	13.57 ± 2.99	0. 62
School grade achieved*: Elementary school 6th to 9th grade 9th certificate and technical certificate 10th to 12th grade High school diploma Technical diploma after high school	 3 14 2 5 1 0	 1 7 1 3 0 1	0.63
Class repetition (1 or more)	6	4	0.71
Disease duration (median, minimum–maximum), years	3.30 ± 2.46	2.30 ± 1.85	0.19
IBD association membership	1	0	1.00
Activity score of disease (mean ± SD)	PCDAI 5,63 ± 1.22	PUCAI 4.23 ± 2.71	0.59
State-Trait Anxiety Inventory for Children	28.59 ± 5.20	33.00 ± 9.02	0.13

CD: Crohn's disease; UC: ulcerative colitis; *p*: significance index; SD: standard deviation; IBD: inflammatory bowel disease; PCDAI: Pediatric Crohn's Disease Activity Index; PUCAI: Pediatric Ulcerative Colitis Activity Index. Values in bold are significant values.

*School class equivalence is available in supplementary data.

Table 2. Comparison of children's demographics, social data, and anxiety score

	Children with IBD (N = 38)	Control children (N = 20)	p
Sex (boy/girl)	20/18	13/7	0.60
Age (mean ± SD), years	13.90 ± 2.88	14.38 ± 2.26	0.16
School grade achieved*:			0.72
Elementary school	4	2	
6th to 9th grade	21	10	
9th certificate and technical certificate	3	0	
10th to 12th grade	8	8	
High school diploma	1	0	
Technical diploma after high school	1	0	
Class repetition (1 or more)	10	3	0.51
IBD association membership	1	0	0.29
Relative with IBD	10	5	1.0
STAIC (mean ± SD)	30.23 ± 7.07	29.9 ± 7.01	0.90

IBD: inflammatory bowel disease; SD: standard deviation; p: significance index; STAIC: State-Trait Anxiety Inventory for Children.
*School class equivalence is available in supplementary data.

Table 3. Description of demographic and social data of parents of children with and without IBD

	Parents of children with IBD ($N = 38$)	Parents of children in the control group ($N = 20$)	p
Age (mean ± SD), years	44.63 ± 6.62	47.30 ± 7.11	0.16
Sex (male/female)	4/34	1/19	0.66
School grade achieved: ≥ high school diploma	22	18	**0.03**
Relative with IBD	10	5	0.91
IBD association membership	4	0	0.29
Internet research about IBD (once a month to once a week)	16	2	**0.04**
Anxiety score (STAI-YB) (Mean ± SD)	42.81 ± 10.01	36.3 ± 12.94	0.08

IBD: inflammatory bowel disease; SD: standard deviation; p: significance index; STAIC: State Trait Anxiety Inventory – YB version. Values in bold are significant values.

Table 4: Description of the health workers group

	Health workers ($N = 62$)	Comparison with parents of children with and without IBD
Age (mean ± SD), years	36.47 ± 11.18	$\mathbf{p < 0.01}$. Between health workers and parents of children with IBD, and health workers and parents of children in the control group.
Sex (male/female)	6/56	$p = 0.92$. Between health workers and parents of children with IBD, and health workers and parents of children in the control group.
School grade achieved: ≥ high school diploma	60	$\mathbf{p < 0.01}$. Between health workers and parents of children with IBD, and health workers and parents of children in the control group.
Relative with IBD	8	$p = 0.20$. Between health workers and parents of children with IBD, and health workers and parents of children in the control group.
IBD association membership	0	$\mathbf{p = 0.02}$. Between health workers and parents of children with IBD, and health workers and parents of children in the control group.
Internet research about IBD (once a month to once a week)	4	$\mathbf{p < 0.01}$. Between health workers and parents of children with IBD, and health workers and parents of children in the control group.

IBD: inflammatory bowel disease; SD: standard deviation; p : significance index. Values in bold are significant values.

Table 5. MICI-MINOTS scores in subgroups of health workers

MICI-MINOTS	Score/23 (mean ± SD)	Score/24 (mean ± SD)
Pediatric juniors (*N* = 17)	17.82 ± 3.46	18.47 ± 3.71
Senior doctors (*N* = 11)	16.81 ± 2.42	17.45 ± 3.73
Non-pediatric juniors (*N* = 5)	16.8 ± 2.59	17.2 ± 2.17
Nurse pool (*N* = 20) Childcare nurses (*N* = 13) General nurses (*N* = 7)	11.75 ± 3.4 12.0 ± 2.78 11.29 ± 4.68	12.00 ± 3.55 12.31 ± 2.81 11.46 ± 4.86
Ward clerks (*N* = 9)	8.67 ± 2.40	8.67 ± 2.40

SD: standard deviation.

Table 6. Performance of pediatric patients with IBD and their parents on select MICI-MINOTS questions

Concept	No. correct answers, $N = 38$	
	Patient	Parent
No risk of IBD transmission	34	35
Emotional stress and IBD flare-up	28	32
IBD is familial	27	32
Most patients with IBD have normal life expectancy	27	22
Correct order of digestive tract	23	28
The etiology of IBD is unknown	21	21
Risk of colon cancer in IBD	19	16
IBD can affect other organs	18	27
No foods proven to cause IBD flare-ups	9	13
Role of salicylates and azathioprine in maintenance therapy	5	3
TNF-alpha inhibitors	5	13
Herbal remedies can have adverse effects and interact with drugs	4	6
Osteoporosis is related to IBD, steroids, and poor nutrition	3	5
Role of enteral nutrition (treatment and prevention of CD/growth)	3	6
Role of surgery in CD and UC	2	2

IBD = inflammatory bowel disease; TNF = tumor necrosis factor; CD = Crohn's disease; UC: ulcerative colitis.

Table 7. Comparison of IBD knowledge of four IBD populations assessed with the IBD-KID and 23-question MICI-MINOTS

IBD-KID or MICI-MINOTS (mean score ± SD)	Canada	Sydney	Australia	Marseille	*F*	*p*
Patients with IBD	*N* = 99 11 ± 4	*N* = 20 12.1 ± 4.6	*N* = 128 11.75 ± 3.55	*N* = 38 9.58 ± 3.01	3.80	**0.01**
Parents of children with IBD	*N* = 99 15 ± 4	*N* = 20 16.8 ± 2.7	*N* = 262 14.19 ± 4.02	*N* = 38 10.63 ± 3.16	15.01	**< 0.001**
Pediatric residents	*N* = 12 19.08 ± 0.84	*N* = 20 19.5 ± 2.1	*N* = 0	*N* = 17 17.82 ± 3.46	2.20	0.12
Nurses (childcare nurses and general nurses)	*N* = 19 15.79 ± 0.64	*N* = 20 13.2 ± 2.7	*N* = 0	*N* = 20 11.75 ± 3.4	15.96	**< 0.001**
Ward clerks	*N* = 21 9.24 ± 1.07	*N* = 20 7.3 ± 4.1	*N* = 0	*N* = 9 8.67 ± 2.40	2.40	0.10

IBD: inflammatory bowel disease; SD: standard deviation; *F*: value for ANOVA test. *p*: significance value. Values in bold are significant values.

Matériels complémentaires:
Appendix 1: MICI-MINOTS: French knowledge questionnaire on inflammatory bowel diseases
http://www.sciencedirect.com,doi...

Appendix 2: School class equivalence between France and Canada/USA (Wikipedia)
http://www.sciencedirect.com.doi...