Knowledge in Inflammatory Bowel Disease: Translation to Portuguese, Validation, and Clinical Application of the IBD-KNOW Questionnaire

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Abstract

Background/Aims: Inflammatory bowel disease (IBD)-related knowledge empowers patients, providing the development of adaptative coping strategies. Recently, a more comprehensive questionnaire for evaluating IBD-related knowledge was developed, the IBD-KNOW. The main aim of our study was to translate to Portuguese and validate the IBD-KNOW questionnaire. We also explored the predictors of high scores of disease-related knowledge and the effect of knowledge on health-related quality of life (HRQoL) and therapeutic adherence. ***Methods:*** This is an observational, unicentric, and cross-sectional study. We translated and adapted the original English version of the IBD-KNOW questionnaire into Portuguese. Afterwards, IBD patients in the outpatient clinics were invited to fill out a multimodal form including the Portuguese version of IBD-KNOW, a visual analogue scale (VAS) of self-perceived knowledge, the Portuguese version of Short IBD Questionnaire (SIBDQ) and the Portuguese version of Morisky Adherence Scale 8-item (MMAS-8). Demographic and disease characteristics were collected. We assessed validity (through discriminate validity among non-IBD volunteers and correlation between IBD-KNOW and VAS) and reliability (through internal consistency, test-retest, and intraclass correlation). Statistical analysis was performed using SPSS version 25.0. ***Results:*** The mean IBD-KNOW score was significantly different among non-IBD validation group (doctors: 23, nurses: 18, and non-medical volunteers: 12, $p < 0.001$). IBD-KNOW showed a high internal consistency (Cronbach's α 0.78) and intraclass correlation (0.90). As expected, the IBD-KNOW score was positively correlated with VAS for self-perceived knowledge ($r = 0.45$, $p < 0.001$). One hundred and one patients with IBD (54 with ulcerative colitis and 47 with Crohn's disease) completed the questionnaire at baseline. Multivariate analyses showed that a high IBD-KNOW score was associated with longer disease duration (OR: 2.59 [CI 1.11–5.74]; $p = 0.04$), previous hospitalization (OR: 3.63 [CI 1.301–9.96]; $p = 0.01$), current biologic treatment (OR: 3.37 [CI 1.31–8.65]; $p = 0.02$), and higher educational level (OR: 4.66 [CI 1.74–10.21]; $p = 0.02$). Moreover, there was no significant correlation between overall IBD-KNOW and SIBDQ, nor between IBD treatment adherence (MMAS-8 = 8) and a higher mean IBD-KNOW score ($p = 0.552$). ***Conclusion:*** The Portuguese version of IBD-KNOW is a simple, valid, and reliable tool for assessing IBD-related knowledge. Longer disease duration, hospitalization, use of biologics, and higher educational level are

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associated with higher levels of knowledge. Higher patient knowledge was not associated with higher HRQoL and adherence to therapy.

Conhecimento na doença inflamatória intestinal: tradução para português, validação e aplicação clínica do questionário IBD-KNOW

Resumo
Introdução/objetivos: O conhecimento relacionado com a Doença Inflamatória Intestinal (DII) visa capacitar os doentes, proporcionando o desenvolvimento de estratégias adaptativas de *coping*. Recentemente, foi desenvolvido um questionário mais abrangente para avaliar os conhecimentos relacionados com a DII, o IBD-KNOW. O principal objetivo do nosso estudo foi traduzir para português e validar o questionário IBD-KNOW. Também explorámos os preditores de um elevado nível de conhecimento relacionado com a DII e avaliámos o impacto do conhecimento na qualidade de vida associada a cuidados de saúde (QVACS) e na adesão terapêutica. ***Métodos:*** Este é um estudo observacional, unicêntrico e transversal. Traduzimos e adaptámos para português a versão original inglesa do questionário IBD-KNOW. Posteriormente, os doentes com DII de ambulatório foram convidados a preencher um questionário multimodal que incluía, a versão portuguesa do IBD-KNOW, uma escala visual analógica (EVA) de autoperceção do conhecimento, a versão portuguesa do Short IBD Questionnaire (SIBDQ) e a versão portuguesa do Morisky Adherence Scale 8-item (MMAS-8). Foram colhidos dados referentes a aspetos demográficos e da doença. Avaliámos a validade (através da validade discriminatória entre voluntários sem DII e da correlação entre IBD-KNOW e a EVA) e a fiabilidade (através da consistência interna, do teste-reteste e da correlação intraclasse). A análise estatística foi realizada utilizando a versão 25.0 do SPSS. ***Resultados:*** A pontuação média do IBD-KNOW foi significativamente diferente entre os voluntários não-DII (médicos: 23, enfermeiros: 18 e voluntários não-médicos: 12, p < 0,001). O IBD-KNOW mostrou uma elevada consistência interna (Cronbach's α 0,78) e uma correlação intraclasse (0,90).

Como esperado, a pontuação IBD-KNOW correlacionou-se positivamente com a EVA de autoperceção do conhecimento (r=0,45, p < 0,001). Cento e um doentes com DII (54 com colite ulcerosa e 47 com doença de Crohn) preencheram o questionário. A análise multivariada mostrou valores médios de IBD-KNOW superiores em indivíduos com doença de longa duração (OR: 2,59; [IC 1,11-5,74] p=0,04), hospitalização prévia (OR 3,63 [IC 1,301-9,96]; p=0,01), sob tratamento biológico atual (OR 3,37 [1,31-8,65]; p=0,02) e com nível educacional superior (OR 4,66 [IC 1,74-10,21]; p=0,02). Além disso, não houve correlação significativa entre IBD-KNOW e SIBDQ, nem entre a adesão ao tratamento IBD (MMAS-8=8) e um IBD-KNOW acima da média (p=0,552). ***Conclusão:*** A versão portuguesa do IBD-KNOW é uma ferramenta simples, válida e fiável para avaliar os conhecimentos relacionados com a DII. Uma maior duração da doença, hospitalização, utilização de biológicos e um nível de educação mais elevado estão associados a níveis de conhecimento mais elevados. Na nossa coorte, níveis superiores de conhecimento não se associaram a melhor qualidade de vida nem a maior adesão à terapêutica.

Introduction

Inflammatory bowel disease (IBD), that includes Crohn's disease (CD) and ulcerative colitis (UC), is a chronic, idiopathic inflammatory disease of the gastrointestinal tract. IBD is characterized by an early onset with a relapsing-remitting disease course that requires lifelong treatment. Unpredictable course and challenging complications or symptoms affect the quality of life (QoL) of IBD patients [1], so providing tools to manage the disease and encouraging patients to play an active role in disease management are of utmost importance. A higher level of disease-related knowledge is associated with the development of more adaptive coping among IBD patients [2]. Moreover, knowledge has relevant implications for health outcomes. A higher level of knowledge is associated with reduced healthcare costs [3] and reduced need for step-up strategy in IBD patients [4]. Finally, knowledge measurement tools evaluate educational programs' effectiveness and identify "gaps" in knowledge [5].

For this purpose, three questionnaires are available. First, in 1993, the Patient Knowledge Questionnaire was developed; however, it is rarely used [6]. Then, Eaden et al. [7], in 1999, published the Crohn's and Colitis

Knowledge (CCKNOW) score; although widely applied, given the emergence of numerous innovative therapies, it currently does not adequately reflect treatment-related knowledge. Recently, Yoon et al. [8] developed a questionnaire, the Inflammatory Bowel Disease Knowledge (IBD-KNOW).

IBD-KNOW is a 24-item questionnaire assessing up-to-date knowledge about IBD, which includes aspects of anatomy, function, diet and lifestyle, epidemiology, general knowledge, medication, complications, surgery, reproduction, and vaccination [8]. The IBD-KNOW was developed and validated in English among patients from various populations.

The main objective of this study was the translation of the IBD-KNOW into Portuguese language and its validation. We also aimed to assess the predictors of a high level of disease-related knowledge and evaluate the association between knowledge and QoL and therapeutic adherence in patients with IBD.

Materials and Methods

Study Design

We conducted an observational, cross-sectional study that included the translation into Portuguese, validation, and application of the IBD-KNOW questionnaire. All participants received a letter explaining the study and gave their written informed consent.

Translation

The English version of IBD-KNOW was translated into Portuguese by two independent bilingual individuals (Portuguese and English). The translations were evaluated, reconciled, and back-translated by two gastroenterologists with English proficiency and experience in following patients with IBD. The back-translators had no prior knowledge of the content of IBD-KNOW. Moreover, a group of five IBD patients filled out the preliminary version to assess comprehensiveness. Finally, the previous gastroenterologists made minor changes to obtain the final translation (online suppl. File 1; for all online suppl. material, see https://doi.org/10.1159/000530628).

Preparation of the Questionnaire

A multimodal self-administered form was developed, including questions regarding (1) sociodemographic data (age, gender, educational level, employment status), (2) clinical information (IBD subtype, date of IBD diagnosis, family history of IBD, smoking status, previous IBD-related hospitalization and surgery, current medications), and (3) sources of IBD knowledge information. The form also included three questionnaires: the translated IBD-KNOW, the Portuguese version of the Short Inflammatory Bowel Disease Questionnaire (SIBDQ) [9], the Portuguese version of the Morisky Adherence Scale 8-item (MMAS-8) [10], and yet the visual analogue scale (VAS) for perceived knowledge.

For the 24 items of the IBD-KNOW, three choices ("true," "false," and "don't know") were applicable, with a maximum score of 24 points. We calculated the mean IBD-KNOW score and assessed the factors affecting the level of knowledge. Total higher values of the IBD-KNOW questionnaire represented higher knowledge of the disease.

The SIBDQ was applied to assess health-related quality of life (HRQoL), consisting of 10 questions scored by a 7-point Likert scale. An absolute SIBDQ score of less than 50 was considered a poor QoL. Medication adherence was assessed with the MMAS-8, which includes seven dichotomous (Y/N) and 1 item of the 5-point Likert Scale. A MMAS-8 score equal to 8 meant good adherence. Finally, we applied a VAS for self-awareness about IBD knowledge. It consists of a 10 cm long line, with a mark at the beginning corresponding to very poor knowledge (0) and another at the end corresponding to very high knowledge (10).

Selection of Patients and Measurement of Patient's Knowledge

Patients were chosen to participate by convenience, with the invitation addressed to patients who attended the IBD outpatient clinic or the Gastroenterology Day Care Unit at Setúbal Hospital between July and November 2021. Patients who met the following criteria were included: older than 18 years; diagnosis of CD or UC at least 3 months before; at least one previous IBD outpatient visit; and signed informed consent. We excluded patients who completed less than 80% of the IBD-KNOW questions. We asked 15 patients to fill out the IBD-KNOW questionnaire twice with a minimum interval of 1 month.

Validation of Questionnaire

Since there are no external criteria for IBD-related knowledge, validity and discriminatory ability were assessed by (1) applying the IBD-KNOW questionnaire in different groups expected to have different levels of IBD-related knowledge, (2) demonstrating the association between IBD-KNOW scores and surrogate markers of IBD-related knowledge, and (3) assessing the correlation between IBD-KNOW and perceived self-awareness of the disease.

Therefore, the IBD-KNOW questionnaire was submitted to 3 groups of non-IBD volunteers with different levels of IBD knowledge (eleven gastroenterologists, ten nurses, and ten non-medical professional volunteers). For the second hypothesis, the IBD-KNOW score should positively correlate with disease duration. The score should also be higher in patients with higher education; however, it should not differ according to gender and disease type (CD or UC). Furthermore, we analysed convergent validity by assessing the correlation between the IBD-KNOW and the VAS for disease self-perceived knowledge.

Reliability was determined as test-retest reliability (reproducibility) and internal consistency. We assessed reproducibility, asking 15 patients to answer the questionnaire twice, with a minimum interval of 1 month, to decrease the possibility of recalling previous answers (recall bias) [8, 9, 11–13].

Statistical Analysis

Statistical analysis was performed using SPSS – Statistical Package for the Social Sciences – version 25.0, with a significance level set at $p < 0.05$. The normality of variables was verified. Descriptive analysis determined the absolute and relative frequency for categorical variables, the mean ± standard deviation for normal continuous variables, and the median and interquartile range

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Table 1. Sociodemographic and clinical characteristics

IBD patients' characteristics	Overall cohort ($n = 101$)
Age, years, mean (±SD)	42 (±12)
Sex (females), n (%)	51 (50.5)
Type of IBD, n (%)	
CD	47 (46.6)
UC	54 (53.4)
Disease duration, years, median (interquartile range)	5 (1–16)
Smoking status, n (%)	
Never or past smoker	78 (77.2)
Current smoker	23 (22.8)
History of IBD-related hospitalization, n (%)	53 (52.5)
History of IBD-related surgery, n (%)	20 (19.8)
Family history of IBD, n (%)	22 (21.8)
Current medical therapy, n (%)	
5-Aminosalicylates monotherapy	31 (30.6)
Immunomodulators (mono- or combo therapy)	26 (25.7)
Biologic therapy	53 (52.5)
Education level, n (%)	
University	21 (20.8)
Secondary	28 (27.8)
None, primary, or basic	52 (51.4)
IBD-KNOW score, mean (±SD)	13 (±4)
SIBDQ score, mean (±SD)	51 (±16)
MMAS-8 score, median (interquartile range)	7 (5–8)
Good adherence (=8)	79 (78.2%)

MMAS-8, Morisky Adherence Scale 8-item; SD, standard deviation.

for non-normal ones. Fisher exact tests were used to compare categorical variables. To analyse the association between the score of IBD-KNOW-IBD and sociodemographic and clinical variables, the Mann-Whitney U test, the Kruskal-Wallis H test, Spearman's correlation, and Student's t test. Variables significantly associated with high IBD-KNOW score in univariate analysis were included in multiple logistic regression analyses. The internal consistency of the IBD-KNOW was evaluated using Cronbach's alpha coefficient, which was considered high for alpha values ≥0.70. Reproducibility was assessed using the intraclass correlation coefficient, considered appropriate if ≥0.70. We calculated the sample size calculation for intraclass correlation [11, 13, 14].
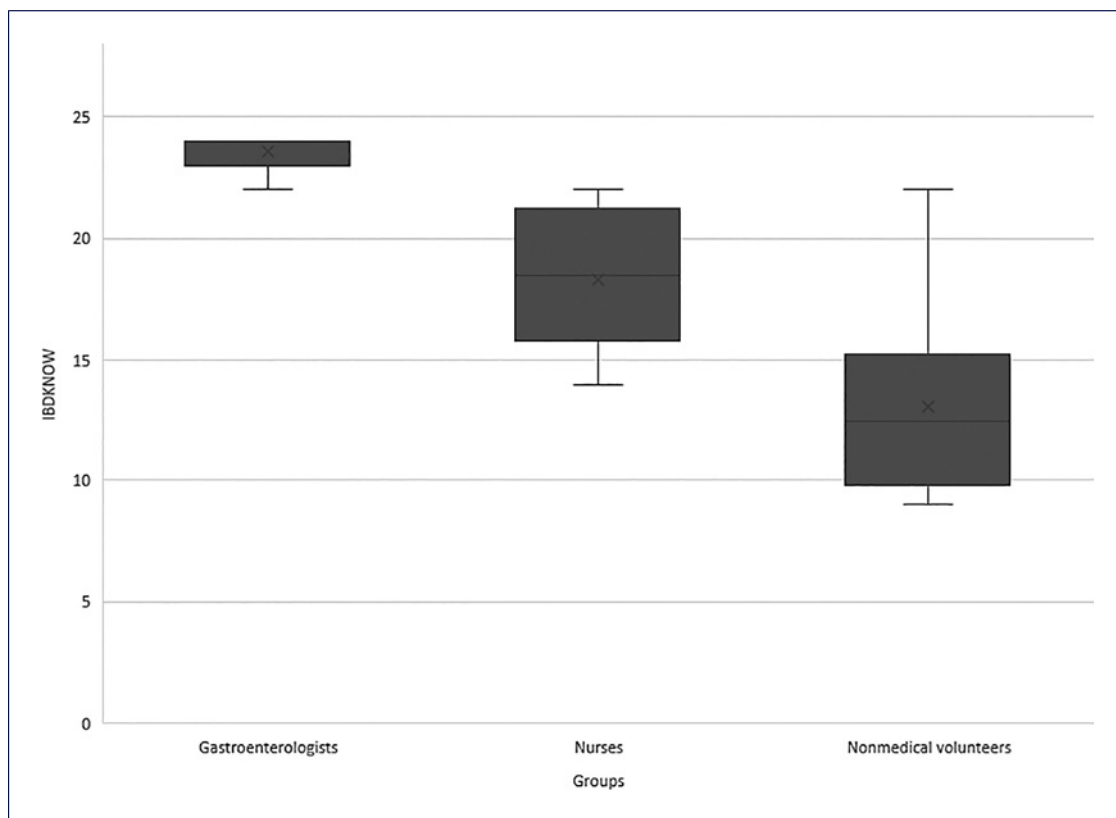
Results

Patients

From July to November 2021, 108 patients with IBD completed the multimodal questionnaire; we excluded 7 patients from the final analysis due to less than 80% completion of the IBD-KNOW questionnaire. Thus, we included 101 patients (54 with UC and 47 with CD); the mean age was 42 (±12) years, with a similar number of female ($n = 51$) and male ($n = 50$) patients. The mean duration of IBD was 5 years, and most patients were treated with biologics ($n = 53$). Almost one-fifth of patients (19.8%) had undergone surgery at least once when they completed the questionnaire. Of the patients enrolled, 21 (20.8%) had a university degree. The sociodemographic and clinical characteristics of the participants at the time of completing the questionnaire are shown in Table 1.

Validity

The IBD-KNOW questionnaire was first tested on the three groups of non-IBD volunteers with different expected levels of IBD-related knowledge, including ten non-medical volunteers, ten nurses, and eleven gastroenterologists (seven seniors and four fellows). The mean questionnaire score was significantly different between the three validation groups (12 non-medical, 18 nurses, and 23 gastroenterologists; $p < 0.001$) (shown in Fig. 1).

In addition, the IBD-KNOW score was positively correlated with disease duration ($r = 0.606$; $p < 0.001$). The score was also higher in patients with higher level education (secondary or higher vs. primary education or lower: 15.1 ± 4.5 vs. 12.2 ± 4.3; $p = 0.01$) and did not differ according to gender (female vs. male: 12.3 ± 4.4 vs. 13.9 ± 4.3; $p = 0.06$) and IBD subtype (CD vs. UC 13.1 ± 4.7 vs.

Fig. 1. Level of IBD-KNOW score among the three groups for validation.

12.9 ± 4.7; p = 0.518) (shown in Table 2). IBD-KNOW score showed a moderate but significant correlation with VAS for perceived knowledge (r = 0.45, p < 0.001).

Evaluation of IBD-Related Knowledge

Patients acquired IBD-related knowledge mainly from doctors and the Internet. The sources of information related to IBD are summarized in Table 3.

The mean IBD-KNOW questionnaire score was 13/24, with no significant difference regarding age, gender, and IBD subtype. The correct response rate was 54%; the "vaccination" domain performed the highest (78%). The vast majority of patients (74%) recognized the importance of colorectal cancer (CRC) screening in long-term disease. Among the ten domains of the IBD-KNOW, the correct response rate of the domains "reproduction" (24%), "function" (17%), and "surgery" (16%) was the lowest. The correct answer rate for each domain is shown in Figure 2.

Univariate and multivariate analyses of the predictive factors for high IBD-KNOW are summarized in Tables 2 and 4, respectively. Multivariate analysis showed that a high IBD-KNOW score (higher than the mean score) was associated with longer disease duration, previous IBD-

related hospitalization, current biological treatment, and a higher level of education.

HRQoL in IBD patients (SIBDQ) showed no correlation with IBD-KNOW (r = −0.188, p = 0.383). There was no statistically significant association between adherence to IBD treatment (MMAS-8 = 8) and a mean IBD-KNOW score above the mean (p = 0.552).

IBD-KNOW – Internal Consistency and Reproducibility

We assessed the internal consistency between the 24 questions of IBD-KNOW. We obtained high internal consistency (Cronbach's α 0.78). Fifteen patients filled out two sets of questionnaires within 1 month. The intraclass correlation was 0.90 (95% confidence interval 0.70–0.96).

Discussion

Patient education is a critical determinant for managing chronic diseases such as IBD. Patient empowerment has been shown to contribute to improved QoL and therapeutic adherence, with consequent improvement in
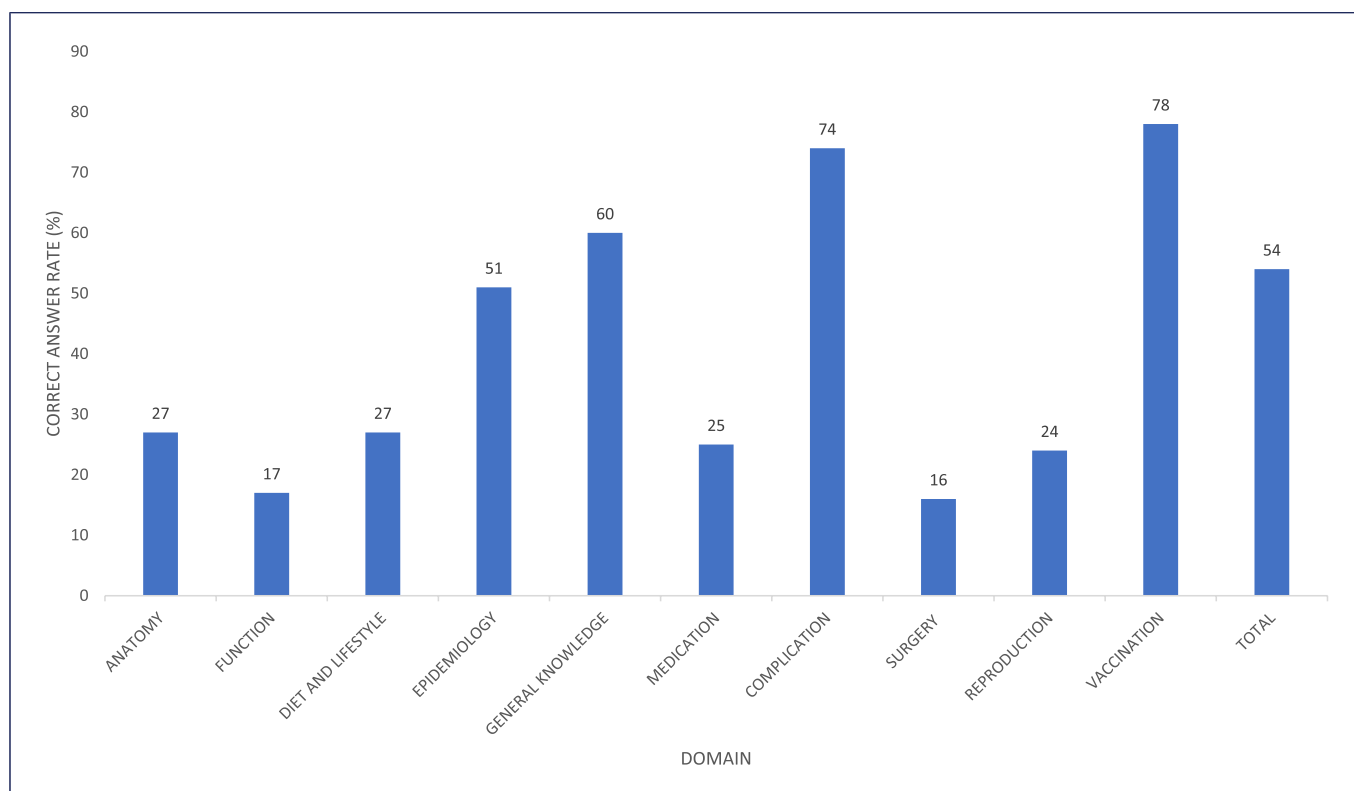
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Table 2. Univariate analysis

	Mean of IBD KNOW score	*p* value
Sex		
Female	12.3±4.4	0.06
Male	13.9±4.3	
Type of IBD		
CD	13.1±4.7	0.518
UC	12.9±4.7	
Disease duration		
<5 years	14.1±4.3	0.004
≥5 years	11.5±4.3	
Smoking status		
Never or past smoker	14±3.2	0.278
Current smoker	12.9±4.8	
IBD-related hospitalization		
No	11.3±4.4	<0.001
Yes	14.7±3.9	
IBD-related surgery		
No	12.5±4.2	0.003
Yes	15.7±4.5	
Family history of IBD		
No	13.1±4.6	0.974
Yes	13.1±4.4	
Current medical therapy		
5-Aminosalicylates monotherapy		
No	11.9±4.6	0.08
Yes	13.6±4.3	
Immunomodulators (monotherapy or combo)		
No	13.4±4.9	0.339
Yes	12.3±2.8	
Biologics		
No	11.4±3.2	0.01
Yes	14±4.5	
Highest level of education		
Secondary or higher	15.1±4.5	0.01
None, primary, or basic	12.2±4.3	
MMAS-8 score		
Good adherence (=8)	13.0±4.6	0.723
No adherence <8	13.4±3.9	

MMAS-8, Morisky Adherence Scale 8-item.

Table 3. Source of acquired IBD-related information

Source of acquired IBD-related information (multiple selection is possible)	*N* (%)
Doctor	94 (93)
Nurse	35 (34.6)
Internet	51 (50.5)
Books	17 (16.8)
Patient's organization	9 (8.9)

Fig. 2. Correct answer rate of each domain.

Table 4. Multivariate analyses of predictive factors for high IBD-KNOW score (IBD-KNOW above the mean)

	Patients with high IBD KNOW score – multivariate analysis	
	odds ratio (95% confidence interval)	*p* value
Disease duration ≥5 years	2.599 (1.112–5.740)	0.04
Previous IBD-related hospitalization	3.629 (1.309–9.962)	0.01
Previous IBD-related surgery	0.398 (0.105–1.503)	0.174
Biologic treatment	3.366 (1.310–8.651)	0.02
Education level: secondary or higher	4.666 (1.744–10.213)	0.02

the course of the disease [15, 16]. Therefore, an instrument that objectively measures IBD-related knowledge allows for identifying "gaps" in patients' disease-related knowledge in order to improve information strategies. This is the first IBD-specific knowledge questionnaire translated into Portuguese language, which has proven to be a valid and reliable tool to measure IBD-related knowledge in a Portuguese cohort.

There is no gold standard to assess IBD-related knowledge, and there are no previously validated questionnaires in Portuguese. The validity of the IBD-KNOW questionnaire

was evaluated, showing that the mean score was significantly different between the groups of non-IBD volunteers, as previously reported in other studies that validated questionnaires assessing IBD-related knowledge [7, 8, 12, 17]. Furthermore, the IBD-KNOW was predicted to correlate with variables which are well-known markers of IBD-related knowledge [6, 7]; these findings were also corroborated by other questionnaire studies [12]. Finally, IBD-KNOW score was significantly correlated with self-perceived knowledge about the disease, similar to previous questionnaire validation studies [18, 19].

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The questionnaire also demonstrated excellent test-retest reliability and the Cronbach α of the IBD-KNOW was high (0.78) facilitating comparison between groups of patients. The IBD-KNOW allowed quantification of patients' level of IBD knowledge and highlighted specific areas where knowledge was lacking. The mean score for IBD-KNOW was 13, similar to the score reported in the original IBD-KNOW publication [8]. The mean score obtained in this study is better than that of Eastern IBD patients but lower than that of North American IBD patients [20]. The mean correct answer rate was similar to the original study [8].

The domains "reproduction," "medication," "function," and "surgery" had the lowest correct response rates, similar to those reported by the original study [8]. Reproduction is a well-known area of knowledge deficit [8, 17, 21]; a more focused questionnaire is available to address this issue [22]. The proportion of patients who recognized the importance of screening colonoscopy for CRC in long-term disease is higher than previously reported in the literature [23]. The question on vaccination showed a very high rate of correct answers, reflecting the knowledge gained from the recent vaccination campaign for COVID-19. Physicians and the Internet were the most important reported sources of information; these results are consistent with previous studies [2, 8, 20, 24].

In addition, we also studied variables with potential impact on the level of knowledge related to IBD. According to previously published studies, a higher educational level was positively correlated with higher scores [8, 12, 17, 20, 21], partly explained by the ease of understanding the more technical terms. Despite the attempt to simplify the response method ("true," "false," or "don't know") as opposed to traditional multiple-choice tests, in which the influence of education would tend to be greater [17], the level of education remained a determining factor for knowledge levels.

We found that disease duration (≥5 years), previous IBD-related hospitalization, and use of biologics are associated with higher score in multivariate analysis. These findings may be explained by direct exposure to IBD-related environments over an extended period, providing the patient with more opportunities to obtain disease-related information. Danion et al. [17] showed that an IBD diagnosis ≤3 years and the absence of anti-TNFα treatment for IBD are independent risk factors for low levels of knowledge. In addition, other studies corroborated that disease duration [8, 20], previous hospitalization for IBD [8], and use of biologics [20] affected IBD-KNOW scores. The need for step-up treatment strategy or the development of complicated disease (need for hospitalization or surgery) makes patients more concerned about their condition, which drives the search for information related to their illness. Contrary to the available literature [20], our study revealed no difference in IBD-KNOW score in patients with a family history of IBD, which may be due to the significant impact of direct exposure to IBD-related environments (e.g., hospitalization, surgery) among our patients compared to indirect exposure (e.g., family history).

Lack of knowledge about the chronic nature of IBD and fear of adverse drug effects are the most frequently reported causes of non-adherence among IBD patients, particularly those in clinical remission [25]. Few studies have addressed the impact of knowledge on adherence; however, knowledge appears to have a positive effect on compliance [26]. The MMAS-8 is a self-reported survey, and it was the first adherence scale validated in IBD [27], although there are conflicting data on its performance. This scale is more accurate for assessing adherence to oral therapy; previous data showed that only patients on immunomodulators had the MMAS-8 score positively correlated with knowledge [28]. Taking into account that half of our patients were on biologic therapy and these patients generally present with good adherence, it may have contributed to the lack of association between the level of knowledge and adherence in our cohort. Moreover, our patients had a higher adherence rate than that described in the literature [28].

The authors found no association between knowledge and HRQoL in this population. According to previously published studies [2, 29, 30], although education is desirable, knowledge does not necessarily translate into improved HRQoL and well-being. One reason for this finding is that higher knowledge about IBD empowers patients and also creates more anxiety [16].

Our study has several limitations. First, this study was conducted at a single centre, limiting our findings' generalizability. Second, the relatively small sample size may influence our results. Third, patient association status (e.g., Portuguese Association of Inflammatory Bowel Disease in Portugal) was not recorded, which is a well-known factor of better level of knowledge in the field of IBD. Finally, the present study was designed cross-sectionally, so it did not assess patients' knowledge longitudinally. Therefore, further longitudinal studies and multicentre studies would be needed.

In conclusion, the Portuguese version of the IBD-KNOW is a valid and reliable instrument for measuring patients' IBD-related knowledge. Further evidence of the validity and reliability of IBD-KNOW will be mostly based on its continued use in the clinical setting.

Considering the growing interest in patient-tailored care model, IBD-KNOW allows the identification of significant knowledge deficits and factors affecting the level of IBD-related knowledge. This is of great interest as it allows rethinking methods of informing patients to increase their health and well-being. IBD teams can develop educational programs that address potential knowledge gaps among IBD patients. Furthermore, IBD-KNOWs allow the objective assessment of the impact of these educational programs. Finally, future studies may explore the role the impact of IBD-KNOW score on patient behaviour (adherence), medical outcomes (medical acceleration), and QoL.

Statement of Ethics

This observational study was reviewed and approved by the Ethics Committee at Centro Hospitalar de Setúbal (Ethics Committee for Health of CHS; n. 013/2022), and it was performed in accordance with the Declaration of Helsinki. Participation in this study was voluntary, and all patients provided consent before enrolment.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

Cristiana Sequeira, Cristina Teixeira, and Isabelle Cremers: study design; Cristiana Sequeira, Mariana Coelho, and Inês Costa Santos: data collection; Cristiana Sequeira: statistical analysis, interpretation of data, and manuscript drafting; and all authors: final approval of the article.

Data Availability Statement

All data generated or analysed during this study are included in this article and its online supplementary material. Further enquiries can be directed to the corresponding author.

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