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## Prospective Study

**Determinants of disease-specific knowledge among children with inflammatory bowel disease and their parents: A multicentre study**

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**Abstract****BACKGROUND**

Disease knowledge is associated with increased treatment compliance and improvement of symptoms in inflammatory bowel disease (IBD). IBD-knowledge inventory device (IBD-KID) was developed and validated specifically as a tool to measure disease-related knowledge in children with IBD and their parents.

**AIM**

To prospectively assess the determinants of disease-related knowledge regarding paediatric IBD patients and their parents, using the IBD-KID.

**METHODS**

A questionnaire-based survey was carried out in paediatric patients and their parents. The determinants of patients' and parents' IBD-KID scores were assessed according to hierarchical linear regression models.



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## RESULTS

The study group consisted of 269 IBD patients and 298 parents. The patients' mean (standard deviation, SD) IBD-KID score was 10.87 ( $\pm$  3.97), while the parents' was 11.95 ( $\pm$  3.97). Both groups exhibited poor knowledge of the side effects of steroid therapy, the role of surgical treatment in IBD, dietary restrictions and the risks associated with the use of herbal medicines. The patients' IBD-KID scores were statistically associated with patient sex [B coefficient (standard error, SE) = 1.03 (0.44),  $P$  = 0.021] and patient age [B (SE) = 0.03 (0.01),  $P$  < 0.001]. The parents' IBD-KID scores were significantly related to patient age [B (SE) = 0.02 (0.01),  $P$  = 0.003], and treatment with immunosuppressive agent [B (SE) = 1.85 (0.48),  $P$  < 0.001]. The final models explained 26.9% of the variance of patients' IBD-KID scores and 18.5% of the variance of parents' scores.

## CONCLUSION

The variables originating from parents' knowledge were significantly associated with patients' IBD-KID scores. The study results indicate the need to implement better education programmes for patients and parents.

**Key Words:** Crohn's disease; Inflammatory bowel disease-knowledge inventory device; Knowledge; Parents; Ulcerative colitis

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**Core Tip:** This was a prospective study that assessed the disease-related knowledge regarding paediatric inflammatory bowel disease (IBD) among children and their parents using previously validated IBD-knowledge inventory device (IBD-KID). The variables originating from parent's knowledge, were significantly associated with patient's IBD-KID score. Parents of patients treated with immunosuppressive agents showed higher diseases-specific knowledge. The results of the study indicate the need to implement better education programmes for patients and parents.

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## INTRODUCTION

The burden and prevalence of inflammatory bowel disease (IBD), comprising Crohn's disease (CD) and ulcerative colitis (UC), are increasing among children and adolescents in many regions of the world, including Poland[1-3]. IBD is chronic in nature, potentially occurring with unpredictable periods of exacerbation even during pharmacologically supported remission. The chronic course of the disease is characterised by numerous exacerbations and complications and the need for a wide range of medication (including aminosalicylates (5-ASA), corticosteroids (CS), immunosuppressants, biologics) and, sometimes, surgical treatment, significantly affecting the quality of life of young patients and their families[4]. The disease poses challenges to participation in school activities, social life and travelling, along with dietary restrictions and concerns about the future[5,6]. Parents of sick children and teenagers may experience difficulties understanding and complying with the necessary treatment regimens and dietary recommendations at different stages of the disease. Research has shown that understanding the causes of chronic disease and the principles of treatment results in improved adherence to therapeutic recommendations, facilitated contact with medical personnel and higher quality of life[7-9]. In the case of paediatric patients, especially the youngest ones, the sources of information and the knowledge that parents and guardians gain is of utmost importance. The use of common sense or popular but unproven opinions, instead of reliable sources of

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information, can augment the frustration associated with childhood chronic disease and adversely impact the treatment process. Moreover, the lack of professional dietary or psychological support may further affect the quality of life, resulting in excessive restrictions of a young patient's diet or age-appropriate activity.

IBD-Knowledge Inventory Device (IBD-KID) was developed and validated specifically as a tool to measure disease-related knowledge in children with IBD and their parents[10]. It was previously used among children Canada, Australia and France[10-12]. In Poland, no study has yet assessed the disease-related knowledge of children and teenagers having IBD, nor that of their parents. Therefore, a multicentre study of disease-specific knowledge and its determinants among paediatric patients and their parents was carried out with the use of IBD-KID that was translated into Polish and validated.

## MATERIALS AND METHODS

### Sampling and ethics

The survey involved a convenience sample of patients with IBD and their parents from four Polish university centres specialising in paediatric gastroenterology between 2016 and 2018. The participating departments were based in Warsaw, Olsztyn, Wrocław and Kraków. Patients aged 10 years and older and their parents or guardians completed the questionnaire used in the survey. In the case of younger patients, parents filled out the questionnaires.

The study was approved by the University Bioethical Committee (Consent No AKBE/120/16). After participants were informed about the study aims, only those who provided their consent were invited to fill the questionnaire. Each pair of surveys (or survey) was assigned a unique code to preserve respondents' anonymity.

### Questionnaire

The questionnaire used in the survey consisted of the IBD-KID instrument that is available at [https://cdn-links.lww.com/permalink/mpg/a/mpg\\_2013\\_10\\_11\\_otley\\_135\\_sdc1.pdf](https://cdn-links.lww.com/permalink/mpg/a/mpg_2013_10_11_otley_135_sdc1.pdf); the 23 items asking about general knowledge (2), IBD course (6), risk factors (4), therapeutic modes and adverse effects of treatment (11). Scoring of the questionnaire was one point for each correct answer with no negative marking; the maximum score was 23 points. Demographic characteristics of patients and parents and membership of the Polish patient Crohn's & Ulcerative Colitis Association *J-elita* were also collected. Parents were also queried about preferred sources of information and asked to provide a self-assessment of their knowledge about their child's disease.

The Polish version of the IBD-KID scale used in the study was obtained after cultural adaptation consisting of three stages, including forward translation, backward translation and cognitive debriefing, according to the guidelines provided by Prof. Anthony Otley, the author of the original version of the scale[10]. The conformance to the guidelines provided by the authors of the scale was confirmed with the validation certificate from 31 March 2015[13].

### Statistical analysis

Statistical analysis was carried out using IBM SPSS v25 software (IBM Corp. Armonk, NY, United States). The mean and standard deviation were provided for the continuous variables as well as absolute and relative frequencies for categorical variables. The Kolmogorov-Smirnov test was applied to check whether continuous variables conformed to the normal distribution. The internal consistency of the IBD-KID scale was assessed using Cronbach's alpha. A *P* value < 0.05 was deemed to be statistically significant.

In the first stage of analysis, the association between IBD-KID scores and potential predictors was assessed using univariate linear regression. Next, hierarchical linear regression models were developed for both patients' and parents' IBD-KID scores. In multivariate models, only those independent variables for which the *p*-value in the univariate model was at least 0.1 were included.

Hierarchical multivariate linear regression modelling was performed for both parents' and patients' IBD-KID scores. In three consecutive steps of the hierarchical multivariate regression for patients' scores, the following independent variables were introduced: (1) Patient's demographic characteristics and self-assessment of knowledge; (2) Parent's IBD-KID score and their self-assessment of knowledge, membership in the *J-elita* Association and the use of the Internet as a source of knowledge; and (3) The use of treatment options.

Hierarchical regression modelling for parents' IBD-KID scores also consisted of three steps, in which the following variables were introduced: (1) Patient's demographic characteristics and their self-assessment of knowledge; (2) Parent's demographic characteristics, self-assessment of knowledge, membership in the J-elita Association and the use of books and journals as sources of knowledge; and (3) The use of treatment options.

Hierarchical regression was chosen to expose the relative importance of variables potentially associated with the level of IBD-KID scores in both groups of respondents. The assumption was also made that a parent's IBD-KID score might play the role of a predictor of the patient's score.

Unstandardised regression coefficients (B), standard errors (SE), standardised regression coefficients (beta), 95% confidence intervals, and *P*-values were reported for independent variables included in the univariate analysis. For those included in the hierarchical linear regression models, 95% confidence intervals were omitted. In the case of hierarchical linear regression models, standardised R<sup>2</sup> values and F for the change in R<sup>2</sup> were also provided.

## RESULTS

### *Study group characteristics*

The survey was completed by 269 IBD patient-parent pairs (for patients 10 years and older) and 29 parents of patients under 10 years old. The mean age (SD) of patients was 167.3 (37.5) mo, and the mean duration of disease (SD) was 40.7 (33.8) mo. [Table 1](#) displays patient characteristics.

### *IBD-KID scores*

Cronbach's alpha coefficient for patients' IBD-KID scale was 0.75, while this value for parents was 0.60. The patients' and parents' mean (SD) IBD-KID scores were 10.87 (3.97) and 11.95 (3.97), respectively. Both patients with CD and their parents reached higher scores [mean (SD): 11.06 (3.99) and 12.18 (4.14), respectively] than those with UC and their parents [10.52 (SD ± 3.93) and 11.52 (SD ± 3.60), respectively]. The percentage of correct answers given by patients was in the range of 74.83% (item No 13) and 12.08% (item No 20). In the case of parents' responses, the range was 87.92% (item No 3) - 11.74 (item No 17). The distribution of correct answers to the KID-IBD scale items is shown in the supplementary file ([Supplementary Table 1](#)).

### *Regression modelling of IBD-KID scores*

Univariate linear regression analysis showed that patients' scores were significantly associated with patient age and sex, patient's and parent's self-rated knowledge, membership in the Jelita Association, parent's use of the Internet as a source of knowledge and parent's IBD-KID score ([Table 2](#), [Supplementary Figure 1](#)). Furthermore, nutritional and surgical therapy and the use of immunosuppressive or biological agents were also statistically related to the patient's score. Parents' IBD-KID scores showed a significant relationship with parent sex and education, place of residence, parent's and patient's self-assessment of knowledge, membership in the J-elita Association, and the use of books or journals for accessing knowledge about the disease ([Table 2](#), [Supplementary Figure 2](#)). As in the case of the patients' scores, the use of immunosuppressive or biological agents was associated with higher scores.

Tables 3 and 4 show the final model obtained with hierarchical linear regression for the IBD-KID scores of both patients and parents, respectively (details of all three models are shown in [Supplementary Tables 2 and 3](#)). The assumptions for multiple linear regression were met for both models. In the first step, patient sex and age, place of residence and self-assessment of knowledge were introduced to the model for the patient's IBD-KID score. All four independent variables were significant predictors, as the resulting model explained 14.1% of the variance of the score ([Supplementary Table 2](#)). In the second step, parent's self-assessment of knowledge, J-elita Association membership, using the Internet as a source of knowledge and parent's IBD-KID score were added. The resulting model explained an additional 12.7% of the variance of the patient's IBD-KID score ([Supplementary Table 2](#)). The third step included variables reflecting specific therapeutic modalities used in a patient. This technique explained an additional 0.1% of the variance, and the change in R<sup>2</sup> was not statistically significant ([Table 3](#)).



**Table 1** Demographics of inflammatory bowel disease patients participating in inflammatory bowel disease-knowledge inventory device study

Variable	Categories of variable	Patients, n (%)
Patient's gender	Female	140 (52.0)
	Male	129 (48.0)
Parent's gender	Female	232 (80.0)
	Male	58 (20.0)
Place of residence	Rural	172 (57.9)
	Urban	125 (41.1)
Parent's education	Lower than secondary	48 (16.2)
	Secondary	123 (41.6)
	Higher than secondary	125 (42.2)
Disease type	CD <sup>1</sup>	196 (65.8)
	UC <sup>2</sup>	102 (34.2)
IBD family history		50 (16.8)
J-elita membership		64 (21.8)
Treatment modes		
Aminosalicylates	All patients	248 (83.2)
	CD	160 (81.6)
	UC	88 (86.3)
Immunomodulators	All patients	205 (68.8)
	CD	143 (73.0)
	UC	62 (60.8)
Biologic therapy	All patients	99 (33.2)
	CD	81 (41.3)
	UC	18 (17.6)
Exclusive enteral nutrition	All patients	98 (32.9)
	CD	85 (43.4)
	UC	13 (12.7)
Dietary counselling	All patients	90 (30.2)
	CD	67 (34.2)
	UC	23 (22.5)
Psychological support	All patients	53 (17.8)
	CD	34 (17.3)
	UC	19 (18.6)
Surgical treatment	All patients	30 (10.1)
	CD	27 (13.8)
	UC	3 (2.9)
Patient's self-assessment of knowledge	Good	120 (45.1)
	Average	125 (47.0)
	Low	21 (7.9)
Parent's self-assessment of knowledge	Good	152 (51.7)
	Average	122 (41.5)

	Low	20 (6.8)
Sources of parent's information about disease		
Physician		241 (80.9)
Nurse		66 (22.1)
Internet		197 (66.1)
Journals		82 (27.5)
Books		77 (25.8)

<sup>1</sup>One hundred and seventy-four questionnaires filled both by a child and a parent and 22 only by parents.

<sup>2</sup>Nity-five questionnaires filled both by a child and a parent and 7 filled only by parents. CD: Crohn's disease; UC: Ulcerative colitis.

As for the parents' IBD-KID scores, the first step of hierarchical linear regression introduced patient age, patient's self-assessment of knowledge and place of residence. All three variables exerted a significant effect on the parent's IBD-KID score (Supplementary Table 3). The model explained 7.5% of the variance of the parent's score. The second step added the parental education level and self-assessment of knowledge, J-elita Association membership and the use of books and journal as sources of knowledge (Supplementary Table 3). The change in  $R^2$  with this model was equal to 0.045 and statistically significant. The third step introduced the variables reflecting treatment modalities. The results explained a further 6.5% (18.5% in total) of the variance of the parent's score. In the final model, patient age, parental education level, and the use of immunosuppressive agent were significant predictors of the parent's score (Table 4).

## DISCUSSION

This study assessed the disease-specific knowledge of a large sample of paediatric IBD patients and their parents. This investigation is the first to be based on the dedicated tool in this particular group in Poland. We found that both patients and their parents had insufficient IBD-related knowledge. Univariate models developed for the patients' IBD-KID scores showed that these scores were higher among older than younger patients, among girls compared to boys, among patients who more highly assessed their knowledge about the disease and whose parents did the same. Furthermore, higher scores were found among patients whose parents indicated the Internet as a main source of information, reported membership in the J-elita Association and noted nutritional, surgical immunosuppressive or biological treatment. The patient's score was also positively associated with the parent's score. A fully developed hierarchical regression model maintained a significant association between patients' scores and their gender and age, parents' self-rated knowledge, and IBD-KID scores. Univariate analysis revealed that parents' scores were significantly higher among women compared to men, among the parents of younger *vs* older children, among those with higher self-rated knowledge and whose children better assessed their knowledge, among parents with higher *vs* lower levels of education, and among those using books and journals as sources of information. Membership in a patients' association and earlier immunosuppressive or biological treatment in a child were also associated with a higher score. The hierarchical regression model showed that a significant association was retained only for patient's age, prior immunosuppressive therapy and parental education level.

The average scores of our study's parents and patients agree with results obtained in paediatric studies carried out using the same questionnaire in Canada, Australia and New Zealand [11,14]. Other studies reported similar findings on factors influencing the IBD-KID scores as in our study. For example, a significant relationship between patients' and parents' IBD-KID scores and self-rated knowledge was reported by Haaland *et al* [10]. We have shown, as have they, a correlation between parents' level of education and parents' but not patients' scores [10]. However, this relationship was not observed by Vernon-Roberts *et al* [15] in an investigation using a modified version of the questionnaire: IBD-KID2.

We have found no correlation between IBD-KID score and disease duration. On the other hand, both uni- and multivariate analysis revealed a link between the IBD-KID

**Table 2 Univariate linear regression models for patient's and parent's inflammatory bowel disease-knowledge inventory device scores**

Independent variables	Categories of independent variables	Patient's score			
		B (SE)	95%CI		P value
Univariate models for patient's IBD-KID score					
Patient's age		0.03 (0.01)	0.02 to 0.05	0.24	< 0.001
Parent's sex		-0.69 (0.61)	-1.89 to 0.52	-0.07	0.26
Patient's sex		-1.12 (0.48)	-2.07 to -0.17	-0.14	0.021
Place of residence		0.86 (0.48)	-0.09 to 1.82	0.11	0.076
Type of disease	UC <i>vs</i> CD	-0.54 (0.51)	-1.54 to 0.46	-0.07	0.29
Time from the diagnosis		0.01 (0.01)	-0.01 to 0.02	0.05	0.43
Parent's self-assessment	Low <i>vs</i> medium	-2.29 (0.94)	-4.15 to -0.43	-0.15	0.016
	Good <i>vs</i> medium	1.63 (0.49)	0.67 to 2.59	0.21	0.001
Patient's self-assessment	Low <i>vs</i> medium	-3.25 (0.90)	-5.03 to -1.48	-0.22	< 0.001
	Good <i>vs</i> medium	0.90 (0.49)	-0.06 to 1.86	0.11	0.067
Parents level of education	Lower than sec. <i>vs</i> sec.	0.23 (0.70)	-1.15 to 1.62	0.02	0.74
	Higher than sec. <i>vs</i> sec.	0.61 (0.53)	-0.43 to 1.66	0.08	0.25
Source: Physician	Yes <i>vs</i> no	-0.10 (0.63)	-1.34 to 1.14	-0.01	0.87
Source: Nurse	Yes <i>vs</i> no	-0.10 (0.59)	-1.26 to 1.05	-0.01	0.86
Source: Books	Yes <i>vs</i> no	0.61 (0.57)	-0.51 to 1.73	0.07	0.28
Source: Journals	Yes <i>vs</i> no	0.77 (0.54)	-0.30 to 1.84	0.09	0.15
Source: Internet	Yes <i>vs</i> no	1.22 (0.50)	0.23 to 2.21	0.15	0.016
J-elita Ass. Membership	Yes <i>vs</i> no	1.22 (0.59)	0.06 to 2.37	0.13	0.039
Close family	Yes <i>vs</i> no	1.16 (0.85)	-0.51 to 2.83	0.08	0.17
Family 2nd grade	Yes <i>vs</i> no	0.43 (0.85)	-1.24 to 2.11	0.03	0.61
Parent's score	Yes <i>vs</i> no	0.42 (0.06)	0.31 to 0.53	0.41	< 0.001
Nutritional treatment	Yes <i>vs</i> no	1.03 (0.51)	0.01 to 2.04	0.12	0.047
Psychologist	Yes <i>vs</i> no	0.73 (0.63)	-0.51 to 1.98	0.07	0.25
Dietitian	Yes <i>vs</i> no	-0.12 (0.53)	-1.15 to 0.92	-0.01	0.82
Surgical treatment	Yes <i>vs</i> no	2.36 (0.80)	0.79 to 3.93	0.18	0.003
Salicylates	Yes <i>vs</i> no	0.19 (0.66)	-1.12 to 1.49	0.02	0.78
Immunosuppressive agent	Yes <i>vs</i> no	1.15 (0.52)	0.14 to 2.17	0.14	0.026
Biological agent	Yes <i>vs</i> no	1.29 (0.52)	0.28 to 2.31	0.15	0.013
Univariate models for parent's IBD-KID score					
Patient's age		-0.01 (0.01)	-0.02 to 0	-0.11	0.073
Parent's sex		-1.23 (0.54)	-2.3 to -0.15	-0.13	0.025
Patient's sex		0.23 (0.48)	-0.73 to 1.18	0.03	0.64
Place of residence		1.45 (0.48)	0.51 to 2.39	0.18	0.003
Type of disease	UC <i>vs</i> CD	-0.66 (0.49)	-1.61 to 0.30	-0.08	0.18
Time from the diagnosis		0.01 (0.01)	-0.01 to 0.02	0.06	0.32
Parent's self-assessment	Low <i>vs</i> medium	-2.97 (0.92)	-4.78 to -1.16	-0.19	0.001
	Good <i>vs</i> medium	1.15 (0.46)	0.24 to 2.07	0.15	0.014

Patient's self-assessment	Low <i>vs</i> medium	-3.64 (0.89)	-5.39 to -1.88	-0.25	0.000
	Good <i>vs</i> medium	0.53 (0.48)	-0.43 to 1.48	0.07	0.28
Parents level of education	Lower than sec. <i>vs</i> sec.	-0.89 (0.67)	-2.21 to 0.43	-0.08	0.18
	Higher than sec. <i>vs</i> sec.	1.17 (0.50)	0.20 to 2.15	0.15	0.019
Source: physician	Yes <i>vs</i> no	-0.05 (0.59)	-1.20 to 1.10	0.00	0.93
Source: nurse	Yes <i>vs</i> no	-0.79 (0.55)	-1.88 to 0.30	-0.08	0.16
Source: books	Yes <i>vs</i> no	1.28 (0.52)	0.24 to 2.31	0.14	0.016
Source: journals	Yes <i>vs</i> no	1.31 (0.51)	0.30 to 2.32	0.15	0.011
Source: Internet	Yes <i>vs</i> no	0.67 (0.49)	-0.28 to 1.63	0.08	0.17
J-elita Ass. Membership	Yes <i>vs</i> no	1.45 (0.55)	0.36 to 2.53	0.15	0.009
Close family	Yes <i>vs</i> no	0.30 (0.81)	-1.29 to 1.90	0.02	0.71
Family 2nd grade	Yes <i>vs</i> no	0.87 (0.84)	-0.78 to 2.52	0.06	0.30
Nutritional treatment	Yes <i>vs</i> no	0.97 (0.49)	0 to 1.93	0.11	0.050
Psychologist	Yes <i>vs</i> no	0.90 (0.60)	-0.28 to 2.08	0.09	0.14
Dietitian	Yes <i>vs</i> no	0.19 (0.50)	-0.81 to 1.18	0.02	0.71
Surgical treatment	Yes <i>vs</i> no	1.27 (0.76)	-0.23 to 2.77	0.10	0.097
Salicylates	Yes <i>vs</i> no	0.50 (0.62)	-0.71 to 1.72	0.05	0.41
Immunosuppressive agent	Yes <i>vs</i> no	1.45 (0.49)	0.48 to 2.41	0.17	0.003
Biological agent	Yes <i>vs</i> no	1.23 (0.49)	0.27 to 2.18	0.15	0.012

B: Unstandardised regression coefficient; SE: Standard error; : Standardised regression coefficient; 95%CI: 95% confidentiality interval; sec.: Secondary education; IBD-KID: Inflammatory bowel disease-knowledge inventory device.

scores and patient's age. Other authors have suggested that the patients' and parents' core knowledge is obtained during the period of diagnosis of the disease. However, while patients' awareness and knowledge of the disease increases with age, parents gradually become less involved, eventually forgetting some information[10,16].

Numerous studies, both in children and adults with IBD, confirm that membership in organisations supporting IBD patients increases disease awareness and disease-specific knowledge[14,17,18]. Our study findings also seem to confirm these observations. Membership in the patient Crohn's and Ulcerative Colitis Association J-elita correlated with higher patient and parent scores. J-elita is a Polish patient association of adults and children diagnosed with IBD and a member of The European Federation of Crohn's & Ulcerative Colitis Associations. The aims of J-elita are to raise awareness about IBD and improve the life of the several thousand people living with IBD in Poland. This outcome may reflect patients' and their parents' involvement in the organisation's educational activities. Interestingly, the effect of membership was not retained in the multivariate models, possibly because both membership and higher scores could be achieved by more active patients or parents as reflected by the preserved effect of self-rated knowledge.

Our study revealed that the therapy modes used in a patient might be related to both patients' and parents' scores. Concerning exclusive enteral nutrition, which is recommended as a treatment inducing remission in paediatric CD patients[19], the specific nature of this treatment and the need for medical follow-up may explain why these patients usually remain longer under close medical monitoring during the first period of illness. Consequently, they have more frequent contact with qualified staff who can provide them with reliable information. Presumably, this situation contributes to greater and more systematic involvement in the treatment process.

In the case of the parent's score, a significant association was present for immunosuppressive treatment even after adjusting for other factors included in the multivariate model. Both immunosuppressive therapy and biological treatment are applied in more severe forms of IBD, and surgical intervention may be necessary when treating complications. Such patients usually have a longer history of multiple hospitalisations and treatment of exacerbations. Studies performed in adult IBD patients showed that more frequent hospitalisations were associated with better disease-

**Table 3 Hierarchical linear regression for patient's inflammatory bowel disease-knowledge inventory device score as an independent variables (model 3; details of model 1 and 2 are shown in Supplementary Table 2)**

Independent variables		Model 3		
		B (SE)	Beta	P value
Patient's sex		-1.03 (0.44)	-0.13	0.021
Place of residence		0.41 (0.45)	0.05	0.37
Patient's age		0.03 (0.01)	0.24	< 0.001
Patient's self-assessment of knowledge	Low <i>vs</i> medium	-1.87 (1.46)	-0.12	0.20
	Good <i>vs</i> medium	-0.74 (0.74)	-0.09	0.32
Parent's self-assessment of knowledge	Low <i>vs</i> medium	-1.24 (1.68)	-0.08	0.46
	Good <i>vs</i> medium	-1.66 (0.74)	-0.21	0.026
J-elita membership		0.69 (0.55)	0.07	0.21
Internet as a source of knowledge		0.67 (0.47)	0.08	0.16
Parent's IBD-KID score		0.33 (0.06)	0.32	< 0.001
Immunosuppressive agent		-0.12 (0.51)	-0.01	0.82
Biological agent		0.26 (0.52)	0.03	0.61
Nutritional therapy		0.38 (0.48)	0.05	0.43
Surgical therapy		1.26 (0.76)	0.10	0.098
Raw/Corrected R <sup>2</sup>		0.311/0.269		
F for change in R <sup>2</sup>		1.108		
P value for R <sup>2</sup> change		0.35		

P value for the significance of the independent variable in the multivariate model. Dependent variable: patient's IBD-KID score, model assessment: model 3 – df = 14, F = 7.562, P < 0.001. IBD-KID: Inflammatory bowel disease-knowledge inventory device; B: Unstandardised regression coefficient; SE: Standard error; Beta: Standardised regression coefficient; sec.: Secondary education.

specific knowledge on the part of patients[20]. Therefore, in such circumstances, paediatric patients and their parents are also highly likely to be strongly motivated and more engaged in searching for additional information about the disease. Moreover, it is probable that greater parent's knowledge may lead to better disease management; the immunosuppressive therapy is currently most recommended in IBD.

In general, our study revealed that parents were much more likely to give correct answers compared to children (Supplementary material, Table 1). Both patients and parents revealed relatively adequate knowledge about anatomical conditions, risk of disease transmission, factors leading to exacerbations, and principles of treatment in remission. Areas of insufficient knowledge included the side effects of steroid therapy, the role of surgical treatment in IBD, dietary restrictions and the risks associated with the use of herbal medicines.

The pattern of knowledge seems very similar to that found in other countries[10-12, 14]. Fewer than 40% of children and slightly more than 50% of parents were aware that the disease itself, as well as poor nutrition and the use of steroids, could cause osteoporosis. Fewer than one-third of respondents knew that steroids could suppress a child's growth. Lack of sufficient knowledge regarding side effects caused by corticosteroids may be at least partially related to actual recommendations of avoiding steroid therapy, particularly on a long-term basis. Therefore, the side effects of steroid therapy may currently be seen less often than decades ago.

Particularly important is the lack of proper knowledge of nutrition for sick children. A significant proportion of those surveyed expressed the opinion that dietary restrictions, including the withdrawal of certain products from the diet, could prevent aggravation of the disease. This misunderstanding is a cause for serious concern, as frequent and unjustified food avoidance may influence the nutritional status and general well-being of paediatric patients[6]. Lack of awareness of the risks associated with the use of herbal medicines related to their potential interaction with other drugs turned out to be another area of poor knowledge. Similar results were obtained using



**Table 4 Hierarchical linear regression for the parent's inflammatory bowel disease-knowledge inventory device score as independent variables (model 3; details of model 1 and 2 are shown in Supplementary Table 3)**

Independent variables		Model 3		
		B (SE)	Beta	P value
Place of residence		0.77 (0.44)	0.11	0.085
Patient's age		-0.02 (0.01)	-0.18	0.003
Patient's self-assessment of knowledge	Low <i>vs</i> medium	0.36 (1.56)	0.02	0.89
	Good <i>vs</i> medium	-1.06 (0.72)	-0.15	0.14
Parent's self-assessment of knowledge	Low <i>vs</i> medium	-2.65 (1.73)	-0.17	0.13
	Good <i>vs</i> medium	-1.10 (0.71)	-0.15	0.12
J-elita membership		-0.02 (0.56)	0.00	0.97
Parent's sex		-0.54 (0.54)	-0.06	0.32
Source books		0.66 (0.55)	0.08	0.23
Source journals		0.38 (0.55)	0.05	0.49
Parent's level of education	Lower than sec. <i>vs</i> sec.	-1.99 (0.63)	-0.21	0.002
	Higher than sec. <i>vs</i> sec.	-1.14 (0.48)	-0.16	0.019
Immunosuppressive agent		1.85 (0.48)	0.24	< 0.001
Biological agent		0.33 (0.52)	0.04	0.53
Nutritional therapy		0.58 (0.47)	0.08	0.23
Surgical therapy		1.17 (0.73)	0.10	0.11
Raw/Corrected R <sup>2</sup>		0.238/0.185		
F for change in R <sup>2</sup>		5.550		
P value for R <sup>2</sup> change		< 0.001		

P value for the significance of the independent variable in the multivariate model. Dependent variable: Parent's inflammatory bowel disease-knowledge inventory device score. Model assessment: Model 3 – df = 16, F = 4.440, *P* < 0.001. B: Unstandardised regression coefficient; SE: Standard error; Beta: Standardised regression coefficient; sec.: Secondary education.

the shortened, simplified research tool IBD-KID2[21]. Therefore, this problem is not an isolated concern affecting only Polish patients. We can assume that certain information that doctors and medical staff consider obvious is not properly passed on to patients and their parents.

Proper education of patients with IBD, including paediatric patients and their parents, regarding their disease and treatment principles, may have a significant impact on the treatment compliance and ability to self-cope with the disease[22-24]. Research has also proved that the benefits of educational programmes outweigh anxiety regarding greater disease knowledge[25].

Better knowledge regarding drug mechanisms and drug side effects as well as better IBD-specific knowledge have also been shown to contribute to treatment compliance[7, 8,26,27].

The strength of our study is its sample size; to date, this study is the largest investigation that has assessed disease-related knowledge in children with IBD. Polish validation of the questionnaire allowed comparing the IBD knowledge of both children with this disease and their parents to their peers in different countries undergoing different types of health care. The survey's main limitations include the use of the first version of the IBD-KID, which was recently revised. The new, simplified and shortened version, the IBD-KID2, was not available at the time of our study.

## CONCLUSION

This study identified gaps in the IBD-related knowledge of Polish children with IBD

and their parents. The variables originating from the parents' knowledge, apart from the patients' demographic characteristics, were significantly associated with the patients' IBD-KID scores. Parents of patients treated with immunosuppressive agents showed higher disease-specific knowledge. The study results also confirmed that information acquired from a patient organisation can play a vital role in correct IBD-related knowledge. This finding forms a basis for intensified action aimed at creating educational programmes. Increased awareness of the disease and knowledge about treatment can have a positive effect on compliance with therapeutic recommendations.

## ARTICLE HIGHLIGHTS

### **Research background**

Patient knowledge is associated with increased treatment compliance and improvement of symptoms in a variety of chronic diseases, including inflammatory bowel disease (IBD). IBD-knowledge inventory device (IBD-KID) was developed and validated specifically as a tool to measure disease-related knowledge in children with IBD and their parents.

### **Research motivation**

Until now, assessment of IBD-related knowledge in children with IBD and their parents were performed in Canada, Australia and France. However, the results of these studies cannot be simply projected to Poland due to the differences in lifestyle, diet and healthcare model. The importance of such factors for understanding and knowledge about disease in Polish patients with IBD requires a separate study.

### **Research objectives**

Our present study aimed to assess disease-related knowledge in children with IBD and their parents.

### **Research methods**

A questionnaire-based survey was carried out in 269 children with IBD and 298 parents. The determinants of patients' and parents' IBD-KID scores were assessed with hierarchical linear regression models.

### **Research results**

We found that both patients with IBD and their parents had insufficient IBD-related knowledge. Patients' IBD-KID scores were higher among older than younger patients, among girls compared to boys, among patients who more highly assessed their knowledge about the disease and whose parents did the same. Furthermore, higher scores were found among patients whose parents indicated the Internet as a main source of information, reported membership in the patient Crohn's and Ulcerative Colitis Association J-elita and noted nutritional, surgical immunosuppressive or biological treatment. The patient's score was also positively associated with the parent's score.

### **Research conclusions**

This study identified gaps in the disease-related knowledge of Polish children with IBD and their parents. Increased awareness of the disease and knowledge about treatment can have a positive effect on compliance with therapeutic recommendations.

### **Research perspectives**

Further studies on disease-related knowledge among patients with IBD in countries undergoing economic transformation are needed. IBD-KID may be a good tool to assess transition of adolescents with IBD from pediatric to adult care. It could be also used in assessment of any intervention aimed to increase the level of patients' self-care.

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