PSYCHOSOCIAL ADJUSTMENT OF PATIENTS WITH BEHÇET'S DISEASE: THE EXAMPLE OF TURKEY•

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Abstract

Living with Behçet's Disease, the chronic disease causes serious negative effects on the patients' quality of life and adjustment due to its symptoms and disruptions in patients' physical activities. This study was conducted to evaluate the psychosocial adjustment level of the patients with Behçet disease. The population of this study consisted of all patients, diagnosed with Behçet's disease according to the International Working Group Diagnostic Criteria and registered at Behçet and Familial Mediterranean Fever Patients Association and who were above 18. It was aimed to reach all these patients and 64 patients with Behçet's Disease were included in this study. In this study, a questionnaire and Psychosocial Adjustment to Illness Scale-Self Report (PAIS-SR) were utilized in order to collect data. The mean score of the patients with Behçet's Disease-related to the sub-scales of the Psychosocial Adjustment to Illness Scale-Self Report (PAIS-SR) was found to be 57.16±11.2. This score refers that the patients had a poor disease adjustment level. According to the Psychosocial Adjustment to Illness Scale-Self Report, 48.4% of the patients had poor disease adjustment levels while 39.1% of them had moderate and 12.5% of them had good disease adjustment levels. The scores related to the sub-scales are as follows: healthcare orientation X =12.86 ±3.82; psychological distress X =9.52 ± 4.72; domestic environment X =8.56 ±4.97; social environment X =8.31±5.24; vocational environment X =7.63 ± 3.41; sexual relationship X =5.92 ±4.57 and extended family relationships X=4.36 ±3.46. This study has shown that the psychosocial adjustment of the patients with Behçet's Disease to this illness is low, and there are problems related to health care orientation, psychological distress, domestic environment, and social environment. The evaluation of the conclusions of this study is of importance for providing both healthcare and psychosocial services.

Keywords: Behçet's Disease; Psychosocial Adjustment; Chronic Diseases; Illness Experience.

1. Introduction

The Behçet's Disease (BD) is "a widely distributed vasculitis going on with attacks, showing recurrent oral aphthae, genital ulcers and eye symptoms as well as musculoskeletal, neurological, respiratory and gastrointestinal system involvements" (Behçet, 1937). The most basic feature of this disease is to cause involvements in various systems of the human body with a potentially negative effect on the whole body system. The BD occurs with remissions and relapses, it's uncontagious (Dalvi et al., 2012). There isn't any specific laboratory finding in the diagnosis of BD, it is diagnosed by examining the symptoms a

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patient has, and this makes the diagnosis difficult (Valencia and Guajardo, 2016, 138). The most common cause of morbidity seen as a result of the disease is the development of blindness due to eye involvement and organ loss (Güngör et al., 2012). The involvements in the neurological and digestive system are particularly the most frequent causes of death (Baş, 2009). The reason for the BD is unknown exactly, thus, only medical treatment is applied to eliminate symptoms (Mat, 2009; Saadoun and Wechsler, 2012). The rheumatic conditions of the patients with the BD and chronic and rare nature of the disease result in many difficulties.

The BD is mostly seen in the many areas located on the road of Silk Road. When examining the distribution of the disease across the world, it is observed that it is seen most in Turkey (Önder, 2009; Woźniacka et al., 2014). Prior studies urged that the incidence of the BD in Turkey ranged between 8 and 42 out of ten thousand. This disease generally begins in the 20s and 30s. The incidence is equal in both genders (Azizlerli et al., 2003; Calamia et al.,2009; Demirhindi et al.,1981; Yurdakul et al., 1989).

Living with a chronic diseaseas the BD, causes serious negative effects on the patients' quality of life and adjustment due to its symptoms and disruptions in patients' physical activities (Boyvat, 2009; TuğrulAyanoğlu et al., 2015; Mumcu et al., 2007). The psychosocial adjustment of patients to this disease is affected negatively by the problemslike difficulty in the diagnosis, lack of a definite treatment, its progressive and recurrent feature, unpredictable attacks and their potential to affect all organs, physical difficulty caused by symptoms. On the other hand, the studies conducted in Turkey mostly focused on medical research (Gazioğlu et al., 2020; Mumcu et al., 2020; Şaş et al., 2020), and the psychosocial aspect of the disease was neglected. This investigation was conducted to evaluate psychosocial adjustment level of the patients with the BD. The strategies for developing healthcare services for the patients with the BD would be developed in accordance with the results of this study.

2. Methods
2.1. Study settings and participants
The universe of this study consisted of all patients, diagnosed with the Behçet's disease according to the International Working Group Diagnostic Criteria and registered at Behçet and Familial Mediterranean Fever Patients Association and who were above 18. It was aimed to reach all these patients and 64 patients with the Behçet's Disease were included.

2.2. Data collection
In this study, a questionnaire and Psychosocial Adjustment to Illness Scale-Self Report (PAIS-SR) were utilized in order to collect data. Firstly, the questionnaire improved by the researchers based on the related literature review. While the first section involved questions on socio-demographic characteristics, the second section included questions related to the experience of having the Behçet's Disease. The aim of the Psychosocial Adjustment to Illness Scale-Self Report (PAIS-SR) was to evaluate the psychosocial adjustment to this disease with a multidimensional approach and to measure mutual interaction of the patients with other individuals and the structures constituting the sociocultural environment. It was developed by Derogatis and Lopez in 1983, which was then adapted into the Turkish language.[20] Its validity and reliability studies were performed by Adaylar (1995), and its Cronbach-alpha value was determined to be 0.90. A permission was received in order to use this scale in the study.[21] The Psychosocial Adjustment to Illness Scale-Self Report (PAIS-SR) consists of 46 components. The questions address seven dimensions of the psychosocial adjustment to this disease. These domains are as follows:" healthcare orientation (8 items), vocational environment (6 items), domestic environment (8 items), sexual relationship (6 items), extended family relationships (5 items), social environment (6 items) and psychological distress (7 items)". There are four descriptive statements determining the level of adjustment for each question in the scale. The items are rated between 0 and 3, and responses are converted into numeric values. While the negative changes emerging with the disease are rated by 3, no change or positive changes are rated by 0. The scores below 35 indicate a good psychosocial adjustment, the scores between 35 and 51 refer to a moderate and the scores above 51 are associated with poor psychosocial adjustment. The questionnaire was administered using face-to-face interviews that took approximately 15 minutes to complete.

2.3. Statistical analysis
The obtained data were entered in the SPSS 22.0 package program and were analysed by utilising appropriate descriptive statistical techniques.

2.4. Ethics statement

This study was approved by the Baskent University Institutional Review Board (Project no: 17162298.600-101).

3. Results

53.1% of the subjects were male. The ages of subjects ranged between 19 and 52 with an age average of 35.35 (sd: 8.4). 76.6% of them were married and 75% had children. 48.4% of the subjects had a bachelor's degree and 40% of them were working. 92.5% of these working subjects had a job with a regular income. 91.6 % of the subjects, who were not working, stated that the reason for their not working in a job was the Behçet's Disease. 39.9% of the subjects were living in Konya. 26.6% of them in Ankara and 18.8% of them in Istanbul (Table 1).

Table 1. Sociodemographic Characteristics of the Patients with Behçet's Disease

Gender	N	%
Male	34	53.1
Female	30	46.9
Educational Background		
University	31	48.4
High School	18	28.1
Primary School	7	10.9
Secondary School	7	10.9
Marital Status		
Married	49	76.6
Single	10	15.6
Widow	5	7.8
Having Children		
Yes	48	75.0
No	16	25.0
Employment Status		
Working	40	62.5
Not Working	24	37.5
Type of Employment		
Permanent Paid	37	92.5
Employer	2	5.0
Casual Worker	1	2.5
City		
Konya	23	39.9
Ankara	17	26.6
Istanbul	12	18.8
Karaman	6	9.4
Nevsehir	1	1.6
Kayseri	1	1.6
Isparta	1	1.6
Antalya	1	1.6

It was found out that the participants had the Behçet's Disease between 9 months and 34 years (An average of 8.67 years;sd: 7.25). The duration of disease was determined to be 8.38 years in males (sd: 6.47) while it was 9 years (sd: 8.14) for females. 31.3% of the subjects had a family member with the Behçet's Disease. 45.3% of the subjects stayed in a hospital at least once due to the Behçet's Disease. It was determined that the subjects received inpatient treatment for an average of 5.36 times (sd: 5.29) during their illness (Table 2).

When examining the physical symptoms due to the Behçet's Disease, it was concluded that the subjects had more than one symptoms and the most common ones were: 24.4% mouth ulcers, 15.5% joint involvement, 13% acnes and 10.5% wounds in the genital region. 3.36% of the subjects expressed that they had eye involvement due to the Behçet's Disease, which finally led to blindness (Table 2).

40.6% of the subjects had different chronic diseases in addition to the Behçet's Disease. The most frequent of these diseases were Familial Mediterranean Fever, hypertension diabetes and ankylosing spondylitis. 43.9% of the subjects went to another city different from their home cities to receive health

services. 51.5% of them had adverse effects due to the drugs they used in the treatment of the Behçet's Disease. Diarrhoea, stomach pain, tiredness, and weakness were some of these adverse effects (Table 2).

Table 2. Distribution of Subjects' Knowledge on the Behçet's Disease

Any Family Member with the Behçet's Disease	N	%
Yes	20	31.3
No	44	68.7
Symptoms of the Behçet's Disease		
Oral Aphthae	58	24.4
Joint Involvement	37	15.5
Pseudofolliculitis	31	13
Genital Ulcer	25	10.5
Uveitis	21	8.82
Erythema Nodosum-Like Lesion	16	6.72
Involvement in the Digestive System	16	6.72
Blindness	12	3.36
Neurobehçet	11	4.62
Involvement in the Cardiovascular System	9	2.74
Involvement in the Respiratory System	2	0.61
Having Other Chronic Diseases		
Yes	40.6	26.0
No	59.4	38.0
Going to Different Cities for Treatment of the Behçet's Disease		
Yes	29	43.9
No	35	56.1
Having Adverse Effects in Drug Use due to the Behçet's Disease		
Yes	33	51.5
No	31	48.5
Adverse Effects due to Drug Use		
Diarrhoea	9	27.2
Fatigue - Weakness	7	21.2
Stomach-ache	8	24.2
Vitamin B Deficiency	3	9.09
Anaemia	3	9.09
Hair Loss	2	6.06
Bone Thinning	1	3.03

The mean score of the patients with Behçet's Disease related to the sub-scales of the Psychosocial Adjustment to Illness Scale-Self Report (PAIS-SR) was found to be 57.16±11.2. This score refers that the patients had a poor disease adjustment level. According to the Psychosocial Adjustment to Illness Scale-Self Report, 48.4% of the patients had poor disease adjustment level while 39.1% of them had moderate and 12.5% of them had good disease adjustment level. The scores related to the sub-scales are as follows: health care orientation $\bar{X}$ =12.86 ±3.82; psychological distress $\bar{X}$ =9.52 ± 4.72; domestic environment $\bar{X}$ =8.56 ±4.97; social environment $\bar{X}$ =8.31±5.24; vocational environment $\bar{X}$ =7.63 ± 3.41; sexual relationship $\bar{X}$ =5.92 ±4.57 and extended family relationships $\bar{X}$ =4.36 ±3.46 (Table 3).

Table 3. The Scores of the Patients with the Behçet's Disease Related to the Psychosocial Adjustment to Illness Scale-Self Report

Adjustment Level	N		%	
Poor Adjustment (52 Score and Above)	31		48.4	
Moderate Adjustment (Scores between 35-51)	25		39.1	
Good Adjustment (34 Score and Below)	8		12.5	
Sub-Scales of the Scale	Min	Max	$\bar{X}$	sd
Health Care Orientation	0	24	12.86	3.82
Psychological Distress	0	21	9.52	4.71
Domestic Environment	0	24	8.56	4.97
Social Environment	0	18	8.31	5.24
Vocational Environment	0	18	7.63	3.41
Sexual Relationship	0	18	5.92	4.57
Extended Family Relationships	0	15	4.36	3.46

While 45.3% of the subjects expressed that they had knowledge about the Behçet's Disease, 29.6% of them reported that they had knowledge on its treatment. The most common knowledge sources were found to be healthcare professionals (22.8%), internet (20.65%) and other people with the Behçet's disease (20.65%). Regarding the social support resources, it was stated that the subjects received professional mental health service most by 44.1% and they were supported by their families by 35.3%. 64.1% of the subjects stated that the spending they made for treatment had a serious negative impact on their economic status. Regarding the services needed, the following services are needed related to the difficulties lived in medical processes: 13.5% increase in medical research, 9.2% increase in the awareness of healthcare providers about the disease, 6.1% eliminating problems in the appointment system and not waiting, 5.5% increase in health institutions and personnel related to the Behçet's Disease and 3.2% to provide convenience in taking drug reports. Regarding the economic difficulties, it was indicated that there was a need related to medicine expenses by 8.6%, reduction in examination fees by 6.9%, disability pension right by 3.5% and disability report by 2%. When considering in terms of psychosocial needs, there were needs in the following fields: 10.1% to be informed about the disease, 9.5% psychological support, 5.8% taking leave from the workplace and working in a less stressful environment, 5.5% increase in social awareness, 3.2% family counselling, 2.6% sexual counselling and 1.4% genetic counselling (Table 4).

Table 4. Distribution of the Problems Lived by the Patients with Behçet's Disease and the Services They Need

Thinking About Having Sufficient Knowledge About The Disease	N	%
Yes	29	45.3
No	35	57.7
Thinking About Having Sufficient Knowledge About The Treatment		
Yes	19	26.9
No	45	73.1
Knowledge Sources		
Healthcare Professionals	28	30.44
Internet	19	20.65
Other Individuals With The Behçet's Disease	19	20.65
Training and Information Studies Made At Associations	17	18.48
Family Members and Friends	5	5.43
Television or Radio	4	4.35
Social Support Resources		
Receiving Professional Mental Health Service	15	44.1
Family Members	12	35.3
Friends	5	14.7
Health Team	1	2.9
Other Individuals With The Behçet's Disease	1	2.9
Living Economic Difficulty Caused by This Disease		
Affecting Seriously Negative, I Have Difficulty In Affording	41	64.1
Affecting Negatively But I Can Afford	11	17.2
Not Affecting Negatively	12	18.7
The Services Needed		
Increasing Medical Research	47	13.5
Need For Information About The Disease	35	10.1
Psychological Support	33	9.5
Raising Awareness of Health Service Providers About The Disease	32	9.2
Reducing Medicine Expenses	30	8.6
Reduction In Examination Fees	24	6.9
No Problem In The Appointment System, Not Waiting	21	6.1
Taking Leave From Workplace And Working In A Less Stressful Environment	20	5.8
Increase In Health Institutions and Personnel Related to Behçet's Disease	19	5.5
Increase In Social Awareness	19	5.5
To Retire On Disability	12	3.5
Providing Convenience In Receiving Drug Reports	11	3.2
Family Counselling	10	2.9
Sexual Counselling	9	2.6
Obtaining Disability Report	7	2.0
Genetic Counselling	5	1.4

4. Discussion

In this study, the questionnaire, developed by the researcher, and PAIS-SR were administrated to the 64 patients with the Behçet's Disease in order to evaluate their psychosocial adjustment to this disease, and it was concluded that 48.4% of the patients had a poor adjustment level. Regarding the sub-scales, high scores were obtained in health care orientation, psychological distress, domestic environment and social environment. In the study conducted by Öyke (2008), PAIS-SR was performed and it was reported that 30% of the subjects had a poor adjustment.

In this research, it was firstly identified that the subjects had a poor adjustment in health care orientation. In this respect, Özdemir and Kural (2011) argue that the adjustment of the patients with the Behçet Disease is difficult as they need to receive a developed consultation service. Ideguchi et al., (2011) and Khairallah et al., (2012) urge that the lack of specific laboratory findings in the diagnosis of the Behçet Disease makes adjustment in the health care orientation difficulty. In an investigation conducted by Mather et al., (2010) with 650 patients with the Behçet's Disease in England, they report that the Behçet Disease is diagnosed wrongly or an average of 12 years is required for a correct diagnosis, thus, the adjustment in health care orientation decreases. In addition, TuğrulAyanoğlu et al., (2015) states that the adjustment in health care orientation decreases when the patients the Behçet Disease cannot reach to health care services. McArthur and Goodacre (2013) argues that as the patients must receive health care services continuously due to the chronic nature of the Behçet's disease, this makes it difficult for patients to have the adjustment in health care orientation.

The results of the study have revealed that the subjects have secondary diseases in addition to the Behçet's disease. In this respect, Evereklioglu (2005) and Hellwing (2012) conclude that the secondary diseases in the patients with the Behçet's disease postpone to make a correct diagnosis for the Behçet's disease, make the treatment difficult and damage the adjustment in health care orientation.

The second highest score has been obtained by the psychological distress in the scale scoring. In this study, the results regarding the difficulty of the patients with the Behçet's disease to have the adjustment in psychological respect have been achieved. Prior studies show that increased disease activity (Melikoglu&Melikoglu, 2010), stressful life events and low coping skills (Karlıdağ et al., 2003) increase depression and anxiety. What is more, the patients with the Behçet's disease show a restricted performance in daily activities, have inability in fulfilling their routine tasks and accordingly, experience sadness, tension, and other negative emotions (Hellwing, 2012; Canpolat&Yurtsever, 2011). Another study has been carried out with 73 patients with the Behçet's disease and has been concluded that the disease affects the quality of life negatively by causing anxiety and depression in individuals and this has a significant effect in triggering the attacks in this disease (Uğuz et al., 2006: 134). In the study conducted by Karlıdağ et al., (2003) argued that 79.4% of the patients with the Behçet's disease has a stress factor before attack periods, and the reactions of fear and sadness emerge. TürelErmertcan et al., (2004) report that the patients with the Behçet's disease, receiving inpatient treatment, are administrated psychiatric consultation due to stress-distress, crying spells, insomnia and fear of death. On the other hand, YurtmanHavlucu et al., (2011) state in their study performed with 33 patients with the Behçet's disease that depression and anxiety have been observed more in the patients with eye involvement. Thirdly, this study discussed the negative effects caused by the Behçet's disease in terms of the domestic environment and social environment. Goodacre and McArthur (2013) have reported that the family members of the patients with the Behçet's disease have been affected negatively in providing care and social support mechanisms. In the study conducted by Okyayuz (2004) by examining the families of 37 patients with the Behçet's disease, significant disruptions were stated in family functions. In studies related to rheumatic diseases in the literature (Calikoglu et al., 2001; Najim et al., 2007; Goodacre and McArthur, 2013: 10), it has been argued that the individuals diagnosed in the early stages of the onset of the disease have experienced a process of understanding what was happening, and social adjustment has been damaged. Ogden (2016) stated that perceptions of family members, friends, colleagues and social environment about the disease has affected social adjustment. Tsutsui et al., (2020) reported that the symptoms of the Behçet's disease has caused negative effects on the socialization of patients.

The results of this study have revealed that the financial burden of this disease is high and patients leave their jobs due to this disease. Hellwing (2012) argues that the patients with the Behçet's Disease have problems in their education and working lives, and there is workforce loss, especially in the periods they have intense pain. According to the study conducted by Süt et al., (2006) the patients with the Behçet's Disease have averagely workforce loss for 119 days in a year. Kurt et al., (1997) reported that the course of

illness is affected negatively in the event of cases such as, when the patients with the Behçet's Disease live in low socioeconomic conditions, they delay doctor check, they ignore complaints, and medical expenses cause a costly public health problem due to loss of work and time.

In addition, the difficulties have been also found in the sexual life of the patients with the Behçet's Disease regarding adjustment to this illness. Prior studies show that the Behçet's Disease leads to sexual health problems as it is mostly seen in the 20s and 30s, in the young and middle age period, when sexuality and fertility are at the highest level (Özdemir et al., 2010; Erturan et al., 2014; Özkan, 2013). In the study carried out by Kılınç (2009) et al. with 72 patients with the Behçet's Disease, it has been concluded that the psychological problems of the patients have increased due to the pain they had during attack periods, have had difficulty in fulfilling their daily activities, have had problems related to body perception and sexual life due to the wounds on their bodies, which was resulted in a significant decrease in their quality of life, thus, interventions should be made together with psychosocial examinations. In this respect, the results of this study on sexual health are similar to the ones reported in the literature. In this research, the knowledge level of the subjects on the disease and treatment has been found be to be low. The most common used knowledge sources are healthcare professionals and internet. While the subjects used the quality of communication between staff and patient as the knowledge source in the study conducted by Ahlménet et al., (2005) with the individuals having rheumatic disease, it has been argued by Van der Vaart et al., (2010) in his study carried out with 18 individuals having rheumatic disease that the subjects have considered healthcare professionals and patient support groups to be the knowledge source during their diseases.

The subjects request an increase in medical services and knowledge level as well as providing psychosocial support. Pak and İnce (2018) urge that the quality of health care services provided to the patients with the Behçet's Disease in Turkey should be raised while Pak and Özden (2018) suggest that the health care services provided to these patients should be performed in a multidisciplinary team understanding. What is more, Uğuz et al (2006) and Dursun et al. (2007) state that it is necessary to provide psychosocial support to the patients with the Behçet's Disease.

This study has some limitations. As this study was designed as a cross-sectional field research, generalising all results as a whole may lead to wrong conclusions. Although the cross-sectional design of the study resulted in an adjustment of the patients with the Behçet's Disease to this illness, longitudinal studies are required to determine the causality between dependent and independent variables.

In further studies to be carried out with the patients with the Behçet's Disease, the effect of the Behçet's Disease to the psychosocial adjustment and how the life of quality and caregiver burden are affected may be discussed.

5. Conclusion

In this study, the questionnaire, developed by the researcher, and PAIS-SR were administrated to the 64 patients with the Behçet's Disease in order to evaluate their psychosocial adjustment. This study has showed that the psychosocial adjustment of the patients with the Behçet's Disease to this illness is low, and there are problems related to health care orientation, psychological distress, domestic environment and social environment. The evaluation of the conclusions of this study is of importance for providing both health services and psychosocial services to the patients with the Behçet's Disease.

In order to increase the adjustment of the patients with the Behçet's Disease to the health care orientation, it is necessary to discuss the difficulties experienced during medical processes in detail, to determine the points of problem, and to develop the way of providing health care services. It is also suggested that the regulations covering the patients with the Behçet's Disease should be made in the health policies, the number of health centers and health professionals should be increased. In addition, it is recommended to create multidisciplinary teams at the health institutions and to respond to the problems of the patients with the Behçet's Disease with a holistic approach.

Organizing psycho-education sessions is suggested in order to ensure psychological and social adjustment to this disease. Psycho-education is expected to develop the problem-solving skills of patients and increase their coping capacity.

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