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Research Article

The Quality of Life in Patients With Behçet's Disease

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SUMMARY

Purpose: This study aims to evaluate the quality of life (QoL) in patients with Behçet's disease.
Methods: This study is a cross-sectional descriptive study. The sample of the study consists of 94 volunteer patients, who were diagnosed with Behçet's disease at least 3 months before the study, were literate, and never diagnosed with a psychiatric illness. Short Form-36 QoL Scale and personal information form were used to collect data. The mean, percentage distribution of the sample were calculated; one-way analysis of variance, student *t* test, Mann-Whitney *U*, Kruskal Wallis, Shapiro-Wilk tests were used to evaluate the data.
Results: It was found that QoL scores in patients with Behçet's disease were low and wasaffected by gender, age, work status, education status as well as complaints of oral and genital ulcerations, arthritis, skin lesions and bodily pain. Patients who were suffering from bodily pain, sleeplessness and fatigue were found to score lower in the QoL scale. Moreover, patients who states that their social relationships are affected by the disease had significantly lower QoL scores.
Conclusion: The need for evaluating the patients holistically and of the planning of their care were highlighted.

Introduction

Rheumatologic diseases are common in Turkey and all around the world. In the United States, one in every seven patients visit primary health institutions for a problem related to the musculoskeletal system. Most rheumatologic diseases are chronic and result in loss of labor power. They could also be life-threatening in certain cases (Soy, Üstü, & Dinç, 2000). The mortality rate of rheumatologic diseases in general population is 0.02% (West, 2005 pp. 1–3).

Behçet's disease is one of the rheumatologic diseases related to vasculitis (West, 2005 pp. 1–3). It was first defined by a Turkish doctor called Hulusi Behçet in 1937 as a systemic disease that involves recurring attacks over a long period of time without a known etiology. The disease is relatively more common in Mediterranean countries such as Turkey, Israel, Greece, Cyprus; Middle Eastern countries such as Iraq and Iran as well as Far Eastern countries such as Japan, Korea, China (Alpsoy, 2007; Önder & Gürer, 2001). The fact that this disease is more common in the above mentioned countries, all of which are on the Silk Road, suggests that certain genetic and/or environmental factors play an important role in its development. Among these countries, the disease is most prevalent in Turkey (Alpsoy). It is also prevalent in Japan in east Asia. While the prevalence of Behçet's disease in Japan is 7–8.5/100,000, it is only 0.3/100,000 and 0.6/100,000 in the US and England respectively (Önder & Gürer, 1999; Yurdakul, Tüzün, Mat, Özyazgan, & Yazıcı, 1994, pp. 393–399; Yurdakul & Yazıcı, 2008). In Turkey, the prevalence of Behçet's disease in adults was found to be 80/100,000 and 370/100,000 in two different regional studies conducted by Tüzün et al. (1996). A study conducted by Azizlerli et al. (2003) found that prevalence of Behçet's disease was 42 per 10,000 in the Turkish population. The prevalence of the disease in Turkey is higher in the rural areas (Önder & Gürer, 2001).

In Turkey, it has been shown that the disease starts in early ages (in third decade) and in male it has more severe effects (Yurdakul, Hamuryudan & Yazıcı, 2004). In Korea also it has more severe effects in male (Bang, Oh, Lee, & Lee, 2003). The man to woman ratio in Turkey was calculated to be 5.2 by Atmaca, İdil, and Batıoğlu (1996), 3.16 by Özdal, Ortac, Taşkıntuna, and Fırat (2002) and 1.03 by Ankara University Behçet Center (Tursen, Gürler, & Boyvat, 2003). The mean age at onset is between 20 and 30. The disease is less prevalent in children and seniors (Atmaca & Sönmez, 2004).

In addition to certain symptoms on the skin and mucosa where the pathology is primarily vasculitis, the disease could also involve ocular, articular, vascular, pulmonary, gastrointestinal, urogenital, cardiac and nervous systems (Alpsoy, 2007; Seyahi, 2007). Patients

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with Behçet's disease generally suffer from weight loss, malaise and fatigue over the course of the disease. Erythema nodosum, pustular rashes and involvement characterized by pseudofolliculitis are also common. Oligo-arthropathy can be seen in big joints such as knee, elbow or shoulder (Seyahi).

Common symptoms of the disease include oral and genital ulcers, skin lesions and arthritis, which might be accompanied by ocular and vascular involvements (Gilworth et al., 2004). These symptoms not only affect the physical and mental health of patients negatively, but they also diminish their quality of life (QoL) by causing several physical impairments (Uğuz, Dursun, Kaya, & Çilli, 2006).

Chronic rheumatologic problems in patients with Behçet's disease are reported to limit their daily activities and have a negative impact on their self-esteem and relationships with others. It was also found that painful oral ulcers impede alimentation and speech as well as negatively affect the body image of the patients (Gilworth et al., 2004).

All these problems related to Behçet's disease negatively affect the biopsychological and social life of the patients and reduce their QoL (Bodur, Borman, Özdemir, Atan, & Kural, 2006). QoL is a concept that encompasses being able to satisfy one's own basic needs, being satisfied with life, showing an adequate level of social interaction, allocating time to fun, feeling good emotionally and physically, being good at interpersonal relationships, having self-esteem as well as previous experiences. Previous studies have shown that QoL in patients with Behçet disease was negatively affected by the disease (Bernabe, Marcenes, Mather, Phillips, & Fortune, 2010; Bodur, Borman, Özdemir, Atan, & Kural, 2006; Ertam et al., 2009; Gür, Saraç, Burkan, Nas, & Çevik, 2006; Moses, Fisher, & Yazıcı, 2008; Mumcu et al., 2006; Tanrıverdi et al., 2003; Uğuz, Dursun, Kaya, & Çilli, 2006, 2007). Most previous studies have shown the impact of a symptom on Behçet disease patients' QoL. Evaluations of QoL could assist in developing care plans that ensure a better understanding of the behaviors and the psychological reactions of the patients as well as the difficulties they experience with adjusting to the disease and developing effective coping mechanisms (Acaray & Pınar, 2004). Complaints associated with Behçet's disease deteriorate the physical and mental health of the patients on the one hand, and reduces QoL by generating certain physical impairments on the other (Uğuz, Dursun, Kaya, & Çilli, 2006). It could be also said that assessing QoL in patients with Behçet's disease could also assist in developing more comprehensive nursing care plans. The importance of patients being evaluated by a holistic approach will be revealed.

As mentioned above, in previous studies the parameters that may affect Behçet disease patients' QoL focused on only one symptom. However, Behçet's disease may negatively affect patients physically, mentally and socially and may decrease their QoL significantly.

This study was conducted for the purpose of evaluating QoL in Behçet's disease patients. The objectives of our study are as follows: (a) Evaluating the association between QoL and sociodemographic characteristics (age, gender, education level, working status); (b) evaluating the association between QoL and disease characteristics (disease duration, oral ulcer, genital ulcer etc.); (c) evaluating the association between QoL and experiencing symptoms (bodily pain, sleep problems, fatigue symptoms) and affected daily lives; (d) evaluating the association between QoL and social relationship affected by the Behçet disease.

Methods

This cross-sectional descriptive study was performed in the rheumatology outpatient unit of an educational and research hospital in Turkey. The study was approved by the Ethics Committee of the institution where it was conducted. Over the course of the study, a total of 102 patients with Behçet's disease visited the rheumatology outpatient unit from January 22 to May 14, 2009. Among the volunteering patients, those who conformed to all of the following criteria were included in the study: having been diagnosed at least 3 months before their last visit, having never been diagnosed with a psychiatric disease and being literate. Eight patients in total were not included in the study. Among the eight patients excluded from this research, five of them had received their diagnosis less than 3 months ago at the time of the study; the diagnosis of the two were still in progress; and one of them was suffering from a neurological involvement.

The data were collected using the personal information form, which consisted of descriptive info about the patients and "Short Form-36 Quality of Life Scale" (SF-36 QoL Scale), which was used to evaluate their QoL. The personal information form was designed as a document consisting of 38 questions about the patients' sociodemographical background and characteristics of their disease. Ten of these questions were about sociodemographical backgrounds (age, gender, working status, education level, marital status etc.), while 28 of them were aimed at addressing the factors (disease duration, system involvements, symptoms etc.) that determine the QoL in these patients. While all of the questions that aim at determining sociodemographic characteristics were multiple-choice., 16 of the other questions were multiple choice, and 12 were open ended. The personal information form was created by searching the literature. The characteristics of Behçet's disease were determined based on the literature (e.g. oral ulcer, genital ulcer, arthritis; Alpsoy, 2003; Atmaca & Sönmez, 2004; Azizlerli, 1997; Blackford, Finlay, & Roberts, 1997; Karaoğlan, 2008; Kılınç, Yıldırım, & Ceyhan, 2009; Korkmaz, 2005).

The SF-36 QoL Scale was used to evaluate the QoL in patients diagnosed with Behçet's disease. The scale, which was first developed by Ware, consists of the following 8 subcategories: (a) Physical Functioning (10 items), (b) Social Functioning (2 items), (c) Role Physical (4 items), (d) Role Emotional (3 items), (e) Mental Health (5 items), (f) Vitality (4 items), (g) Bodily Pain (2 items), (h) General Health (5 items). The scale was evaluated taking the last 4 weeks into account. All items except the third and fourth were rated on a Likert scale. The third and fourth items were yes or no questions. The scores assigned to each category ranged from 0 to 100, where 0 and 100 stood for the lowest and highest QoL respectively. This scale was first translated into Turkish and tested for validity and reliability by Pınar (1996) in Turkey. The validity and reliability of SF-36 scale have been tested for various illnesses. The Cronbach's alpha coefficients of SF-36 scale were found to be between .73 and .76 in a study conducted by Koçyiğit, Aydemir, Ölmez, and Memiş (1999) that evaluateed the validity and reliability of the Turkish version of the scale . In the present study, the Cronbach's alpha for the subscales of SF-36 QoL Scale were found to be between .77 and .92.

In order to test the efficacy of the data collection forms, 10 patients who were previously diagnosed with Behçet's disease were included in a prestudy test after their visit to the rheumatology outpatient unit for a control examination. A question that was not clear enough in the first version was rewritten; the final draft for the form was completed after this prestudy test. After taking permissions from the institution where the study would be conducted, data were collected between January 22 and May 14 2009. A written consent was obtained from the participating patients who were informed of the aim and method of the study. They were also told that they can withdraw from the study anytime they want, and that all personal information will be kept confidential. Data were collected by interviewing the patients on

a one-on-one basis in a private room. All the interviews were held this way to make the patients feel more comfortable while answering the questions. It took 10–15 minutes and 15–20 minutes on average for the patients to answer the questions in the personal information form and SF-36 QoL Scale respectively. The data on the symptoms of individual patients were accessed from personal medical records.

The statistical analysis of the data was performed using SPSS13.0 for Windows (SPSS Inc., Chicago, IL, USA). The mean, standard deviation, median, percentage distribution of the sample was calculated. The Shapiro-Wilk test was used in order to evaluate the normal distribution of parameters. The distribution of the SF-36 QoL Scale scores was evaluated with the Shapiro-Wilk test, which demonstrated that physical function, social function, physical role, vitality/fatigue, pain, and general health subscales scores presented normal distribution, and parametric tests were utilized in the statistical analysis. The Student *t* test of the difference between the two mean scores was used in the statistical evaluation of the physical function, social function, physical role, vitality/fatigue, pain, and general health subscales scores with two-category classification; analysis of variancewas used in the evaluation with more than two categories. For the statistical analysis of the role emotional and mental health subscales scores, which do not present normal statistical distribution, the Mann-Whitney *U* test used for measuring two-category classifications and the Kruskal-Wallis test utilized for those with more than two categories. Significance level was chosen as .05 for all tests.

Results

Patients QoL scores

The patients' QoL scores were found to be low. The means and standard deviations for the SF-36 QoL subscales were calculated as follows: physical functioning (63.82 ± 23.23), social functioning (66.19 ± 26.31), role-physical (32.97 ± 42.63), role-emotional (33.33 ± 40.60), mental health (51.65 ± 13.76), vitality (35.15 ± 21.21), bodily pain (51.18 ± 24.93) and general health (44.29 ± 21.47).

Sociodemographic characteristics and QOL scores

The number of male and female participants was the same. Men had a higher mean role-physical score than women did ($p < .05$; Table 1). Of all the participating patients 25.5% were between 20 and 30 years of age, while 32% were 42 or older. Patients over 42 years of age had a higher mean general health score than other age groups ($p < .01$; Table 1).

Of all the participating patients, 21.2% were primary school graduates; 46.8%, high school graduates; and 32%, university graduates. University graduates had a higher mean mental health score than the other groups, while primary school graduates had the lowest score ($p < .05$). The mean vitality score was higher for university graduates ($p < .05$; Table 1). Of all participants, 37.2% were housewives, and 31.9% were civil servants. Participants that were retired had higher mean bodily pain scores than the other groups ($p < .01$; Table 1).

Disease characteristics and QoL scores

Of all the participants, 42.6% had Behçet's disease for at least 7 years; 80.9% of the patients had oral ulcers. Patients with oral ulcers were found to have lower mean vitality, bodily pain and general health scores than the ones who had no oral ulcers (Table 2). Of all patients, 33% had genital ulcers. Patients with genital ulcers had lower mean role-emotional scores than thosewho had no genital ulcers ($p < .05$). Of all patients, 33% patients had arthritis. Those who had arthritis had higher mean physical functioning, role-physical, role-emotional, vitality and bodily pain scores than those who did not (Table 2). Of all patients, 32% of the patients had skin lesions. Those who had skin lesions had lower mean physical functioning and social functioning scores than those who did not ($p < .05$). Mean bodily pain and general health scores were higher in patients who had skin lesions than the ones who did not ($p < .05$;

Table 1
Sociodemographic Characteristics and Short Form-36 Quality of Life Scores (SF-36 QoL).

Sociodemographic characteristics	*n*	%	SF-36 QoL subscales *M* ± *SD*							
			Physical function	Social function	Role physical	Role emotional	Mental health	Vitality/fatigue	Pain	General health
Gender										
Female	47	50	60.10 ± 24.43	65.01 ± 26.71	24.46 ± 40.87	30.49 ± 41.01	50.12 ± 14.22	30.95 ± 19.41	49.64 ± 23.38	42.53 ± 20.56
Male	47	50	67.55 ± 27.59	67.37 ± 26.15	41.48 ± 43.07	36.17 ± 40.42	53.19 ± 13.26	39.36 ± 22.30	52.71 ± 26.56	46.06 ± 22.43
p			.121[a]	.617[a]	.022[a]	.370[b]	.283[b]	.075[a]	.789[a]	.428[a]
Age (yr)										
20–30	24	25.5	65.62 ± 21.68	65.27 ± 31.30	31.25 ± 40.54	34.72 ± 42.25	50.00 ± 16.25	34.58 ± 23.12	49.07 ± 26.39	42.33 ± 21.59
31–41	40	43.5	65.12 ± 21.85	60.00 ± 24.75	27.50 ± 40.35	27.50 ± 39.86	53.10 ± 13.46	35.50 ± 19.57	47.50 ± 22.22	38.17 ± 16.48
≥42	30	32	60.66 ± 26.48	75.18 ± 21.96	41.66 ± 47.03	40.00 ± 40.49	51.06 ± 12.19	35.16 ± 22.45	57.77 ± 26.64	54.03 ± 24.31
p			.667[c]	.055[c]	.382[c]	.440[d]	.661[d]	.986[c]	.209[c]	.007[c]
Education level										
Primary school	20	21.2	57.75 ± 25.77	72.22 ± 21.77	23.75 ± 40.93	33.33 ± 44.59	48.80 ± 13.27	28.80 ± 16.73	56.11 ± 24.57	47.70 ± 22.01
Secondary school	44	46.8	61.59 ± 22.53	60.60 ± 27.57	32.38 ± 42.65	26.51 ± 38.43	49.45 ± 14.07	32.04 ± 21.05	46.21 ± 26.24	42.00 ± 19.40
University	30	32	71.16 ± 21.32	70.37 ± 26.31	40.00 ± 43.84	43.33 ± 40.25	56.80 ± 12.57	44.50 ± 21.50	55.18 ± 22.50	45.40 ± 24.20
p			.091[c]	.151[c]	.419[c]	.218[d]	.044[d]	.010[c]	.193[c]	.586[c]
Working status										
Housewife	35	37.2	59.71 ± 24.55	67.93 ± 24.81	25.71 ± 43.08	28.57 ± 41.33	51.31±14.24	30.85 ± 20.16	50.15 ± 25.75	45.20 ± 20.87
Civil servant	30	31.9	69.16 ± 20.68	62.22 ± 28.67	36.66 ± 43.41	33.33 ± 40.11	53.06 ± 14.36	40.83 ± 22.44	51.48 ± 24.49	40.06 ± 21.19
Worker	3	3.2	55.00 ± 25.98	51.85 ± 27.96	25.00 ± 25.00	22.22 ± 38.49	37.33 ± 9.23	20.00 ± 5.00	55.55 ± 19.24	34.00 ± 12.76
Retired	9	9.6	68.88 ± 22.74	81.48 ± 22.90	69.44 ± 42.89	66.66 ± 37.26	58.66 ± 4.00	48.33 ± 20.31	77.77 ± 17.56	66.00 ± 22.17
Self-employed	8	8.5	56.87 ± 20.16	62.50 ± 26.51	28.12 ± 36.44	33.33 ± 39.84	48.50 ± 16.89	26.87 ± 17.10	34.72 ± 18.24	38.87 ± 19.33
Others	9	9.6	66.11 ± 28.80	65.43 ± 27.46	19.44 ± 34.86	22.22 ± 37.26	48.88 ± 12.12	32.22 ± 21.08	40.74 ± 18.42	41.44 ± 18.54
p			.510[c]	.483[c]	.127[c]	.144[d]	.244[d]	.071[c]	.006[c]	.059[c]

[a] *t* test; [b] Mann-Whitney *U* test; [c] analysis of variance; [d] Kruskal-Wallis test.

Table 2
Disease Characteristics and Short Form–36 Quality of Life Scores (SF-36 QoL).

Disease characteristics	*n*	%	SF-36 QoL subscales $M \pm SD$							
			Physical function	Social function	Role physical	Role emotional	Mental health	Vitality/fatigue	Pain	General health
Disease duration										
3–12 mo	7	7.4	74.28 ± 20.70	66.66 ± 22.22	35.71 ± 45.31	33.33 ± 47.14	50.28 ± 14.20	33.57 ± 20.14	63.49 ± 21.95	36.57 ± 19.19
1–3 yr	21	22.3	62.85 ± 21.12	63.49 ± 32.03	29.76 ± 41.54	33.33 ± 39.44	47.04 ± 16.04	30.00 ± 24.34	46.03 ± 26.36	42.38 ± 18.57
4–6 yr	26	27.7	65.38 ± 23.27	60.68 ± 24.59	30.76 ± 42.01	29.48 ± 35.68	50.15 ± 12.30	35.76 ± 18.79	51.70 ± 21.76	42.03 ± 22.96
≥ 7 yr	40	42.6	61.50 ± 24.86	71.11 ± 24.75	32.62 ± 44.53	35.83 ± 44.26	55.30 ± 12.83	37.75 ± 21.42	51.38 ± 26.59	48.12 ± 22.30
p			.585[c]	.436[c]	.948[c]	.945[d]	.135[d]	.601[c]	.461[c]	.458[c]
Oral ulcer										
Yes	76	80.9	62.89 ± 23.05	65.49 ± 26.57	32.23 ± 42.78	32.45 ± 39.99	50.68 ± 13.78	32.17 ± 20.17	48.24 ± 24.38	41.82 ± 20.37
No	18	19.1	67.77 ± 24.26	69.13 ± 25.72	36.11 ± 43.06	37.03 ± 44.11	55.77 ± 13.26	47.77 ± 21.43	65.58 ± 24.04	54.72 ± 23.44
p			.426[a]	.601[a]	.731[a]	.669[b]	.159[b]	.004[a]	.018[a]	.021[a]
Genital ulcer										
Yes	31	33.0	58.38 ± 20.30	64.87 ± 27.23	21.77 ± 37.49	21.50 ± 35.01	47.74 ± 14.04	30.00 ± 21.05	44.80 ± 24.92	42.16 ± 16.93
No	63	67.0	66.50 ± 24.25	66.84 ± 26.05	38.49 ± 44.18	39.15 ± 42.13	53.58 ± 13.31	37.69 ± 20.99	54.32 ± 24.53	45.34 ± 23.44
p			.112[a]	.735[a]	.060[a]	.035[b]	.052[b]	.098[a]	.082[a]	.454[a]
Eye involvement										
Yes	29	30.9	68.79 ± 24.98	69.34 ± 25.99	38.79 ± 43.60	40.22 ± 43.98	54.62 ± 12.92	40.68 ± 20.64	55.55 ± 26.39	46.62 ± 19.01
No	65	69.1	61.61 ± 22.25	64.78 ± 26.53	30.38 ± 42.27	30.25 ± 38.96	50.33 ± 14.01	32.69 ± 21.15	49.23 ± 24.21	43.26 ± 22.55
p			.168[a]	.441[a]	.380[a]	.274[b]	.165[b]	.092[a]	.258[a]	.487[a]
Arthritis										
Yes	31	33.0	53.54 ± 21.14	60.21 ± 30.05	12.09 ± 30.18	21.50 ± 36.05	48.25 ± 14.67	26.77 ± 21.03	40.86 ± 21.15	40.09 ± 21.63
No	63	67.0	68.88 ± 22.69	69.13 ± 23.98	43.25 ± 44.26	39.15 ± 41.71	53.33 ± 13.09	39.28 ± 20.21	56.26 ± 25.23	46.36 ± 21.26
p			.002[a]	.156[a]	< .001[a]	.038[b]	.093[b]	.007[a]	.004[a]	.185[a]
Skin lesion										
Yes	50	53.2	58.60 ± 23.25	60.22 ± 26.85	27.50 ± 39.84	27.33 ± 37.30	50.88 ± 13.32	31.50 ± 19.22	44.88 ± 21.17	38.86 ± 18.04
No	44	46.8	69.77 ± 21.99	72.97 ± 24.24	39.20 ± 45.23	40.15 ± 43.47	52.54 ± 14.34	39.31 ± 22.78	58.33 ± 27.12	50.47 ± 23.51
p			.019[a]	.018[a]	.189[a]	.131[b]	.561[b]	.075[a]	.010[a]	.009[a]
Vascular in involvement										
Yes	15	16.0	73.00 ± 18.40	66.66 ± 24.84	40.00 ± 37.55	26.66 ± 33.80	56.80 ± 13.02	44.3 ± 3 19.89	53.33 ± 25.61	42.33 ± 21.70
No	79	84.0	62.08 ± 23.74	66.10 ± 26.74	31.64 ± 43.61	34.59 ± 41.83	50.68 ± 13.76	33.41 ± 21.13	50.77 ± 24.95	44.67 ± 21.55
p			.096[a]	.940[a]	.490[a]	.491[b]	.115[b]	.068[a]	.718[a]	.701[a]

[a] *t* test; [b] Mann-Whitney *U* test; [c] analysis of variance; [d] Kruskal-Wallis test.

$p < .01$, respectively). Of all the patients, 30.9% had ocular involvement and 16% had vascular involvement (Table 2).

Symptoms and QoL

Of all patients 75.5% stated that they often had bodily pains due to problems associated with the disease. Those who had bodily pains had lower mean in all eight subscales of the SF-36 scores than who did not (Table 3). Of all pateints, 59.6% stated that bodily pains affected their daily lives. Mean physical functioning, role-physical, role-emotional, bodily pain and general health scores were found to be lower in patients who indicated that bodily pains affected their lives than who did not (Table 3).

Of all patients, 31.9% stated that they had sleep problems. Those who had sleep problems had lower mean social functioning and mental health scores than the ones who did not ($p < .05$). Of the patients who had sleep problems, 30.9% of them stated that sleep problems affected their daily lives (Table 3).

Of all the patients 23.4% stated that they suffered from fatigue. Patients that experienced fatigue had lower mean in all eight subscales of the SF-36 scores than those who did not (Table 3); 69.1% of these patients stated that fatigue affected their daily lives. The patients who stated that fatigue affected their daily lives were found to have lower mean physical functioning, role-physical, role-emotional, vitality, bodily pain and general health scores than who did not (Table 3).

Social relationship and QoL scores

Of all the patients 23.4% stated that the disease affected their social relationships. Mean social functioning, role-emotional and general health scores were lower in patients who stated that the disease affected their relationships than who did not (Table 4).

Discussion

We found that Behçet's disease patients had low scores of QoL. Oral ulcer, genital ulcer, arthritis, skin lesion, bodily pain, sleeplessness and fatigue affected the patients' scores of QoL. Patients' social relationships are affected by the disease. Previous studies have shown that the impact of Behçet's disease on QoL (Bernabe, Marcenes, Mather, Phillips, & Fortune, 2010; Bodur, Borman, Özdemir, Atan, & Kural, 2006; Ertam et al., 2009; Gür, Saraç, Burkan, Nas, & Çevik, 2006; Moses, Fisher, & Yazıcı, 2008; Mumcu et al., 2009; Tanrıverdi et al., 2003; Uğuz et al., 2006, 2007).

In our study, we found that women's physical role subscale scores are lower than men's. Similarly, Uğuz et al. (2006) found that men score higher on physical categories. This difference between men and women could be attributed to the different gender roles socially assigned to men and women or to the physiological and hormonal differences. The fact that women are physically weaker than men, that they give birth and menstruate, that they are mothers and often do the household chores distinguish women from men and drastically affect their QoL.

We found that the patients between 31 and 41 years of age had lower mean scores especially on social functioning and general health. Patients who received their diagnosis in the third decade were mostly in their late twenties or early thirties at the time they received a diagnosis (Pamuk & Çakır, 2005). People around these ages have to assume a lot of responsibilities both in their families and in the work place. These patients have to cope with the problems associated with Behçet's disease while they are struggling to

Table 3
Symptoms and Short Form–36 Quality of Life Scores (SF-36 QoL).

Characteristics of symptoms	*n*	%	SF-36 QoL subscales *M* ± *SD*							
			Physical function	Social function	Role physical	Role emotional	Mental health	Vitality/fatigue	Pain	General health
Experiencing pain										
Yes	71	75.5	57.74 ± 21.07	61.97 ± 26.67	25.00 ± 37.55	24.88 ± 35.50	49.35 ± 12.96	29.78 ± 17.77	42.56 ± 18.68	38.76 ± 18.58
No	23	24.5	82.60 ± 19.53	79.22 ± 20.73	57.60 ± 48.52	59.42 ± 44.89	58.78 ± 13.98	51.73 ± 22.74	77.77 ± 23.21	61.39 ± 21.12
p			< 001[a]	.006[a]	.006[a]	.002[b]	.004[b]	< .001[a]	< .001[a]	< .001[a]
Bodily pains affected daily living										
Affected	54	59.6	55.17 ± 21.69	60.91 ± 26.03	21.87 ± 36.01	20.23 ± 32.83	48.71 ± 12.94	29.46 ± 18.28	39.68 ± 19.05	36.35 ± 17.47
No Affected	20	21.3	73.00 ± 16.96	68.33 ± 28.21	45.00 ± 44.12	46.66 ± 41.03	55.20 ± 13.33	38.50 ± 22.54	58.33 ± 20.03	50.95 ± 19.35
p			.001[a]	.288[a]	.044[a]	.015[b]	.060[b]	.079[a]	< .001[a]	.003[a]
Experiencing ± sleep problems										
Yes	30	31.9	58.83 ± 20.32	56.29 ± 25.75	30.00 ± 40.15	23.33 ± 35.17	47.60 ± 13.98	31.33 ± 21.49	43.70 ± 24.04	38.10 ± 19.22
No	63	67.0	66.34 ± 24.43	70.72 ± 25.65	34.92 ± 44.11	38.62 ± 42.42	53.77 ± 13.33	37.14 ± 21.13	54.49 ± 24.90	47.15 ± 22.17
p			.148[a]	.013[a]	.606[a]	.072[b]	.043[b]	.221[a]	.051[a]	.058[a]
Sleep problems affected daily living										
Affected	29	30.9	58.96 ± 20.97	56.32 ± 24.29	28.44 ± 39.93	24.13 ± 37.68	48.96 ± 13.96	31.55 ± 21.34	43.67 ± 24.65	38.00 ± 19.43
No Affected	7	7.4	57.14 ± 26.74	55.55 ± 34.54	42.85 ± 47.24	38.09 ± 35.63	49.14 ± 10.51	35.00 ± 19.14	46.03 ± 24.36	35.57 ± 22.41
p			.846[a]	.945[a]	.413[a]	.381[b]	.975[b]	.699[a]	.822[a]	.775[a]
Experiencing fatigue										
Yes	72	76.6	59.16 ± 22.51	62.03 ± 26.15	20.48 ± 35.43	25.46 ± 36.89	49.94 ± 13.64	28.81 ± 18.04	45.83 ± 21.42	39.20 ± 19.44
No	22	23.4	79.09 ± 18.93	79.79 ± 22.38	73.86 ± 38.94	59.09 ± 42.32	57.27 ± 12.91	55.90 ± 17.43	68.68 ± 27.99	60.95 ± 19.61
p			< .001[a]	.005[a]	< .001[a]	< .001[b]	.028[b]	< .001[a]	.001[a]	< .001[a]
Fatigue affected daily living										
Affected	65	69.1	57.53 ± 22.31	62.05 ± 25.29	17.30 ± 32.75	23.07 ± 35.80	49.60 ± 13.97	27.53 ± 17.92	44.78 ± 21.24	38.23 ± 18.87
No Affected	9	9.6	78.33 ± 19.03	70.37 ± 35.13	61.11 ± 46.95	59.25 ± 43.39	57.33 ± 12.32	50.00 ± 22.91	65.43 ± 27.46	55.22 ± 25.13
p			.010[a]	.382[a]	.024[a]	.007[b]	.120[b]	.001[a]	.010[a]	.018[a]

[a] *t* test; [b] Mann-Whitney *U* test.

fulfill their responsibilities at home and in the workplace. It is thought that QoL diminishes as the patients are going through such stressful periods.

A significant increase in scores was observed in QoL as the patients' level of education got higher. Level of education determines how reasonable one is in one's reactions to the events that happen around them. For the patients who are informed of the course of their disease, it is much easier to come to terms with the effects of the treatment if they approach these effects reasonably. People with a higher level of education could also have a higher income and better social status. Because of all these factors, one could say that people with a higher level of education might have higher QoL.

Patients that were retired had higher mean bodily pain scores than other groups. Self-employed patients had the lowest mean score in this category. Self-employed people are exposed to higher levels of stress in the work place and might not have enough time to rest during the periods of attack. It is thought that decrease in efficiency in the work place due to physical pain, stress, hectic schedule, lack of resting time, sadness and dejection negatively affect the quality of live of working patients.

In this study, it was observed that oral ulcers negatively affect QoL subscales. In their study, Mumcu et al. (2006) found that patients with oral ulcers had lower mean scores on physical functioning, role-physical, bodily pain and general health compared to healthy individuals. In the same study, it was concluded that the patients with an active Behçet's disease had lower mean scores on physical functioning, role-emotional, vitality compared to those who did not have the disease actively. Bodur et al. (2006) found that mean scores on physical and psychosocial categories were lower for the patients with oral ulcers. The results of the present study are in line with the results of these studies.

Recurrent aphthous ulcers, which are defined as elliptical ulcers that can appear anywhere on the oral mucosa, surrounded by erythematous on the sides and covered with a grayish yellow membrane, is a universally recognized symptom of Behçet's disease. Oral ulcers, as the most prevalent of symptom of the disease, negatively affect not only motor functions such as speaking, swallowing, and chewing (Al-Otaibi, Porter, & Poate, 2005; Pamuk & Çakır, 2005). Bodily pain is the most important symptom in patients with oral ulcers and may result in fatigue as it makes eating much harder. QoL also diminishes when one is not able to perform one's daily activities.

In this study, it was found that genital ulcers negatively affect QoL subscales. Bodur et al. (2006) concluded that patients with genital ulcers had low QoL scores. According to Kılınç et al. (2009), patients with oral ulcer, genital ulcer, lesions that looks like erythema nodosum and gastrointestinal ulcer had lower emotional

Table 4
Social Relationship and Short Form–36 Quality of Life Scores (SF-36 QoL).

Social relationship affected by the disease	*n*	%	SF-36 QoL-Subscales *M* ± *SD*							
			Physical function	Social function	Role physical	Role emotional	Mental health	Vitality/fatigue	Pain	General health *M* ± *SD*
Yes	22	23.4	58.86 ± 22.46	51.01 ± 23.17	22.72 ± 34.42	18.18 ± 32.08	52.36 ± 14.65	30.90 ± 19.61	46.46 ± 21.85	35.40 ± 14.29
No	72	76.6	65.34 ± 23.41	70.83 ± 25.59	36.11 ± 44.58	37.96 ± 41.97	51.44 ± 13.58	36.45 ± 21.64	52.62 ± 25.77	47.01 ± 22.62
p			.354[a]	.002[a]	.145[a]	.024[b]	.786[b]	.285[a]	.313[a]	.006[a]

[a] *t* test; [b] Mann-Whitney *U* test.

life, daily activity, symptom and sexual life scores. In a study that had a sample of 335 patients with Behçet's disease, Blackford et al. (1997) reported that the subcategories that were affected most were the symptoms reflecting painful oro-genital ulcers, emotions and personal relationships. The results of these studies are in line with that of the present study.

Genital ulcers, which look like holes pierced with a stapler, start with itching and are extremely painful. These ulcers appear on the penis or scrotum in men and on the vulva, labia minora and majora or cervix in women (Al-Otaibi, Porter, & Poate, 2005; Gürler, 1997). These painful ulcers might cause not only difficulty in walking and moving but also result in lower self-esteem due to the negative effect these ulcers have on the sex life of patients. Leaving scars after healing, genital ulcers also affect the body image of the patients negatively.

It was found that the QoL subscale scores went down when articular involvement was the case. In the study conducted by Bodur et al. (2006), 73% of the patients had articular involvement. Patients with articular involvement were found to have lower mean scores on physical and psychosocial categories in the QoL scale. The results of their study are parallel to the present study. Pain, swelling and movement difficulties are prominent in arthritis (Karaoğlan, 2008; Korkmaz, 2005). Articular involvement in patients with Behçet's disease causes pain, movement difficulties, and damages patients' social relationships. Patients who have difficulty fulfilling their roles and obligations due to bodily pain and movement difficulties thus suffer from reduced QoL.

In their study, Kılınç et al. (2009) suggested that the scores of patients with Behçet's disease on daily activities, symptoms and sex life were affected by lesions like erythema nodosum. Skin lesions may cause pain, difficulty in walking, edema and erythema in the surrounding tissue (Azizlerli, 1997; Seyahi, 2007). Bodily pain associated with skin lesions are thought to cause difficulties in walking as well as impairments in other bodily functions, thereby affecting QoL negatively. Ulcers that heal but leave a scar (Alpsoy, 2003; Azizlerli, 2002, pp. 441–444) could have a negative impact on the body image of patients. Skin lesions, which hurt the body image and reduce the self-esteem of patients, might also affect their social relationships negatively by imposing certain limitations.

Patients experiencing bodily pain were found to have lower scores on the QoL subscales. In their study, Mumcu et al. (2007) observed that among the patients with Behçet's disease, those who suffered from oral ulcers had lower QoL. The same results were obtained in the study conducted by Gilworth et al. (2004). In their research, Bodur et al. (2006) concluded that articular involvement reduced QoL in patients with Behçet's disease. Findings of the present study are thus in line with findings of these research.

An increase in the pain-related symptoms leads to negative emotional and cognitive processes and stimulates feelings of pessimism, sadness and desperation. Bodily pain might cause desperation and depression, and patients might reject treatment as a result. Bodily pain might also cause anxiety, fear, loss of concentration and loss of control. Emotional well-being, sexual function, physical appearance and social relationships might get damaged. Bodily pain might also hamper the patients' productivity and cause a dissatisfaction with their roles in the family and society even if the underlying disease shows a stable course. As stated above, bodily pains stemming from various symptoms in patients with Behçet's disease hinder their daily activities by imposing various limitations. These limitations have a big negative impact on the physical, social and mental functions of the patients, thereby reducing their QoL.

Patients who stated that they had sleep problems had lower mean social functioning and mental health scores. Drawing on the mean scores on items about sleep and emotions, Bodur et al. (2006) found that patients with articular involvement as well as oral and genital ulcers had a lower QoL. Sleep disorders might cause sleeplessness and fatigue during the day and prevent the patients from being as productive in handling the tasks in the workplace and in performing daily activities (Solak et al., 2009). Bodily pains associated with articular involvement and oral and genital ulcers may cause sleeplessness. Sleeplessness might hamper carrying out daily activities, thereby reducing QoL.

In their studies, Bodur et al. (2006) suggested that patients suffering from fatigue had higher mean bodily pain and physical activity scores and had lower QoL. The results of their study are similar to with the results of the present study.

Gilworth et al. (2004) noted that 81.1% of the patients with Behçet's disease think that they do not have enough energy to perform daily activities. Similar to the findings of the research conducted by Bodur et al. (2006), the present study also shows that people suffering from fatigue have a lower QoL. Because of the fatigue that stems from bodily pain and sleeplessness, patients with Behçet's disease suffer from hindered performance in daily activities, decreases in physical performance, incompetence in completing routine tasks, sadness, tension and sluggishness. These problems negatively affect the scores on physical functioning, role-physical, role-emotional, vitality, bodily pain and general health, thereby causing reduced QoL.

Of all the patients 23.4% stated that the disease affected their social relationships. These patients had lower mean scores on social functioning, role-emotional, general health than the ones who did not think that way. This finding implies that the rate of social interaction goes down over the course of the disease. Chronic patients who have positive social relationships can have a more positive approach towards the disease, thereby having a higher QoL. Bodily pain, movement difficulties, difficulties in speaking and eating might negatively affect the patients' relationships with their families and environment and might reduce their QoL. Since the number of patients that are involved in our study is limited, the study results only apply to our own group. It would be more appropriate to conduct the study on a bigger group of patients as well as those with different cultural characteristics.

Conclusion

In this study, patients showed low QoL scores. We found that the patients' sociodemographic characteristics such as age, gender, education level and work status affect QoL scores. We also found that disease characteristics such as disease duration, presence of oral ulcer, genital ulcer, arthritis and skin lesion affect QoL scores. Furthermore, we found that the symptoms that the patients experienced such as bodily pain, sleeplessness and fatigue affect the QoL scores. Patients who indicate that the disease damage their social relationships also showed lower qualtiy of life scores.

These results highlight the importance of nursing interventions in managing the symptoms experienced by patients effectively so that the limited effects of the symptoms which decrease QoL can be eliminated.

Patients with Behçet's disease should be informed and psychologically supported by nurses in the rheumatology clinic and outpatient unit during and after the treatment to help them understand the disease better, come to terms with it, continue the treatment, and cope with the symptoms. While informing the patients, their sociodemographic characteristics should be taken into consideration.

A support group should be formed for the patients with Behçet's disease to share their experiences; this group should meet in the presence of a doctor, a nurse, a psychologist and a social service specialist.

Patients should be informed of how they could cope with bodily pain. Patients should be informed of what the stimulating factors are in the etiology of recurrent oral aphthous ulcers and how they can prevent it.

Patients should be contacted individually to find a patient-specific solution to the sleeping problems that reduces their QoL. Fatigue should also be thoroughly evaluated, and a suitable set of activities should be planned for each patient.

Conflict of interest

The authors declare no conflict of interest.

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