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Development and testing of a novel symptom assessment scale for Behçet's disease

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Background/aim: This study was designed to develop a Behçet's disease (BD) symptom assessment scale based on the theory of unpleasant symptoms, which deals with understanding symptom experiences in a disease.

Materials and methods: The BD Symptom Assessment Scale has two sections: the factors influencing symptoms and the situations influenced by symptoms. Both of these sections were developed through an initial item pool, and expert opinions were consulted during a pilot test performed with 30 patients with BD. We then tested the validity and reliability of this scale on 218 different patients with BD fulfilling the ISG criteria. Finally, we scored this scale.

Results: The validity and reliability study of the first section found that the scale had favorable fit indices ($\chi^2 = 525.86$, χ^2 / SD = 3.15, GFI = 0.90, CFI = 0.89, IFI = 0.89), constituting three dimensions and 20 items. The validity and reliability study of the second section found that the scale had favorable fit indices ($\chi^2 = 579.14$, χ^2 / SD = 3.48, GFI = 0.91, CFI = 0.89, IFI = 0.89) and constituted three dimensions and 20 items.

Conclusion: This novel symptom assessment scale for BD is a valid and reliable tool for evaluating patients with BD.

Key words: Behçet's disease, symptom assessment, theory of unpleasant symptoms

1. Introduction

Behçet's disease (BD), a chronic systemic inflammatory disease, is an important cause of morbidity and mortality, with cutaneous and mucosal lesions, articular involvement, and ocular involvement that may cause loss of vision. Additionally, it disturbs both the physical and mental health of sufferers and impairs physical functions. For this reason, it may influence the quality of life negatively (1). As suggested by the theory of unpleasant symptoms (TOUS), not only the symptoms of a certain disease but also the various factors that influence the perception of these symptoms should be considered when assessing patients with a certain disease. We believe that such an assessment is also necessary for BD, and this will provide guidance for nurses in administering nursing care. The TOUS deals with understanding symptom experiences in a disease, and it was developed to integrate the existing knowledge about various symptoms. It departs from the idea that there are common points among different symptoms. The aim of the TOUS is to understand the symptom experience in various cases and to prevent, mitigate, or manage negative symptoms and effects (2–5). The TOUS includes 3 main concepts: symptom(s), influencing factors, and performance (4,6). Symptoms were the point of departure for the conceptualization of this theory and are the central concept of this theory. In line with the purposes of the TOUS, symptoms have been defined as perceived indicators of change in normal functioning as experienced by patients. Three categories of factors that may influence (and that may in turn be influenced by one another) the experience of symptoms are defined in the TOUS: physiological, psychological, and situational factors. In the TOUS, the results of symptoms are conceptualized as performance. Performance represents the consequences of the symptom experience and has three aspects: functional status, cognitive functions, and physical performance (4). It is commonly accepted that understanding the symptom experience is the key to understanding patients (7). Although symptom assessment is of critical importance with BD patients, there is no BD-specific symptom assessment scale in the literature in relation to the lifestyle and symptom formation of patients. Health professionals

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can use BD symptoms to perform evaluations. Therefore, this study aimed to develop a BD symptom assessment scale based on the TOUS.

2. Materials and methods

2.1. Development of the Behçet's Disease Symptom Assessment Scale

The Behçet's Disease Symptom Assessment Scale was developed on the basis of the TOUS to assess the symptoms of BD patients. It was prepared using the following steps:

Step 1. Item pool stage: The relevant literature was reviewed by researchers. Researchers examined quality of life scales, sociodemographic data used in studies, and symptom relationships in the literature (8–35). The pool of questions was created in line with the components of the TOUS, including factors influencing symptoms of BD patients (n = 22) and performance results (n = 20).

Step 2. Expert opinion stage: The items created by researchers were presented to nine experts in BD and theory and they were assessed in terms of language and content validity. Content validity, also known as definition validity or logical validity (5), can be defined as the capability of the selected items to reflect the variables of the construct in the measure. This type of validity addresses the degree to which items of an instrument sufficiently represent the content domain (36). The content validity ratio was ≥0.75, $P < 0.05$, and the items meeting this criterion were included in the pilot form (37). On the basis of expert opinions, an initial item pool with 42 items, including factors that influence BD symptoms (n = 22) and performance results (n = 20), was developed. Since the TOUS includes two parts, the scale is also divided into two parts. The scale development efforts were conducted for both the first and the second sections. The first section had a Likert-type 10-point scale with 22 items with options from "does not influence them at all (0)," to "influences them a lot (10)". The second section used the same kind of scale with options from "never prevented it (0)" to "completely prevented it (10)". Likert-type scale items generally have common choices. As in the original form, the scale includes an optimum number of five choices. However, a 10-point Likert-type scale was used in this study because most of the symptom assessment instruments in the literature had used a 10-point Likert-type scale (e.g., Edmonton Symptom Scale, Brief Pain Inventory, BORG Scale, visual analog scales, and verbal analog scales).

Step 3. Pilot test: The pilot test of the scale was administered to 30 BD patients in face-to-face interviews. The interviewees were contacted once again 2 weeks later to note any changes in the disease status, and the scale was readministered. There were no differences between expert opinions and patient opinions in the pilot test regarding the item scores.

Step 4. Validity and reliability analysis of the Behçet's Disease Symptom Assessment Scale: The Kaiser–Meyer–Olkin (KMO) test, Bartlett's test, exploratory factor analysis (EFA), and confirmatory factor analysis (CFA) were used to test the validity of the scale. The KMO and Bartlett's test show the suitability of the data for item analysis. EFA is done to understand or summarize the relationships between multiple variables and a smaller number of baseline dimensions to facilitate interpretation. CFA is a kind of structural equation model used to determine the relationship between observable and latent variables. CFA was performed to indicate good fit; the results are given in Table 1 (38).

Step 5. Scoring the scale: An item distinctiveness analysis was performed to assess the scale. This test distinguishes the patients who knew about their disease from those who did not in regard to their effectiveness in filling out the forms. The Behçet's Disease Symptom Assessment Scale was developed to determine how the symptoms of BD are influenced by physiological, psychological, and situational factors and to identify the effects of symptoms on patients' performance.

2.2. Sample

The present study was conducted on patients registered at the Rheumatology Outpatients Clinics of the Division of Rheumatology at the Ege University School of Medicine Hospital between February 2013 and March 2014. In the study, the scale form was used and 218 patients (M/F: 55%/45%; mean age ± SD: 45.8 ± 11.2 years) with BD fulfilling the ISG criteria (Table 2) were interviewed. The study sample included only patients with Behçet's disease who did not have any other chronic diseases and could speak Turkish.

2.3. Procedures

Approval was obtained from the Ege University School of Medicine Hospital in order to conduct the study. The aim of the study and its methodology were explained to the participants, and their oral and written consent was received.

Table 1. Compliance goodness indices and normal values used in CFA.

Index	Normal value	Acceptable value
χ^2	$P > 0.05$	-
χ^2 / SD	<2	<5
GFI	>0.95	>0.90
CFI	>0.95	>0.90
IFI	>0.95	>0.90

Table 2. The ISG criteria for classification of patients with Behçet's disease.

Recurrent oral ulceration
*Minor aphthous, major aphthous, or herpetifom ulceration observed by physician or reported reliably by patient Recurrent at least 3 times in one 12-month period
Plus 2 of the following:
*Recurrent genital ulceration Recurrent genital aphthous ulcer or scarring, especially in males, observed by physician or reported reliably by patient *Eye lesions Anterior uveitis Posterior uveitis Cells in vitreous on slit lamp examination Or retinal vasculitis observed by qualified physician (ophthalmologist) *Skin lesions Erythema nodosum-like lesions observed by physician or reported reliably by patient Pseudofolliculitis Papulopustular lesions Or acneiform nodules consistent with Behçet's syndrome, observed by a physician and in postadolescent patients not receiving corticosteroids *Positive pathergy test To be read by a physician at 48 h, performed with oblique insertion of a 20–22 gauge or smaller needle under sterile conditions

2.4. Instruments

A patient identification form and the Behçet's Disease Symptom Assessment Scale were used in the study.

The patient identification form was used to collect data about the sociodemographic characteristics of the patients in the study.

The Behçet's Disease Symptom Assessment Scale was developed on the basis of the TOUS and used to assess the symptoms of BD patients.

2.5. Statistical analysis

The analysis of the study data and the assessments related to the scale development were carried out using SPSS 20.0 (different analyses for every stage) and the LISREL package program (for the CFA). Both SPSS and LISREL were used in the analysis. The statistical results were assessed to be in the confidence interval of 5% ($P < 0.05$).

3. Results

3.1. Sociodemographic data

It was found that 55% of the BD patients in the study were male, 80.7% were married, and all of them had health insurance from Turkey's Social Security Institution. Of them, 46.8% had completed primary school, and 58.3% listed "other" as their profession. Of the patients, 65.1% had incomes equal to their expenses, and 91.3% were not living alone (Table 3). The average age of the patients included in the present study (n = 218) was 45.8 ± 11.2 years (range: 21–82), and the average duration of the disease in years was 11.33 ± 7.74 (range: 0.06–43.38) (Table 4). It was determined that 95% of patients in the study were in treatment: 28% were taking colchicine, while 28.4% took methylprednisolone, 20.2% took azathioprine, 2.3% took sulfasalazine, 1.4% took interferon, 7.8% took colchicine + azathioprine, 4.6% took colchicine + methylprednisolone, and 2.3% took azathioprine + methylprednisolone (Table 5). The frequencies of the symptoms of the patients are given in Table 6.

3.2. Initial item pool, expert opinion stages, and pilot test

The relevant literature was reviewed by the researchers (8–35). The pool of questions was created in line with the components of the TOUS, including factors influencing symptoms of BD patients (n = 22) and performance results (n = 20). In the expert opinion stage, the items created by researchers were presented to nine experts specializing in BD and theory, who assessed the items in terms of language and content validity. The study accepted 0.75 as the content validity ratio/index value. The first section included 22 items and the second section included 20 items. During the pilot test and the test–retest, the correlation value was found to be normal ($P < 0.001$). Thus, the scale was not changed at that stage.

3.3. Testing the validity and reliability of the Behçet's Disease Symptom Assessment Scale

In the validity and reliability stage for the first section, the KMO value was found to be 0.88, showing that there was adequate correlation between the items of the scale and Bartlett's test coefficient ($\chi^2 = 3434.0$, $P < 0.001$). Item and factor total variance explanation analyses showed

Table 3. The distribution of Behçet's patients based upon their demographic features.

Characteristics		Number (n)	Percentage (%)
Sex	Female	98	45
	Male	120	55
Marital status	Married	176	80.7
	Single	41	18.8
	Divorced	1	0.5
Education level	No school education	9	4.1
	Did not graduate from primary school	12	5.5
	Primary school	102	46.8
	Middle school	20	9.2
	High school	47	21.6
	University	28	12.8
Occupation	Unemployed	17	7.8
	Freelance worker	9	4.1
	Laborer	38	17.4
	Civil servant	27	12.4
	Other	127	58.3
Monthly income level	Income lower than the expenses	73	33.5
	Income balanced with the expenses	142	65.1
	Income higher than the expenses	3	1.4
Any household	Living alone	19	8.7
	Not living alone	199	91.3
Total		218	100

Table 4. Age and disease duration of patients with Behçet's disease.

	Mean	Minimum	Maximum	SD
Age	45.8	21	82	11.2
The time/years that passed after the diagnosis	11.3	1	43	7.74

that there were five factors with an eigenvalue above 1. The total contribution of these five factors to the variance was 70.799%. The individual contribution of factors in the percentage of variance column decreased after the third factor, and the differences among them were very small. These results confirmed that the scale had three factors (36,37). The subdimensions of Section I were physiological factors (n = 7), psychological factors (n = 7), and situational factors (n = 8), which correspond to the theoretical model (Table 7). An item analysis was then performed, and the item total test correlations were calculated with EFA. Item analysis results showed that the 22 items in the questionnaire should be reduced to 21 items, since the correlation coefficient was below 0.20 (Table 8). The validity and reliability of the physiological factors section, psychological factors section, and situational factors section were confirmed by Cronbach's alpha coefficient values of 0.75, 0.89, and 0.83, respectively. Additionally, the validity and reliability of the scale were confirmed by a Cronbach's alpha coefficient value of 0.91.

In the second section of the scale, the content validity ratio/index value, test–retest and correlation value, KMO

Table 5. The distribution of the patients with Behçet's disease by the medications they use.

Medications used by the patients	N	%
Colchicine	61	28
Methylprednisolone	62	28.4
Azathioprine	44	20.2
Sulfasalazine	5	2.3
Interferon	3	1.4
Colchicine + azathioprine	17	7.8
Colchicine + methylprednisolone	10	4.6
Azathioprine + methylprednisolone	5	2.3
No treatment	11	5

value, Bartlett's test coefficient, and Cronbach's alpha coefficient were found to be 0.75, $P < 0.001$, 0.89, $\chi^2 = 3966.0$ ($P < 0.001$), and 0.93, respectively. The validity and reliability of the functional status section, cognitive functions section, and physical performance section were confirmed by Cronbach's alpha coefficient values of 0.72, 0.97, and 0.86, respectively. An item analysis was then performed, and the item total test correlations were calculated. Analyses revealed that there were 4 factors with eigenvalues above 1. The total contribution of these 4 factors to the variance is 70.53%. The individual contribution of factors in the percentage of variance column decreases after the third factor, and the differences among them are very small. This indicates that three factors should be used, and the model is thus verified. The subdimensions of Section II were functional status (n = 6), cognitive functions (n = 8), and physical performance (n = 6) (Table 9). The total item correlation coefficient values of every item in the first and second sections were determined (Table 9). In the item analysis, none had a coefficient below 0.20 (Table 10). Therefore, none of the items were omitted.

CFA was performed to verify the 20-item structure of the first section. The first CFA examined the items with t values that were not statistically significant. Item 21 (cold application and environments), which did not have a significant value, was removed from the section. The analysis was repeated with the 20 remaining items. It was determined that all of their t values were significant. The compliance indexes were found to be $\chi^2 = 525.86$, χ^2 / SD = 3.15, GFI = 0.90, CFI = 0.89, and IFI = 0.89. When the coefficient values showing the association between the observed variables and the factors of the model indicating the factorial structure of this section were taken into account, it was concluded that all of the coefficient values were at adequate levels. The compliance statistics calculated using CFA indicated that the previously designated structure of the section was generally consistent with the collected data. The first CFA was performed to verify the 20-item structure of the first section. No nonsignificant t values were encountered. Therefore, all items were retained. In the second section, the compliance indices were found as follows: $\chi^2 = 579.14$, χ^2 / SD = 3.48, GFI = 0.91, CFI = 0.89, and IFI = 0.89. When the coefficient values showing the association between the observed variables and the factors of the model indicating the factorial structure of this section were taken into account, it was concluded that all of the coefficient values were at adequate levels. The compliance statistics calculated using CFA indicated that the previously designated structure of the section was generally consistent with the collected data.

3.4. Scoring the scale

The scale was scored using an item distinctiveness analysis. That analysis calculated a t value of 27% for the supergroups and subgroups, as shown in Table 11. The lower and upper values of the scale are presented in Table 11. The subdimension scores and total scores of the "Factors Influencing Symptoms" and "Situations Influenced by Symptoms" sections were significantly and positively correlated ($P < 0.05$) (Table 11). There were significant and positive correlations between the subscale scores and total scores of both sections ($P < 0.05$) (Table 12). The Behçet's Disease Symptom Assessment Scale is also included at the end of this paper (Appendix).

4. Discussion

4.1. Factors influencing symptoms of Behçet's disease

In the first section of the Behçet's Disease Symptom Assessment Scale, the factors that influence BD symptoms were specified. In this section, the effects of physiological factors, psychological factors, and situational factors on BD symptoms were demonstrated. This section of the scale can be used to measure factors influencing BD in clinical or research settings. We have benefited from the literature in creating this section. In the literature, there are a few studies investigating the effects of physiological factors on BD. Mumcu et al. stated that infectious agents including *Streptococcus* and herpes simplex virus, as well as oral hygiene status, might play a role in the etiopathogenesis of BD. They emphasized that genetic heritage as well as immune mechanisms were also important (39). The role of psychological factors in the pathogenesis of BD was also investigated. Psychological factors may have a primary etiological role in BD, while they may also develop secondary to the disease itself (40). The literature on BD emphasizes the role of smoking and stress. Soy et al. found that 13% of their participants smoked on a daily basis, and they suggested that decreased nicotine levels following the cessation of smoking could increase the

Table 6. The frequencies of the symptoms of the patients with Behçet's disease.

Symptoms	None (0)		Rare (1)		Sometimes (2)		Very often (3)	
	n	%	N	%	N	%	N	%
Mouth sores	26	11.9	57	26.1	55	25.2	80	36.7
Genital sores	93	42.7	58	26.6	30	13.8	37	17.0
Papulopustular lesions	124	56.9	41	18.8	26	11.9	27	12.4
Erythema nodosum	143	65.6	30	13.8	19	8.7	26	11.9
Blood buildup in the eye	145	66.5	31	14.2	17	7.8	25	11.5
Blurred vision	139	63.8	24	11.0	20	9.2	35	16.1
Pain around the eye	165	75.7	19	8.7	14	6.4	20	9.2
Eyes getting disturbed by light	160	73.4	20	9.2	18	8.3	20	9.2
Eye floaters (black spots)	154	70.6	25	11.5	17	7.8	22	10.1
Weakening in vision	192	88.1	9	4.1	1	0.5	16	7.3
Pain in joints	82	37.6	26	11.9	54	24.8	56	25.7
Swollen joints	140	64.2	16	7.3	30	13.8	32	14.7
Redness in joints	151	69.3	15	6.9	22	10.1	30	13.8
Limitation in movements	110	50.5	17	7.8	42	19.3	49	22.5
Headache	156	71.6	16	7.3	17	7.8	29	13.3
Neck pain	199	91.3	6	2.8	7	3.2	6	2.8
Reduction in/loss of senses	214	98.2	1	0.5	0	0	3	1.4
Numbness in arms or legs	172	78.9	12	5.5	26	11.9	8	3.7
Feeling weak	127	58.3	19	8.7	38	17.4	34	15.6
Difficulty balancing oneself	173	79.4	18	8.3	20	9.2	7	3.2
Difficulty with speech	199	91.3	8	3.7	6	2.8	5	2.3
Forgetfulness	153	70.2	20	9.2	24	11.0	21	9.6
Pain in the chest	196	89.9	12	5.5	6	2.8	4	1.8
Persistent cough	198	90.8	15	6.9	3	1.4	2	0.9
Pink or red phlegm	203	93.1	11	5.0	3	1.4	1	0.5
Sore throat	214	98.2	4	1.8	0	0	0	0
Nausea and vomiting	206	94.5	7	3.2	3	1.4	2	0.9
Bloody diarrhea	211	96.8	5	2.3	1	0.5	1	0.5
Tummy ache	201	92.2	6	2.8	10	4.6	1	0.5
Uneasiness	94	43.1	34	15.6	31	14.2	59	27.1
Widespread pain	189	86.7	9	4.1	2	0.9	18	8.3

permeability of intestinal mucosa, thereby activating BD (41). According to the report of Canpolat and Yurtsever, 56.4% of patients with BD believed that their disease was associated with stress. However, 23.4% of the patients in the same study thought that the attack periods of their disease were not associated with stress (11). There are also studies suggesting that situational factors may cause stress in some BD patients, thereby influencing BD symptoms (8,11,14,25,40). In the first part of the scale, we tried to combine situations influenced by symptoms in the

Table 7. The rates of explaining the total variance for the items and factors in "the factors influencing the symptoms" section.

Initial eigenvalues				Extraction sums of squared loadings			Rotation sums of squared loadings		
	Total	Variance %	Aggregate %	Total	Variance %	Aggregate %	Total	Variance %	Aggregate %
1	7.766	35.298	35.298	7.766	35.298	35.298	7.766	35.298	35.298
2	3.164	14.383	49.681	3.164	14.383	49.681	3.164	14.383	49.681
3	2.099	9.542	59.223	2.099	9.542	59.223	2.099	9.542	59.223
4	1.453	6.603	65.826	1.453	6.603	65.826	1.453	6.603	65.826
5	1.094	4.973	70.799	1.094	4.973	70.799	1.094	4.973	70.799
6	0.879	3.996	74.795						
7	0.769	3.495	78.291						
8	0.687	3.123	81.414						
9	0.593	2.695	84.109						
10	0.497	2.257	86.366						
11	0.444	2.017	88.383						
12	0.420	1.908	90.291						
13	0.394	1.793	92.084						
14	0.331	1.504	93.587						
15	0.290	1.317	94.904						
16	0.260	10.184	96.088						
17	0.244	1.111	97.199						
18	0.213	0.970	98.168						
19	0.165	0.748	98.916						
20	0.110	0.501	99.417						
21	0.084	0.382	99.799						
22	0.044	0.201	100.000						

literature and the results of studies related to theory in the literature.

4.2. Situations influenced by symptoms of Behçet's disease

The second section of the Behçet's Disease Symptom Assessment Scale was divided into 3 subsections: functional status, cognitive functions, and physical performance. This section of the scale may be used in clinical or research settings to measure situations influenced by BD symptoms. BD is chronic and involves multiple systems. Clinical findings have shown that BD has negative influences on patients' quality of life. Hence, we want to measure their performance. According to the literature, it causes nutritional problems due to recurrent and painful oral ulcers, and it disrupts sexual activity with genital ulcers and negative body image. At the same time, ocular involvement and loss of vision result in significant morbidity and workforce loss, while articular involvement causes pain, limited movement, and workforce loss, all of which have a negative impact on patients' quality of life (11). Yurtman Havlucu et al. found that patients with systemic involvement had lower scores in physical roles, social function, emotional roles, and mental health compared to patients who had cutaneous and mucosal involvement (oral and genital ulcers) (42). Uğuz et al. found that all of the scores in the SCL-90-R subscales, Beck Depression Scales, and Beck Anxiety Scale were significantly higher in a group of patients with BD compared to the control group (43). Kılınç et al. reported that Beck Depression Scale scores in BD were significantly correlated with the total scores of Dermatological Quality of Life Scale (DQLS) and its subdimensions (social life,

Table 8. The analysis of the items in "the factors influencing the symptoms" section.

Items	Item total score correlation coefficient		
	R	t	P
Item 1	0.41	5.73	0.0001
Item 2	0.80	12.71	0.0001
Item 3	0.52	7.53	0.0001
Item 4	0.33	4.56	0.0001
Item 5	0.77	12.20	0.0001
Item 6	0.61	9.14	0.0001
Item 7	0.41	5.81	0.0001
Item 8	0.93	17.97	0.0001
Item 9	0.96	19.25	0.0001
Item 10	0.97	19.67	0.0001
Item 11	0.96	19.08	0.0001
Item 12	0.37	5.63	0.0001
Item 13	0.47	7.19	0.0001
Item 14	0.24	3.48	0.0001
Item 15	0.81	13.92	0.0001
Item 16	0.87	15.40	0.0001
Item 17	0.77	12.84	0.0001
Item 18	0.73	11.99	0.0001
Item 19	0.29	4.18	0.0001
Item 20	0.52	7.89	0.0001
Item 21	0.18	2.58	0.0001
Item 22	0.37	5.63	0.0001

emotional life, daily activities, cognitive functions, and sexual life) (40). These authors also detected a statistically significant positive correlation between Beck Anxiety Scale scores and total DQLS scores, as well as emotional life, cognitive functions, and sexual life scores. Kılınç et al. also reported that total DQLS scores of BD patients were influenced by oral aphtha, genital ulcer, and erythema nodosum-like lesions (ENLLs); social life scores by ENLLs; emotional life scores by oral aphtha and genital ulcers; daily activities and symptoms scores by genital ulcers and ENLLs; and, finally, sexual life scores by genital ulcers, ENLLs, and GI ulcers (40). Canpolat and Yurtsever found that the average scores for the subscales of the SF-36 Quality of Life Scale (physical function, social function, physical role limitation, emotional role limitation, mental health, fitness/fatigue, pain, and general understanding of health) were higher for patients experiencing no pain compared to patients with pain (11). In the same study, 59.5% and 69.1% of the patients reported that pain and fatigue negatively affected their lives, respectively. The authors also reported that 31.9% of patients had sleep problems, and that patients with sleep problems had lower scores for social function and mental health (11). Özdemir et al. reported that sexual life was negatively affected by the disease in 38.5% of patients with BD; these patients remarked that they had problems such as reduced sexual activity (86.5%), painful sexual intercourse (48.6%), and lack of sexual drive (24.3%) (44). In a study conducted by Bernabe et al., pain and discomfort were reported in 87%, disruption of usual activities in 75%, and restricted mobility in 65% of patients with BD. In the same study, anxiety and depression were reported to be serious

Table 9. The rates of explaining the variance for the items and factors in "the situations influenced by the symptoms" section.

Initial eigenvalues				Extraction sums of squared loadings			Rotation sums of squared loadings		
Components	Total	Variance %	Aggregate %	Total	Variance %	Aggregate %	Total	Variance %	Aggregate %
1	8.843	44.215	44.215	8.843	44.215	44.215	6.667	33.337	33.337
2	2.788	13.939	58.154	2.788	13.939	58.154	3.647	18.235	51.572
3	1.383	6.916	65.070	1.383	6.916	65.070	2.069	10.344	61.916
4	1.094	5.468	70.538	1.094	5.468	70.538	1.724	8.622	70.538
5	0.886	4.429	74.967						
6	0.820	4.102	79.069						
7	0.691	3.455	82.524						
8	0.685	3.427	85.951						
9	0.558	2.790	88.742						
10	0.463	2.313	91.054						
11	0.379	1.896	92.951						
12	0.328	1.641	94.591						
13	0.308	1.539	96.130						
14	0.227	1.136	97.265						
15	0.188	0.938	98.203						
16	0.111	0.557	98.760						
17	0.096	0.480	99.241						
18	0.080	0.399	99.640						
19	0.037	0.185	99.825						
20	0.035	0.175	100.000						

problems for 60% of the patients (8). Yurtman Havlucu et al. found that both the anxiety and depression scores of the patient group were higher than those of healthy individuals (42). Ertam et al. conducted a study using the SF-36 Quality of Life Scale and found that the quality of life of female BD patients was low (14). Onal et al. carried out a study of BD patients with ocular involvement using the SF-36 Quality of Life Scale and underlined female patients' role limitations due to emotional problems (25). On the other hand, Bodur et al. did not observe any effects of sex on quality of life other than the subcategory of pain using the Nottingham Health Profile Scale (45). Illness perception is a cognitive representation of illness (46,47). BD's clinical findings have negative effects on patients' quality of life by causing repetitive and painful oral ulcers, nutrition problems, genital aphthous ulcers, sexual dysfunction/unhappiness/dissatisfaction, and poor body image (11,40). Eye involvement and loss of sight in BD have negative effects on quality of life by causing significant morbidity and inability to work. Joint involvement causes pain, mobility limitations, and inability to work (11,13). Therefore, BD also affects patients economically (13). In addition, psychosomatic illnesses and various psychiatric symptoms such as anxiety and depression that occur in BD reduce quality of life and increase inability to work (48). Kılınç et al. found that patients with BD were unable to maintain daily life activities due to the pain related to various symptoms, which may reduce their quality of life due to serious effects on their physical, social, and psychological functions (11,40). Bernabe et al. determined that usual activities (75%), mobility (65%), and self-care (65%) were the most commonly affected (8). Gilworth et al. found that 81% of patients with BD reported that they did not have enough energy to maintain daily life activities (15). These findings also demonstrated and confirmed that the symptoms of BD influence the lives of individuals

Table 10. The analysis of the items in "the situations influenced by the symptoms" section.

Items	Item total score correlation coefficient		
	R	t	P
Item 1	0.26	3.86	0.0001
Item 2	0.35	5.34	0.0001
Item 3	0.21	3.14	0.0001
Item 4	0.31	4.61	0.0001
Item 5	0.58	9.30	0.0001
Item 6	0.42	6.48	0.0001
Item 7	0.80	14.07	0.0001
Item 8	0.86	15.84	0.0001
Item 9	0.87	16.18	0.0001
Item 10	0.96	19.08	0.0001
Item 11	0.96	19.08	0.0001
Item 12	0.92	17.78	0.0001
Item 13	0.87	16.29	0.0001
Item 14	0.78	13.89	0.0001
Item 15	0.35	5.29	0.0001
Item 16	0.42	6.46	0.0001
Item 17	0.41	6.21	0.0001
Item 18	0.42	6.36	0.0001
Item 19	0.40	6.05	0.0001
Item 20	0.29	4.33	0.0001

Table 11. Data related to the scoring of the scale.

	Number of items	Minimum score	Maximum score	Low score limit (bottom 27%)	Medium score limit (middle 46%)	High score limit (top 27%)
Factors influencing Behçet's disease	20	20	200	0–64	65–127	128–200
Physiological factors	7	7	70	0–26	27–43	44–70
Psychological factors	7	7	70	0–10	11–55	56–70
Situational factors	6	6	60	0–9	10–39	40–70
Situations influenced by the symptoms of Behçet's disease	20	20	200	0–44	45–126	127–200
Functional status	6	6	60	0–17	18–34	35–60
Cognitive functions	8	8	80	0–10	11–62	63–80
Physical performance	6	6	60	0–10	11–42	43–60

Table 12. Correlations of scale subscales.

		Functional status	Cognitive functions	Physical performance	Situations influenced by the symptoms of Behçet's disease
Physiological factors	r	0.392	0.253	0.306	0.363
	p	0.000	0.000	0.000	0.000
Psychological factors	r	0.457	0.537	0.291	0.537
	p	0.000	0.000	0.000	0.000
Situational factors	r	0.523	0.477	0.358	0.545
	p	0.000	0.000	0.000	0.000
Factors influencing Behçet's disease	r	0.543	0.511	0.375	0.576
	p	0.000	0.000	0.000	0.000

negatively, while the symptoms are in turn influenced by this negative situation, bringing about the need for symptom management. Because of these problems recorded in the literature, in the second part of the scale, we tried to determine how the symptoms affected the patients' lives.

In conclusion, this study developed a novel symptom assessment scale for BD based on the TOUS. It should be pointed out that this scale is the first scale developed to assess the symptoms of BD. The study proved that this scale is a valid and reliable tool for evaluating patients with BD. In other words, this study demonstrated that the scale was adequate for assessing both the factors influencing BD symptoms and the situations influenced by BD symptoms. The research was limited to patients monitored by the Ege University Medical Faculty Hospital Rheumatology Outpatient Clinic. This scale should be used in similar studies to refine the factors influencing symptoms and the situations influenced by symptoms, as well as associating the TOUS with BD and obtaining scientific evidence with larger samples.

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Appendix. Behçet's Disease Symptom Assessment Scale.

Section I: Factors influencing the symptoms

What are the conditions that you think have an increasing effect on the frequency, severity, and distress of your symptoms?

***Please fill in the below questionnaire by ranking the factors between **0 (no effect)** and **10 (strong effect)**.

0 = no effect

10 = strong effect

	No effect (0)										**Strong effect (10)**
	0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Physiological factors											
1-Current or acute diseases Please give an example:											
2-Activity											
3-Drug use Please give an example:											
4-Cigarettes											
5-Nutrition											
6-Exercise											
7- Fatigue											
Psychological factors											
1-Anxiety											
2-Fear											
3-Anger											
4-Depression											
5-Stress											
6-Social support (family, friends, associations, or organizations)											
7-Disease-related association membership											
Situational factors											
1-Physical environment (i.e. home conditions)											
2-Business life											
3-Medical history											
4-Access to information about the disease											
5-Obstacles to access to health care services											
6-Economic conditions											

Section II: Situations influenced by the symptoms

How do the symptoms affect your performance?

***Please fill in the below questionnaire by ranking the factors between **0 (no prevention)** and **10 (completely prevented)**.

0 = no prevention

10 = completely prevented

	No prevention (0)										**Completely prevented (10)**
	0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Functional status											
1-Management of roles within the family											
2-Work performance											
3-School performance											
4- Friend relationships											
5- Social support											
6-Economic conditions											
Cognitive functions											
1- Perception status											
2-Learning status											
3- Concentration and memory											
4-Problem solving status											
5- Status of coping											
6-Emotion status											
7- Enjoying life											
8- Sleeping status (e.g., difficulty in falling asleep, falling asleep)											
Physical performance											
1-Energy level											
2-Daily activities (e.g., bathing, eating)											
3- Personal care											
4- Housekeeping											
5- Sexual activity											
6- Leisure activities											