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Validation of the Korean Version of a Knowledge Assessment Tool for Children With Inflammatory Bowel Disease

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ABSTRACT

Background: Inflammatory bowel disease (IBD) is a chronic, relapsing disease of the intestine, with approximately 5–14% of patients diagnosed during childhood. Previous studies have shown that knowledge of IBD is associated with treatment adherence, highlighting that assessment of disease knowledge is an important component of ongoing management. The Inflammatory Bowel Disease Knowledge Inventory Device 2 (IBD-KID2) is a validated English-language knowledge assessment tool for children with IBD, but there is currently no Korean version. This study aimed to develop the Korean version of IBD-KID2 (K-IBD-KID2) and assess the validity and reliability in evaluating disease-related knowledge in Korean children with IBD.

Methods: The cross-cultural adaptation process was conducted in three stages. Conceptual equivalence was assessed by experts using the content validity index, with all items scored for cultural comprehension/appropriateness (proportion required ≥ 0.78). Semantic equivalence was assessed using the forward/back translation process. Measurement equivalence was assessed with a prospective study among Korean children with IBD at a tertiary care center. Participants completed the K-IBD-KID2 twice over a 2-week interval to assess reliability, validity, and generalizability, as measured against the overall scores from English-speaking children with IBD.

Results: Results indicated high conceptual equivalence, with all items scoring > 0.78. The prospective study included 50 children with IBD (mean age, 15.3 years, standard deviation, 2.2); 15 (30%) were female, and 40 (80%) with Crohn's disease The mean initial percentage score for the K-IBD-KID2 was 61.7% (standard deviation 16.3), with no association found with any independent variables. The repeat test showed a mean score of 61.3% (standard deviation 16.4), with no significant difference between baseline and repeat (P = 0.790, confidence interval, −0.39 to 0.51) and a high correlation (r = 0.792; P < 0.001). The mean scores of Korean children with IBD were not significantly different from those of children in English-speaking cohorts and Italian cohorts (P = 0.9 and 0.8, respectively). Items with < 50% correct answers were observed for items related to IBD cause, osteoporosis, food triggers, and nutrient absorption.

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Disclosure
The authors have no potential conflicts of interest to disclose.

Author Contributions
Conceptualization: Park S, Vernon-Roberts A, Day AS. Data curation: Vernon-Roberts A, Noh J, Kim C. Formal analysis: Vernon-Roberts A. Methodology: Park S, Lim H, Lee EJ, Koh H, Vernon-Roberts A, Day AS. Software: Noh J, Kim C. Validation: Lee EJ, Koh H, Lim H. Investigation: Noh J, Kim C, Park S. Writing - original draft: Park S, Vernon-Roberts A. Writing - review & editing: Park S, Vernon-Roberts A, Lim H, Lee EJ, Koh H, Noh J, Kim C, Day AS.

Conclusion: The Korean version of the IBD-KID2 is a valid and reliable tool for assessing disease-related knowledge among Korean children with IBD. It can facilitate tailored educational interventions to improve disease-related knowledge among children with IBD, potentially improving long-term management and outcomes.

Keywords: Inflammatory Bowel Diseases; Child; Knowledge Assessment; Validation; Korean Version

INTRODUCTION

Inflammatory bowel disease (IBD) is a chronic, relapsing inflammatory disease of the gastrointestinal tract that requires lifelong management.[1] The prevalence and incidence of IBD are rapidly rising worldwide, especially in children, a trend also observed in Eastern countries, including South Korea.[2-7] Between 5% and 14% of patients with IBD are diagnosed during childhood, making continuous disease management a critical aspect of their lives.[8-11] Previous studies have shown that suboptimal knowledge about the disease or prescribed medications can significantly impact treatment adherence.[12] Moreover, a successful transition to an adult center relies strongly on having disease-specific knowledge as well as self-management skills.[13-15] Therefore, it is crucial to assess the knowledge of children with IBD to ensure they have the correct understanding of their condition.

Regular assessment of disease-specific knowledge enables physicians to identify and address any knowledge gaps that patients may have.[16] Knowledge assessment should be carried out using validated tools that are appropriate for the target population. The Inflammatory Bowel Disease Knowledge Inventory Device (IBD-KID) was a knowledge assessment tool initially developed by Haaland et al.[17] and validated for children aged 10 years and over. In 2019, Vernon-Roberts et al.[18,19] revised this tool (now called Inflammatory Bowel Disease Knowledge Inventory Device 2 [IBD-KID2]) and demonstrated its validity, reliability, and generalizability among children with IBD. The IBD-KID2 is valid for children with IBD aged 8 years and over and includes 15 items covering a range of topics.[18] Previous research has shown that this IBD-KID2 is a feasible tool for evaluating knowledge in English-speaking children with IBD,[16,18,19] and has also been validated for Italian-speaking children.[20] However, there is currently no Korean version of this knowledge assessment tool that has been evaluated for cross-cultural appropriateness or undergone a formal validation process.

In this study, we aimed to develop the Korean version of IBD-KID2 (K-IBD-KID2) and assess its validity and reliability in evaluating disease-related knowledge in Korean children with IBD.

METHODS

IBD-KID2

IBD-KID2 is a validated knowledge assessment tool for children with IBD.[18] There are 15 questions featuring 9 true/false and 6 multiple-choice questions. It addresses a range of topics, including general information about IBD, treatment, lifestyle, and nutrition. The participants get 1 score for each correct item, with a maximum possible score of 15.

Translation process

To translate questionnaires into different languages, it is important to focus on the translational equivalence during the process of cross-cultural adaptation.[21] Therefore, conceptual and semantic equivalences are considered essential for maintaining the connotative meaning during the translation.[22,23] Measurement equivalence addresses whether the translated version is comparable and interpretable, assessing the reliability, validity, and generalizability of the questionnaire (**Fig. 1**).[24] To confirm that the IBD-KID2 original content aligns with the cultural and clinical contexts of the Korean language, the cross-cultural adaptation process was carried out in three stages.

Conceptual equivalence

Conceptual equivalence refers to ensuring that the underlying concepts and meaning of the original questionnaire are preserved and accurately conveyed in other cultures.[25] The conceptual equivalence of IBD-KID2 to the population of Korean children with IBD was assessed using the content validity index (CVI), with each item assessed for cultural

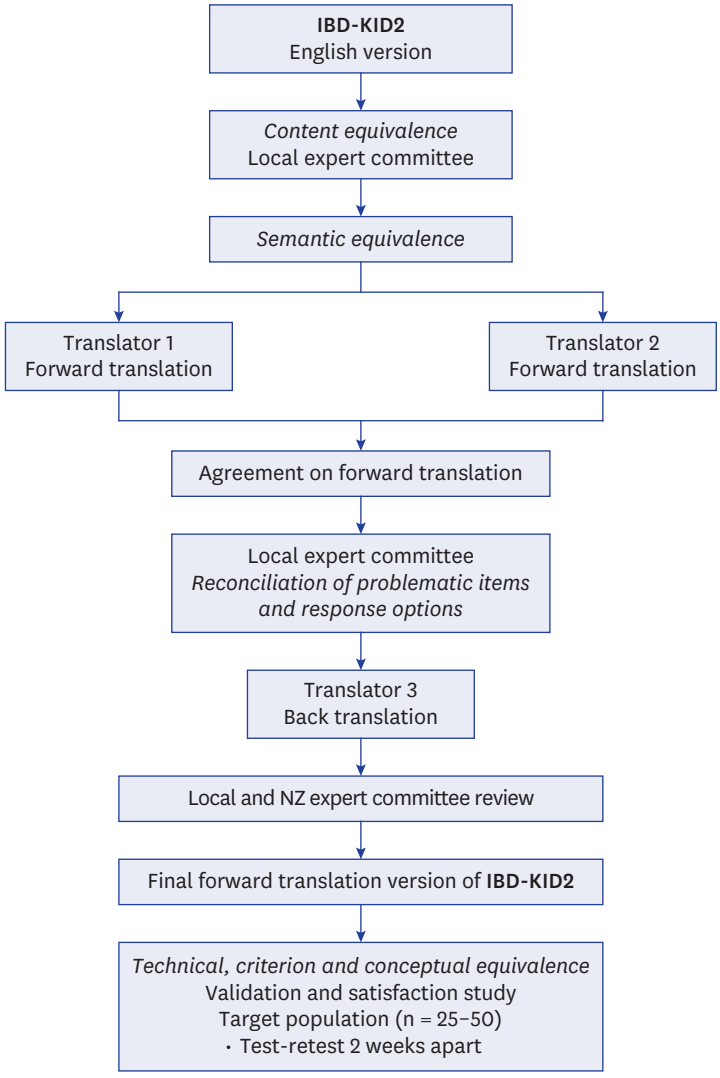

Fig. 1. Translation process of IBD-KID2.
IBD-KID2 = Inflammatory Bowel Disease Knowledge Inventory Device 2, NZ = New Zealand.

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applicability and language comprehension and scored on a Likert scale of 1–10 by Korean pediatric gastroenterologists.[26] Items scoring below 0.78 of the maximum possible proportional score were revised by the Korean and New Zealand teams.

Semantic equivalence

Semantic equivalence ensures that the meaning of items remains the same after translation.[27] Once conceptual equivalence was established, IBD-KID2 underwent a process of forward-backward translation to ensure semantic equivalence.

- Two healthcare professionals with a good understanding of IBD and proficiency in English independently translated the IBD-KID2 survey into Korean, and any differences were resolved through discussion.
- The lead researcher also checked the translation to ensure that there was no loss of meaning during the translation process.
- One of the two translators and another English-proficient healthcare professional then back-translated the Korean version into English, and the content and format were reviewed by the original IBD-KID2 developers in New Zealand. Any items in which the meaning was thought to be different compared to the original version were discussed with the Korean and New Zealand researchers together and revised.

This process led to the completion of the final version of Korean IBD-KID2 suitable to be tested among children with IBD in Korea (**Supplementary Data 1**).

Measurement equivalence

Measurement equivalence is whether the translated version is comparable and interpretable.[28] It usually checks for the reliability and generalizability of the questionnaire. To assess measurement equivalence among Korean children with IBD, a prospective study was conducted among children with IBD, aged 8 to 18 years, followed at a single tertiary care center—Severance Hospital, Yonsei University Health System.

- Participants were asked to complete the K-IBD-KID2 twice, with a 2-week interval to assess the test-retest reliability, and a brief survey was also conducted to evaluate the clarity and readability.
- K-IBD-KID2 survey results were analyzed and tested for their association with independent variables.
- The results were compared with the results from the IBD-KID2 surveys conducted in Canada, New Zealand, Australia, and Italy, using an independent z-test to assess generalizability.
- Item answer patterns were reviewed to determine and compare areas of good knowledge among the cohort, defined as items where ≥ 50% of participants answered correctly.

Statistical analysis

Conceptual equivalence

For calculating the CVI scores for each IBD-KID2 item, the Likert scores assigned by each expert were used to calculate a combined score, which was then divided by the maximum possible score from all of the researchers ($\text{CVI proportion Score} = \frac{\text{Actual Score}}{\text{Maximum Possible Score}}$).[26] The highest possible CVI Proportion Score is 1.0, and scores were considered acceptable when greater than 0.78.[24]

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Measurement equivalence

Measurement equivalence was assessed by calculating the mean K-IBD-KID2 scores for the entire cohort, expressed as a percentage of the maximum score possible (15). To evaluate associations between K-IBD-KID2 scores and demographic variables such as age, gender, diagnosis, and disease duration, analysis of variance was used for categorical variables and linear regression was used for continuous variables. Test-retest reliability was evaluated by comparing means from baseline and repeat assessments using a paired *t*-test, and the Pearson correlation coefficient was calculated to measure the strength and direction of the linear relationship. Internal consistency was measured using the Kuder-Richardson formula 20 (KR-20), with acceptable reliability defined as values greater than 0.5. Knowledge deficiencies were defined as items where fewer than 50% of the children with IBD answered correctly.[29] To assess generalizability, results from the current cohort were compared to those from previous participants who completed the English and Italian versions of the assessment using an independent z-test for both the cohort overall and individual items.

The significance level for all statistical tests was set at $P < 0.05$. The sample size was determined based on the original IBD-KID2 validation study. Initially, a sample size of 25 participants was considered adequate; however, to ensure robustness in the outcomes, the sample size was doubled to 50 participants. Statistical analyses were conducted using SPSS for Windows, version 27.0 (IBM Corp., Armonk, NY, USA).

Ethics statement

This study protocol was reviewed and approved by the Institutional Review Board (IRB) of Severance Hospital, Yonsei University Health System (IRB number: 4-2022-0482). Informed consent was obtained from children aged 8 years and older. As the participants were under 18 years of age, consent was also obtained from all of their parents or guardians.

RESULTS

Conceptual and semantic equivalence

During the conceptual equivalence assessment, all items met the required proportional amount to be included in the Korean IBD-KID2 (> 0.78). Three Korean experts in pediatric gastroenterology, each with 10 or more years of experience, carried out the CVI for cultural, linguistic, and clinical relevance. Two items were identified for review based on expert feedback to ensure cultural alignment; these were discussed collaboratively by the Korean and New Zealand teams to preserve the original meaning and intent. All researchers agreed that conceptual equivalence was achieved.

Following forward-backward translation, all survey items were reviewed by the New Zealand team to reach an agreement that their semantic equivalence and readability were maintained. The final version of K-IBD-KID2 was completed.

Measurement equivalence

Participants

In this prospective study, 50 children with IBD were recruited. The mean age of the patients was 15.3 years (standard deviation [SD], 2.2), and 35 (70%) were male. For the disease subtypes, 40 (80%) had CD, and 10 (20%) had ulcerative colitis (UC), with the mean age at diagnosis being 12.6 years (SD, 2.6) (**Table 1**).

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Table 1. Demographic and disease variables of the study population

Variables	Values
Age, yr	15.3 ± 2.2 (range, 10.3–18.9)
Gender	
Male	35 (70)
Female	15 (30)
Diagnosis	
Crohn's disease	40 (80)
Ulcerative colitis	10 (20)
Age at diagnosis, yr	12.6 ± 2.6 (range, 4.7–17.4)
Time since diagnosis, yr	2.7 ± 2.2 (range ,0.3–9.1)
1st degree relative with IBD	
Yes	6 (12)
No	44 (88)

Values are presented as number (%) or mean ± standard deviation.
IBD = inflammatory bowel disease.

IBD-KID2 scores

The mean score for the K-IBD-KID2 survey (maximum 15) was 9.3 (SD, 2.5; range, 1–13), equivalent to 61.7% (SD, 16.3; range, 7%–87%). No significant associations were observed between K-IBD-KID2 score and demographic variables such as gender, family history of IBD, diagnosis, age, age at diagnosis, and time since diagnosis (**Table 2**).

Reliability

All 50 participants completed the repeated K-IBD-KID2 survey 2 weeks after the baseline survey. The mean score for the repeated test was 9.2 (SD, 2.5; range, 1–13), equivalent to 61.3% (SD, 16.4; range 7%–87%), which was similar to the baseline scores. Test-retest analysis showed a strong correlation between the baseline and repeated tests, with a strong positive linear relationship in Pearson correlation ($r = 0.792$; $^{***}P < 0.001$), with no difference between the mean scores at 2 different time points ($P = 0.790$; confidence interval [CI], −0.39 to 0.51) (**Fig. 2**).

Generalizability

K-IBD-KID2 scores of the Korean children were compared to the scores from previous studies of 130 children with IBD from Canada, New Zealand, and Australia who completed the original English version[16,18] and 25 Italian-speaking children who completed the Italian version.[20] No significant differences were found between the Korean and English-speaking cohorts ($P = 0.900$; CI, −15.0 to 15.8) or the Italian cohort ($P = 0.800$; CI, −18.8 to 25.7).

Areas of good knowledge

Regarding the frequency of correct individual questionnaire items, good knowledge (defined as > 50% of correct answers) was observed for 11 items (73%) (**Fig. 3**). Poor knowledge was observed in items related to osteoporosis, IBD cause, nutrient absorption, and food triggers.

Table 2. Association of IBD-Knowledge Inventory Device 2 scores with demographic and disease variables

Variables	Mean or R values	*P* value
Categorical variables		
Gender	−0.77	0.312
Family history of IBD	0.106	0.922
Diagnosis	−1.55	0.073
Linear variables		
Age, yr	0.167	0.245
Age at diagnosis, yr	0.108	0.454
Time since diagnosis	0.038	0.796

Categorical variables are presented as mean and linear variables are presented as R values.
IBD = inflammatory bowel disease.

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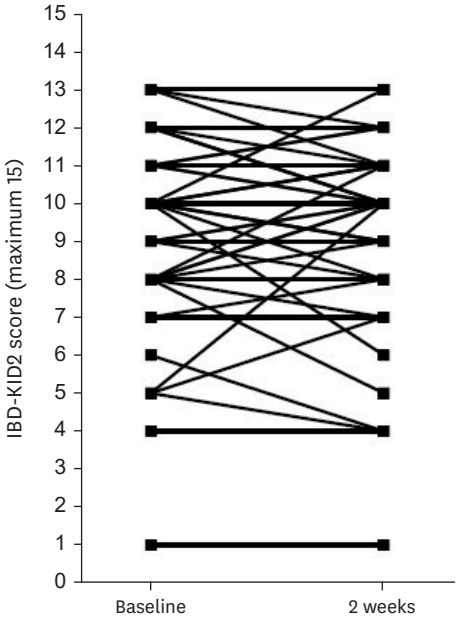

Fig. 2. Test-retest completion IBD-KID2 scores for each study participant.
IBD-KID2 = Inflammatory Bowel Disease Knowledge Inventory Device 2.

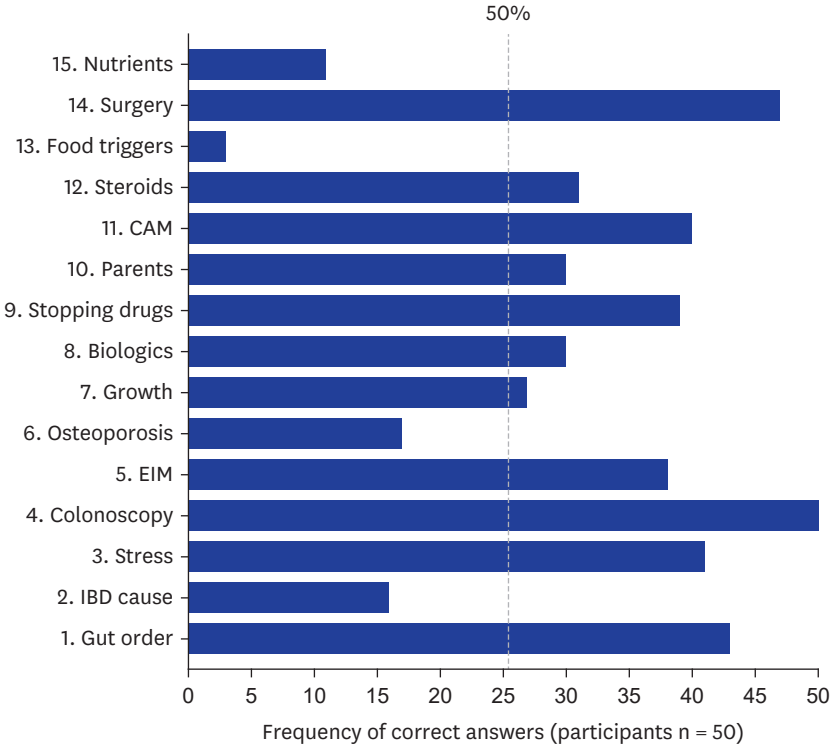

Fig. 3. Frequency of correct individual IBD-Knowledge Inventory Device 2 items.
CAM = complementary and alternative medicine, EIM = extraintestinal manifestation, IBD = inflammatory bowel disease.

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Table 3. Differences in item-specific correct answer rates among children with IBD in Korea, NZ, Aus, Can, and Italy

Item	Korea, %	% Difference[a]		*P* value	
		Korea to NZ/Aus/Can	Korea to Italy	Korea to NZ/Aus/Can	Korea to Italy
Gut order	86	27	14	< 0.001	0.150
IBD cause	32	−28	−12	< 0.001	0.310
Stress	82	20	−2	0.010	0.830
Colonoscopy	100	8	12	0.040	0.010
EIM	76	14	36	0.080	0.002
Osteoporosis	34	−24	−30	0.004	0.010
Growth	54	7	6	0.400	0.630
Biologics	60	14	−12	0.090	0.310
Stopping drugs	78	−12	−18	0.030	0.050
Parents	60	−9	12	0.250	0.330
CAM	80	33	36	< 0.001	0.002
Steroids	62	14	10	0.090	0.410
Food triggers	6	−39	−26	< 0.001	0.003
Surgery	94	6	6	0.240	0.370
Nutrients	22	−13	14	0.090	0.130

NZ = New Zealand, Aus = Australia, Can = Canada, IBD = inflammatory bowel disease, EIM = extraintestinal manifestation, CAM = complimentary or alternative medicine.
[a]% score difference in absolute percentage point difference, positive values indicating Korean children scored that % higher, negative values indicating Korean children scored that % lower.

When compared with the data from the children with IBD from English-speaking countries such as New Zealand, Australia, and Canada, as well as Italian-speaking children with IBD, Korean children showed higher correct answer rates for items regarding colonoscopy and complementary and alternative medicines (CAMs), and lower correct answer rates regarding osteoporosis, stopping drugs, and food triggers (**Table 3**).[16,18]

Internal consistency

The KR-20 score was 0.62, indicating that K-IBD-KID2 had relatively acceptable internal consistency.

DISCUSSION

This study shows that K-IBD-KID2 is a valid and reliable tool for assessing disease-related knowledge among children with IBD in Korea. In particular, these data demonstrated content, semantic, and measurement equivalence with the original English version.

The assessment of disease-related knowledge to identify knowledge gaps among adolescents is essential, particularly in managing chronic conditions like IBD.[12,30] Research indicates that a patient's ability to adhere to medication and medical advice is strongly related to their disease-related knowledge, which also plays a crucial role in the successful transition from adolescent to adult care.[12,20,31] Despite this importance, standardized knowledge assessment tools for Korean children with IBD remain lacking, although several attempts to assess disease-related knowledge have been made in some centers.[12,32-34]

To date, 3 studies on the assessment of disease- or medication-related knowledge have been published in Korea.[32-34] However, 2 of these studies focused on adults with IBD, emphasizing detailed information about the disease and its complications while placing less emphasis on growth and development. Only one study on children with IBD in Korea has been published: this report assessed patients' knowledge of their prescribed medication but did not evaluate

overall disease-related knowledge.[12] Consequently, these studies do not adequately assess the disease-related knowledge in Korean children with IBD. In contrast, completion of K-IBD-KID2 can enable physicians to assess disease-related knowledge in Korean children with IBD and identify where targeted education may be beneficial.

The findings of the current study revealed that the lowest frequency of correct answers was related to food triggers, followed by nutrient absorption. Knowledge about whether certain foods could trigger IBD was notably low at < 5% answering correctly, particularly when compared to the correct answer rates by children in English-speaking countries (33–45%).[16,18] This difference may be due to the number of factors, including education materials provided for patients, or cultural beliefs. In Korean culture, there is a strong belief that food should play a crucial role in relieving and exacerbating disease.[35] Together, patients and parents may have interpreted that since dietary interventions improved IBD, food may also exacerbate IBD disease activity. This is in accordance with the translated version of the Italian IBD-KID2 study, which also showed a low frequency of correct answers regarding food triggers and nutrient absorption.[20] Similar to Korea, the importance of food to Italian people was considered to be one of the reasons for the lower correct answer rate for these items compared to English-speaking cohorts.[18,20] Another study conducted in a French IBD cohort showed that the majority of the patients with IBD were avoiding certain foods due to their dietary beliefs. This suggests that cultural beliefs about food should be considered when educating populations with IBD.[36]

Previous research conducted in Korea among adults with IBD shows higher correct answer rates on this topic, with approximately 40% scoring correctly compared to < 5% among children in the current study.[32-34] This difference may be due to various reasons, such as differences in the IBD education materials given to children and adults. Adults are less focused on education about elemental diet and nutrition than children, while material for children is less focused on pregnancy and breastfeeding.

Several items showed higher correct answer rates among Korean children in the current study than other international cohorts. Higher correct answer rates were noted in gut order, stress, and CAM compared to English-speaking countries.[16,18] Since Koreans believe in the use of traditional herbal medicines, physicians put considerable effort into education about the prescribed medications and CAM to patients and family members.[37] In a survey carried out among Koreans with IBD about longitudinal usage and perception of CAM use between 2006 and 2014, CAM usage increased from 60.2% to 79.6%.[38] Ten years have passed since the last survey about CAM, and the results of the current study regarding this item may indicate that efforts in educating patients about CAM usage have stayed consistent.

In previous studies, repeated knowledge assessments showed a tendency to increase slightly in scores due to practice effect.[39,40] However, in our study, the mean score remained similar or slightly decreased-from 9.3 at baseline to 9.2 at retest. This result is consistent with the previous studies of IBD-KID2, which also showed subtle changes between time points.[18,20] These results suggest that the K-IBD-KID2 measures stable disease-related knowledge and is less affected by short-term familiarity or test practice. This implies that the survey items do not just assess simple recall but a more accurate understanding of the disease. The 2-week interval may also have been sufficient to minimize recall bias but too short for meaningful knowledge acquisition, especially in pediatric patients with limited motivation to study disease related knowledge between tests.

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The results of this study showed no association between demographic factors and the K-IBD-KID2 survey results, which is consistent with the previous studies, suggesting that the scores do not vary according to specific cohorts or sub-groups but are more likely to vary between individuals.[16,18,20] Therefore, K-IBD-KID2 may be more useful for evaluating the level of disease-related knowledge of individual patients and for longitudinal tracking rather than assessing that of a specific group of patients. The different published studies that have translated IBD-KID2 and the original IBD-KID into different languages highlight how cultural beliefs may influence disease-specific knowledge, and clinicians and researchers should be mindful of this when utilizing the assessment tools.[20,41-43] While generalizability is an important component for assessment tools such as IBD-KID2 when validating cross-cultural adaptations, it is inevitable that answer patterns may differ according to the cultural significance of particular items. It should be considered as to whether this is a reflection of cultural diversity and not necessarily due to poor knowledge levels among cohorts.

This is the first pediatric IBD knowledge assessment study translated and implemented in an Asian country, indicating that a survey validated in western countries can also be applicable in eastern contexts as well. Furthermore, the sample size of the current study was approximately twice that of the previous survey study for validation, likely enhancing the statistical power of the findings.

This study was conducted at a single tertiary care center, limiting the generalizability of the findings to the broader population of children with IBD in Korea. Moreover, the proportion of patients with Crohn's disease (CD) in this study was higher than that of patients with UC, which may have influenced the survey results. However, this reflects the distribution of pediatric IBD in Korea, where the number of CD cases exceeds that of UC.[6,44,45] Importantly, the IBD-KID2 questionnaire was originally developed and validated to assess disease-related knowledge applicable across both CD and UC, and includes items relevant to both subtypes. In addition, we did not collect data on sociodemographic variables such as socioeconomic status or educational background which may influence the test results. Future research should consider a multicenter study to more accurately assess the generalizability of the results and determinants of knowledge acquisition in pediatric IBD populations.

In conclusion, the current study provides a comprehensive evaluation of IBD-specific knowledge among Korean children with IBD using K-IBD-KID2. The use of this translated, culturally appropriate, and validated tool enables the identification of the specific areas of knowledge that require improvement. These areas can be targeted in personalized education, ultimately enhancing the disease-related knowledge of children with IBD, optimizing disease management, and facilitating smoother transitions into adulthood.

SUPPLEMENTARY MATERIAL

Supplementary Data 1

Inflammatory Bowel Disease Knowledge Inventory Device Version 2 (IBD-KID2)

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