Research Article / Araştırma Makalesi

Validity of the Turkish Version of the Inflammatory Bowel Disease Distress Scale
İnflamatuar Bağırsak Hastalığı Sıkıntı Ölçeği'nin Türkçe Geçerlik ve Güvenirliği

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Abstract: In inflammatory bowel disease, patients may experience psychological distress due to the impact of symptoms and side effects of treatment on daily life. The aim of this study is to adapt the Inflammatory Bowel Disease Distress Scale (IBD-DS) into the Turkish langugae. This methodological study was conducted with 160 IBD patients admitted to gastroenterology outpatient clinics in a city in Türkiye. For the linguistic validity of the IBD-DS, forward-backward-translation and expert opinion methods were used. For reliability analysis, Cronbach's alpha and test-retest analysis were performed. The Kessler Psychological Distress Scale (K10) and the Hospital Anxiety and Depression Scale (HADS) were used to assess construct validity. The mean IBD-DS score was 54.64±40.99 (0-155). Internal consistency analysis yielded a reliability coefficient of Cronbach's alpha of 0.963, and correlations between the items and the total score ranged from 0.378 to 0.816. Good intraclass correlation (ICC) was found between test-retest scores (ICC, 0.99; 95% confidence interval, .994-1.0). It was found that IBD-DS scores were moderately to strongly correlated with the K10 (r=0.467, p<.001) and HADS (r=0.516, p<.001) scales. The Turkish version of the IBD-DS has been found to be a psychometrically adequate scale for use in the Turkish population.
Keywords: Inflammatory bowel disease, distress, Inflammatory Bowel Disease Distress Scale, reliability, validity

Özet: İnflamatuar bağırsak hastaları semptomların ve tedavinin yan etkilerinin günlük yaşam üzerindeki etkisi nedeniyle psikolojik sıkıntı yaşayabilirler. Bu çalışmanın amacı, İnflamatuar Bağırsak Hastalığı Sıkıntı Ölçeği'ni (İBH-SÖ) Türk diline uyarlamaktır. Bu metodolojik çalışma Türkiye'deki bir şehirde gastroenteroloji polikliniklerine başvuran 160 İBH hastası ile yürütülmüştür. İBH-SÖ'nün dilsel geçerliği için ileri-geri çeviri ve uzman görüşü yöntemleri kullanılmıştır. Güvenirlik analizi için Cronbach alfa ve test-tekrar test analizleri yapılmıştır. Yapı geçerliğini değerlendirmek için Kessler Psikolojik Sıkıntı Ölçeği (K10) ve Hastane Anksiyete ve Depresyon Ölçeği (HADS) kullanılmıştır. Ortalama İBH-SÖ puanı 54.64±40.99 (0-155) bulunmuştur. İç tutarlılık analizinde Cronbach alfa güvenilirlik katsayısı 0,963 olarak bulunmuş ve maddeler ile toplam puan arasındaki korelasyonlar 0,378 ile 0,816 arasında değişmiştir. Test-tekrar test puanları arasında iyi bir korelasyon (ICC) bulunmuştur (ICC, 0.99; %95 güven aralığı, .994-1.0). İBH-SÖ puanlarının K10 (r=0.467, p<.001) ve HADS (r=0.516, p<.001) ölçekleri ile orta ila güçlü korelasyon gösterdiği bulunmuştur. İBH-SÖ'nün Türkçe versiyonu, Türk popülasyonunda kullanım için psikometrik açıdan yeterli bir ölçek olarak bulunmuştur.
Anahtar Kelimeler: İnflamatuar bağırsak hastalığı, sıkıntı, İnflamatuar Bağırsak Hastalığı Sıkıntı Ölçeği, güvenirlik, geçerlik

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1. Introduction

Over the past decade, inflammatory bowel disease (IBD) has emerged as a worldwide public health problem, affecting approximately 6.8 million people worldwide, including 1.5 million in North America and 2 million in Europe (1–3). Inflammatory bowel disease (IBD), which presents in two clinical forms, Crohn's disease (CD) and ulcerative colitis (UC), can cause various psychosocial consequences in patients in addition to symptoms such as diarrhea, abdominal pain, rectal bleeding, and weight loss. One of these consequences is psychological distress. Distress, a factor that can negatively affect the course of the disease, means emotional suffering or "a nonspecific, biological, or emotional response to a demand or stressor that affects the individual" (4,5).

In many chronic diseases (diabetes, asthma, cancer, multipl sclerosis, etc.), disease-related distress has been extensively defined and researched. However, studies reporting "psychological distress" in IBD have generally measured only anxiety and depression. Studies of distress in other chronic diseases show that although distress is related to anxiety and depression, they are distinct concepts. Disease-specific distress is the emotional experience of one's disease. Dibley et al. define IBD distress as 'an emotional response to the burden of chronic illness symptoms which may share symptoms of anxiety and depression, but is not diagnosed as such and is attributable only to the emotional response to disease experience' (4).

Studies have shown that people with IBD are 2-4 times more likely to develop depression and 3-5 times more likely to develop anxiety disorders over their lifetime compared with the general population, but the presence and impact of IBD distress has not been adequately studied (6). Studies conducted to evaluate IBD distress have used scales to measure general anxiety and depression such as the Hospital Anxiety and Depression Scale (HADS), the Kessler Psychological Distress Scale (K10), and the Brief Symptom Inventory (BSI) (1,7–11). However, because these scales may not be sufficient to measure the distress experienced by IBD patients, an instrument, the Inflammatory Bowel Disease Distress Scale (IBD-DS), was developed by Dibley et al. (2018) to assess IBD-specific distress. An assessment tool for IBD distress can identify patients' distress and improve their quality of life and self-management in the long term. This study was conducted to adapt the IBD-DS to the Turkish population.

2. Materials and Methods

2.1 Research Design, Sample and Setting

This study was conducted to evaluate the reliability and validity of the Turkish version of the Inflammatory Bowel Disease Distress Scale. The study was conducted on patients with inflammatory bowel disease treated at the gastroenterology outpatient clinics of two hospitals, Osmangazi University Hospital and Yunus Emre State Hospital, in Eskisehir, a city in Türkiye, between September 2021 and September 2022. The study sample consisted of patients diagnosed with IBD based on endoscopic and histopathological findings who were over 18 years of age and volunteered to participate in the study. Patients who had multiple or severe comorbidities, had serious complications due to existing comorbidities (vision loss, amputation, etc.), or had any psychiatric disorders were not included in the study.

The sample size of the study was set at a minimum of 140 patients based on the principle of 5-10 participants per item (28 items x 5), which is common in validity and reliability studies (12). A total of 190 consecutive patients admitted to the outpatient clinic were invited to participate in the study. However, 160 patients voluntarily participated in the study. Considering missing answers, all patients who volunteered to participate in the study were included in the study. Patients were divided into groups based on diagnosis (CD/UC) and stage of disease (relapse/remission).

Ethics committee approval and institutional permissions were obtained before data collection (Eskisehir Osmangazi University

Non-Interventional Clinical Research Ethics Committee, Decision no: 03, date:21.09.2021). Permission was obtained from the authors to adapt the scale. Written informed consent was obtained from patients to participate in the study.

2.2 Data Collection

Data were collected using the Inflammatory Bowel Disease Distress Scale (IBD-DS) and a patient information form to record sociodemographic and clinical characteristics and the indexes to assess disease activity (Harvey-Bradshaw Index, HBI, for CD or Simple Colitis Clinical Activity Index for UC). The Hospital Anxiety and Depression Scale (HADS) and the Kessler Psychological Distress Scale (K10) were used to test criterion validity of the IBD-DS. To assess the invariance of the scale over time (test-retest), the scale was re-administered to a group of 32 patients at a two-week interval. The retest group consisted of patients (15 CD, 17 UC) who were self-reported to be in remission and in whom drug treatment had not been changed during the two-week period.

Inflammatory Bowel Disease Distress Scale (IBD-DS): It was developed by Dibley et al. (2018) to assess IBD distress. This scale consists of 28 items and responses are scored on a 6-point Likert scale. The score that can be obtained with the test ranges from 0 to 168, and the score indicates the patient's level of distress. It is a unidimensional scale. The scale also includes 3 additional questions that are not included in the score. A higher score means that the patient's distress is high (4).

Harvey-Bradshaw Index (HBI): It was developed by Harvey and Bradshaw to collect data on Crohn's disease activity. The index asks about the patient's general well-being, abdominal pain, number of liquid stools per day, abdominal mass and complications. An HBI score of <5 indicates clinical remission and >16 indicates severe disease (13).

Simple Colitis Clinical Activity Index (SCCAI): It is a scoring system to evaluate disease activity in UC patients. It determines whether the disease is in relapse or remission according to the frequency of daytime and nighttime bowel movements, the need for urgent defecation, blood in the stool, general well-being, and the presence of extraintestinal complications that affect the patient's quality of life. The scores to be obtained with the index range from 0 to 19 points. A total score <2 indicates clinical remission. (14).

Hospital Anxiety Depression Scale (HADS): This is a commonly used scale to assess symptoms of anxiety and depression. It is a four-point Likert scale consisting of a total of 14 questions. The lowest score patients can achieve on both subscales is 0, and the highest score is 21 (15,16). The cut-off points of the Turkish version of the HADS were 10 for the anxiety subscale (HADS-A) and 7 for the depression subscale (HADS-D) (16).

Kessler Psychological Distress Scale (K10): A 10-item, five-point Likert scale developed by Kessler et al. (2003) to assess psychological distress in various patient populations. It is used to measure the extent of depressive symptoms (irritability, hopelessness, sadness, worthlessness, fatigue) experienced by participants in the 30 days preceding the interview. Scores achievable with the scale range from 10 to 50, with higher scores indicating greater psychological distress (17,18).

2.3 Linguistic Validation

The IBD-DS scale was translated from English to Turkish as described in the literature (12). Two independent persons, fluent in both languages, translated the scale from English into Turkish. These two translations were combined into a single text. The scale was then evaluated by a panel of experts. The expert panel consisted of 10 individuals, including gastroenterologists, psychologists, and academic nurses working with IBD patients. The Turkish text of the scale was translated back into English by a translator. The final form was compared with the original scale. The Turkish version was discussed, and consensus was reached. The final version of the scale was applied to five IBD patients. In the pilot study, question 11 (I am distressed because it is difficult to talk to my employer, work colleagues or fellow

students about my IBD) was not completed by two patients who were not working or going to school. After consultation with the researcher who developed the scale, the phrase "If a question does not apply to you, please check the 'No' column" was added to the scale instructions. After this consultation, the scale was finalized.

2.4 Statistical Analysis

Data of the study was analyzed by use of SPSS (v21.0, IBM) software. Descriptive statistics were used to present sociodemographic and clinical characteristics. Descriptive statistics and Cronbach`s alpha value of the scale were calculated. The normality distribution of the data was evaluated by the Shapiro-Wilk test. Since the data did not fit the normal distribution Spearman correlation analysis was used to evaluate the relationship between the scale and other scales. ICC coefficient was calculated for test-retest analysis. ICC

coefficient reflects the correlation between repeated measurements of the same patient. ICC value close to 1 indicates a good correlation between the two measurements. The results were evaluated at 95% confidence interval and p value less than .05 was considered statistically significant.

3. Results

The sample of the study consisted of 160 patients, 93 (58.1%) with ulcerative colitis and 67 (41.9%) Crohn's disease. The mean age of the participants was 44.84±15.20 (21-85) years. More than half of the patients (n=84, 52.5%) were male and 41.3% had university. The mean duration of diagnosis was 6.94±5.60 years and the majority of the patients reported that they did not smoke or drink alcohol (66.9%). Forty-five percent of the patients were in the relapse stage. The mean IBD-DS score of the patients was 54.64±40.99 (0-155) and the median value was 48.5 (Table 1).

Table 1. Sociodemographic and clinical characteristics of the patients

Variables	n	%
Age (mean ±sd; range)	44.84 ±15.20	(21.0-85.0)
Sex		
Female	76	47.5
Male	84	52.5
Education		
Illiterate	2	1.3
Primary school	41	25.6
High school	51	31.9
University	66	41.3
Marital status		
Married	122	76.3
Single /divorced /widow	38	23.8
Working status		
Working	71	44.4
Unemployed	10	6.2
Other (retired, student, homemaker)	79	49.4
Income		
More than expenses	20	12.5
Equal to expenses	90	56.3
Less than expenses	50	31.3
Smoking or alcohol use		
Non-user	107	66.9
User	53	33.1
Smoking	37	23.1
Alcohol	5	3.1
Smoking and alcohol	11	6.9
Duration of diagnosis (mo) (mean±sd; range)	6.94 ±5.60	(0.3-28)
Diagnosis		
Ulcerative colitis	93	58.1
Crohn`s disease	67	41.9
Self-reported disease activity (HBI/SCCAI)		
Relapse	72	45.0
Remission	88	55.0
Scales		
IBD-DS (mean ±sd; range)	54.64±40.99	(0-155)
HADS (mean ±sd; range)	15.00 ±7.56	(0-36)
K10 (mean ±sd; range)	23.58 ±8.37	(10-46)

The data collected in this study proved to be well suited for factor analysis, as indicated by a high Kaiser-Meyer-Olkin (KMO) value of 0.936 and a significant Bartlett's test (x^2 = 3540.001; p=.000) (Table 2). A confirmatory factor analysis (CFA) was then conducted to determine the construct validity of the instrument. Various fit indices, including the χ^2/df ratio, root mean square error of approximation (RMSEA), comparative fit index (CFI), standardized root mean square residual (SRMR), goodness-of-fit index (GFI), the normalized fit index (NFI), the incremental fit index (IFI), parsimony normed fit index (PNFI), were assessed to determine the compatibility of the factor structure of the original scale with the Turkish version. These fit indices are commonly used in scale adaptation studies as indicators of good model fit. The fit indices of the model derived from the conducted CFA were evaluated and found to have a statistically significant minimum chi-square value and fit index values that were within the desired range. Based on these results, it can be concluded that the Turkish adaptation of the IBD-DS supports the underlying structure of the original scale (Table 3).

Table 2. Results of the Kaiser-Meyer-Olkin measure of Sampling Adequacy and Bartlett's Test of Sphericity

Test	Results	p
Kaiser–Meyer–Olkin measure of sampling adequacy	0.936	<.001
Bartlett's test		
Approx. chi-square	3540.001	
df	378	
Sig.	<0.001	

Table 3. Fit Indicis and confirmatory factor analysis values for the scale

Fit Criteria	Results	Good fit	Acceptable fit
χ^2/df	2.345	≤2	≤5
RMSEA	0.092	<0.08	<0.1
CFI	0.990	>0.95	>0.90
SRMR	0.082	<0.05	<0.08
GFI	0.985	>0.95	>0.90
NFI	0.984	>0.95	>0.90
IFI	0.990	>0.95	>0.90
PNFI	0.911	>0.5	

RMSEA, root mean square error of approximation; CFI, comparative fit index; SRMR, standardized root mean square residual; GFI, goodness of fit index; NFI, normed fit index; IFI, incremental fit index; PNFI, parsimony normed fit index;

When the scale was evaluated in terms of ceiling and floor effect, only in the 23rd and 26th questions, more than 20% of the patients were clustered in the high-scoring option (26.9% and 20.6%, respectively) (Table 4).

Table 4. Descriptives and item-total correlations of the Turkish version of the IBD-DS

				Item-total correlation	
Items	**Mean±sd (median)**	**% Floor** [†]	**% Ceiling** [‡]	**r** [§]	**p**
1	1.21±1.72 (0.0)	13.1	3.8	.580	<.001
2	1.00±1.78 (0.0)	7.5	5.6	.378	<.001
3	2.76±2.08 (3.0)	15.6	13.8	.691	<.001
4	1.66±2.02 (1.0)	12.5	7.5	.414	<.001
5	1.34±1.88 (0.0)	11.9	5.6	.496	<.001
6	1.48±1.78 (1.0)	11.9	2.5	.653	<.001
7	2.26±2.06 (2.0)	14.4	10.0	.693	<.001
8	2.46±2.10 (2.0)	10.6	13.8	.816	<.001
9	2.20±2.18 (2.0)	11.9	13.1	.785	<.001
10	2.20±2.24 (1.0)	13.1	13.1	.753	<.001
11	1.44±2.02 (0.0)	11.9	6.9	.647	<.001
12	1.97±2.41 (1.0)	10.6	18.8	.734	<.001
13	1.85±2.24 (0.0)	7.5	11.3	.740	<.001
14	1.04±1.60 (0.0)	11.9	1.9	.509	<.001
15	2.24±2.07 (2.0)	17.5	11.3	.772	<.001
16	2.12±2.17 (1.0)	16.9	13.8	.805	<.001
17	2.20±1.98 (2.0)	16.9	6.3	.808	<.001
18	2.84±2.20 (3.0)	10.6	15.6	.761	<.001
19	1.93±2.14 (1.0)	12.5	9.4	.755	<.001
20	1.54±1.95 (1.0)	13.8	6.3	.662	<.001
21	2.43±2.13 (2.0)	18.1	11.3	.791	<.001
22	1.64±1.95 (1.0)	15.0	5.6	.625	<.001
23	2.73±2.50 (2.0)	11.9	26.9	.557	<.001
24	1.74±1.98 (1.0)	18.1	6.9	.735	<.001
25	1.43±1.86 (0.0)	13.1	2.5	.700	<.001
26	2.93±2.27 (3.0)	11.9	20.6	.687	<.001
27	2.45±2.28 (2.0)	13.1	17.5	.743	<.001
28	1.57±2.03 (0.0)	10.6	5.6	.721	<.001

[†]*Floor effect: Percentage of patients with a minimum score answered on all scale items,* [‡]*Ceiling effect: Percentage of patients with a maximum score answered on all scale items.* [§] *Spearman correlation analysis*

The confirmatory factor analysis showed that the Turkish version of the scale has a unidimensional structure as in the original scale. (Figure 1)
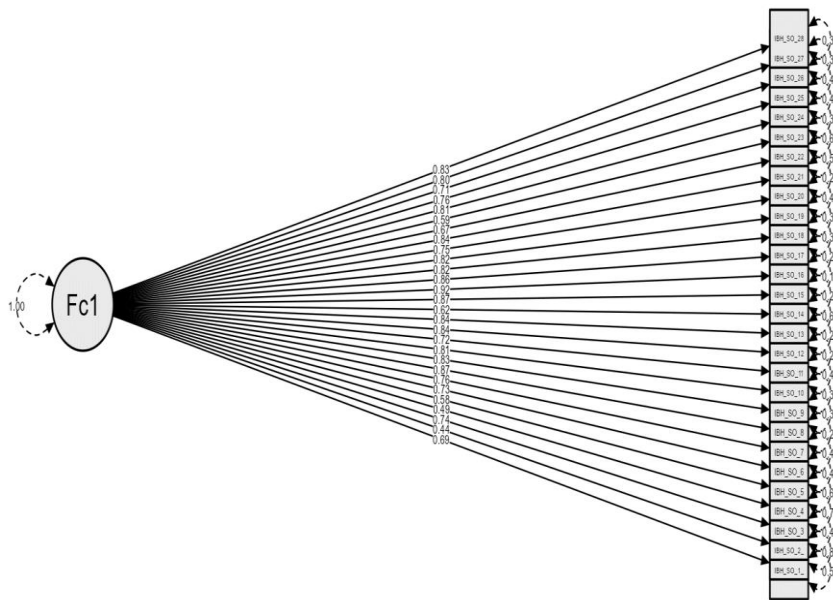

Figure 1. PATH diagram regarding the factor structure of the scale.

Item-total correlations and Cronbach's α coefficient were used to test internal consistency (reliability), which is defined as the interrelationship between items in the questionnaire. The item-total score correlation coefficients of the scale were found to be between 0.378 and 0.816 (Table 4). Cronbach's α coefficient was 0.963. ICC value was calculated as 0.99 (95% CI, 0.994-1.00), which shows that there is an excellent agreement between the test and retest values.

To assess criterion validity, the scale was evaluated in terms of its relationship with other scales. IBD-DS scores of CD patients tended to be worse than those of the UC group (61.0 vs 41.0, p=.079). As expected, IBD-DS scores of patients with relapse were worse than those of patients in remission (55.0 vs 33.5, p=.001). Moderately - strong positive significant correlations were found between IBD-DS and K10 and HADS (p<.001) (Table 5).

Table 5. Relationship of IBD-DS scores with clinical parameters and scales

	Mean ±sd (median)	Z [¶]	p
Diagnosis			
Ulcerative colitis	49.47 ±38.89 (41.0)	-1.754	.079
Crohn`s disease	61.80 ±43.01 (61.0)		
Disease activity			
Relapse	66.38 ±42.27 (55.0)	-3.276	.001
Remission	45.02 ±37.47 (33.5)		
Age (r, p)		-0.20	.010
Duration of diagnosis (r, p)		-0.28	.723
K10 (r, p)		0.47	<.001
HADS (r, p)		0.52	<.001

IBD-DS: Inflammatory Bowel Disease Distress Scale, K10: Kessler Psychological Distress Scale, HADS: Hospital Anxiety and Depression Scale, [¶] Mann-Whitney U test

4. Discussion

IBD can cause patients to feel a significant psychological burden due to its chronic and unpredictable nature, the impact of its symptoms on daily and social life, the side effects of medications, and the financial burden of the disease. The resulting psychological distress can reduce patients' quality of life, exacerbate disease symptoms and trigger disease activity (11,19).

Disease-related distress has been defined and extensively investigated in studies on multiple sclerosis (20), asthma (21,22), diabetes mellitus (23), and cancer (24) and reported to be a different concept from anxiety and depression. Disease-related distress is differed from anxiety and depression in that it focuses uniquely on the emotional response to the disease experience and is not related to any underlying psychological morbidity such as anxiety or depression (4). Until recent years, studies have investigated depression and anxiety as psychological distress in IBD patients (25). Dibley et al. recognized this need and developed a disease-specific scale, IBD-DS, in order to evaluate the distress experienced by IBD patients. In this study, this scale was adapted to Turkish language (4).

The first step of scale adaptation studies is linguistic validation (12). In our study, linguistic validation of the scale was performed by forward-backward translation method and then the scale was reviewed by an expert panel. The Turkish version of the scale was finalized after the pilot application in the 5-person patient group. The psychometric properties of the scale were evaluated using descriptives, item-total score correlation, test-retest, and Cronbach's α. In order to evaluate the construct validity, the correlation of the scale with some variables was also analyzed.

In our study, the mean score of the scale was found to be 54.64±40.99 (range, 0-155) while in the study of Dibley et al. (2018) the mean score of the scale was found to be 100±36. This may be related to the fact that the sample consisted entirely of women and most of them Crohn's patients. Studies have shown a higher level of psychological distress in female patients with IBD compared to male patients (26,27). CD and UC are different diseases in terms of psychological impact on patients (28). Studies have also reported that CD patients experience more psychological distress than UC patients (27–29). Abdominal pain is more prominent in Crohn's disease patients than in ulcerative colitis patients. Considering that pain may affect the quality of life of the person more than other symptoms, which may have a greater effect on distress, it may be thought that the mean score of the distress scale in Crohn's patients is higher for this reason.

In general, floor and ceiling effects should not exceed 20 per cent in scales. No floor-ceiling effect was observed in the study of Dibley et al. (4). In our study, the ceiling effect was slightly above 20% only in two questions (26.9% and 20.6%). Therefore, it is possible to say that the distribution of the answer options in the items was balanced in general.

When the item-total score correlations of the IBD-DS scale are analyzed, moderate-strong correlations were found. The item-total score correlation coefficients of this scale ranged between 0.496 and 0.816, excluding items 2 and 4. This shows that each item evaluates in parallel with the scale score, that is, internal consistency. Only the correlation coefficients of items 2 and 4 of the scale (…I may need a temporary or permanent stoma, or other surgery for my IBD/…I sometimes do not have access to IBD health professionals when I need it) were found to be slightly lower than they should be (>0.4). However, these items were not removed from the scale since the difference was not significant.

Test-retest analyses were performed to evaluate the invariance of the responses to the scale over time. As a result of the analysis, the ICC coefficient between the scores obtained from the scale was 0.999 (CI 0.994-1.00), and a good correlation was found between the measurements.

One of the recommended methods for assessing reliability when using Likert-type

scales is the evaluation of Cronbach's α coefficient. Cronbach's α value of the scale was 0.95 in the original version (4) and found to be 0.963 in our study. For reliable internal consistency, a Cronbach's α value higher than 0.70 is recommended (30). Our results show that the Turkish version of the IBD-DS is a reliable screening test for IBD patients.

Construct validity of scales is tested by evaluating the correlation of the scale with other validated instruments. In this study, in order to evaluate the construct validity, the correlation of the IBD-DS scale with other scales measuring depression and anxiety, which are thought to be related to distress, was examined. Depression and anxiety can be seen alone, especially when faced with stressful events, or as comorbid illnesses or as part of the symptoms of psychological distress. It is very important to accurately assess distress, depression and anxiety. When not diagnosed correctly, they can cause serious impairments in daily life functions such as decreased work/academic performance, tension in interpersonal and family relationships, and decreased health in general (31). As expected, a significant correlation was found between IBD-DS and K10 and HADS in our study.

Studies have shown that disease activity is closely related to psychological distress of patients (1,28,29). In our study, as expected, the level of distress was higher in patients with active disease. The increase in distress due to symptoms that occur with exacerbation of the disease is a finding that supports the construct validity of the Turkish version of the scale.

Limitations

In our study, we evaluated the activation status of the disease based on patients` self-report. Evaluation of disease activity with objective measurements (endoscopy findings, etc.) could have provided more reliable results. Since the majority of the study consisted of UC patients (58.1%), it may not represent all IBD patients.

Implications for practice

The scale can be used in clinical practice by allowing the evaluation of the disease related distress which in turn can exacerbate symptoms of disease.

5. Conclusion

IBD is a disease that affects not only the digestive system, but also the psychology of the patient. A simple scale is needed to determine the distress caused by the disease. Our study confirms that the Turkish version of the IBD-DS is a valid and reliable tool for screening distress in patients with IBD. The Turkish version of the IBD-DS can be used in clinical practice.

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Ethics

Ethics Committee Approval: The study was approved by Eskisehir Osmangazi University University Noninterventional Clinical Research Ethical Committee (Decision no: 03 Date: 21.09.2023).

Informed Consent: The authors declared that getting consent from the patients was unnecessary because the study was a retrospective data analysis.

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