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Effect of Illness Perception on the Quality of Life in Ankylosing Spondylitis

Ankilozan Spondilitte Hastalık Algısının Yaşam Kalitesi Üzerine Etkisi

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Abstract

Objectives: The aim of the study was to assess the illness perception in patients with ankylosing spondilitis (AS), to evaluate disease activity, functional ability, emotional status and to investigate their association with quality of life (QoL).

Materials and Methods: Sixty-seven patients with AS were included in this study. The Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) and Bath Ankylosing Spondylitis Functional Index (BASFI) were used for the assessment of disease activity and of physical functions, respectively. The Ankylosing Spondylitis Quality of Life (ASQoL) questionnaire was used for disease-related quality of life and The Brief Illness Perception Questionnaire (B-IPQ) was used for the assessment of illness perception in AS patients. Beck Depression Inventory (BDI) was used for the assessment of psychological status.

Results: Based on our results, significant association was found between QoL and illness perceptions. However, QoL was most associated with functional status and disease activity.

Conclusion: Assessment of illness perception in routine clinical practice could contribute to a better understanding of problems in patients' behavior that may disturb adherence to treatment. Psychotherapeutic approaches in addition to conventional therapy might attempt to improve patient's QoL in AS.

Key words: Illness representations, depression, quality of life, seronegative spondyloarthropathy

Öz

Amaç: Ankilozan Spondilit (AS), karakteristik olarak sakroiliak eklemleri, omurga ve periferik eklemleri, bağırsakları ve gözleri etkileyebilen, kronik, inflamatuvar romatizmal ilerleyici bir hastalıktır. AS'nin klinik bulguları iyi bilinmekte ancak hastalığın, etkilenen kişinin subjektif sağlığı üzerindeki etkileri yeterince bilinmemektedir. Bu çalışmanın amacı Ankilozan Sondilitli (AS) hastalarda hastalık algısını, hastalık aktivitesini, fonksiyonel ve emosyonel durumunu ve bunların hastalık aktivitesi ile ilişkisini değerlendirmektir.

Materyal ve Metot: Altmışyedi AS'li hasta çalışmaya katıldı. Hastalıkla ilgili yaşam kalitesi Ankilozan Spondilit Yaşam Kalitesi İndeksi (ASQoL) ve hastalık algısı Kısa Hastalık Algı Ölçeği ile değerlendirildi. Hastalık aktivitesi ve fonksiyonel kapasitesi, Bath Ankilozan Spondilit Hastalık Aktivite İndeksi (BASDAI), Bath Ankilozan Spondilit Fonksiyonel İndeksi (BASFI) ile değerlendirildi. Psikolojik durumun değerlendirmesinde Beck Depresyon Ölçeği kullanıldı.

Bulgular: Sonuçlarımıza göre, hastalık algısı ile yaşam kalitesi arasında anlamlı ilişki bulunmuştur. Bununla birlikte, yaşam kalitesini en çok etkileyen faktörler fonksiyonel durum ve yaşam kalitesidir.

Sonuç: Rutin klinik uygulamada hastalık algısının değerlendirilmesi, hastanın davranışlarında tedaviye uyuma engel olabilecek sorunların daha iyi anlaşılmasına katkıda bulunabilir. Konvansiyonel terapiyeek olarak psikoterapötik yaklaşımlar, AS'de hastaların yaşam kalitesini iyileştirmede katkıda bulunabilir.

Anahtar kelimeler: Hastalık algısı, depresyon, yaşam kalitesi, seronegatif spondiloartropati

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Introduction

Ankylosing spondilitis (AS) is a chronic, inflammatory rheumatic progressive disease that characteristically affects the sacroiliac joints, the spinal column and to a smaller extent, the peripheral joints, bowel and eyes.[1] Clinical findings of AS are well known, but overall impact of the disease on the subjective health of affected person is relatevely inadequate.[2] From the patient's perspective, possibly the most important outcome measurement parameter is quality of life(QoL). QoL commonly includes symptoms, pyhsical functioning, work ability, social interaction, treatment side effects and illness perceptions. Recent researches recommend health professionals to assess and treat patients with musculoskeletal pain from a biopsychosocial perspective and may reveal the differences between the doctor's and the patient's view, understanding and reaction.[3,4] Patients develop cognitions about their illness, depended on previous experiences, ensured knowledges and explication of symptoms. These cognitions are often referred to as illness perceptions.[5] Several illness perceptions are associated with QoL in rheumatoid arthritis (RA), systemic sclerosis or psoriatic arthritis. [6-10] To the best of our knowledge, only one study has investigated illness perceptions in AS.[10]

The main objective of this study was to assess illness perception in patients with AS, to evaluate disease activity, functional ability, emotional status and to investigate these factors influencing the QoL.

Materials and Methods

The AS patients were selected from our outpatient clinic and complied with the Modified New York classification criteria for this disease.[11] Patients with insufficient intelligence to provide responses to the tests, patients who had significant comorbidity such as other systemic diseases (decompensated cardiovascular disease, cancer, etc.), cerebrovascular diseases, alcohol and/or any substance abuse or antipsychotic, antidepresant or anxiolytic medication use and who refused to complete the questionnaire were excluded. 80 patients evaluated in the study. After the execution of exclusion criteria of the study, we recruited 67 AS patients.

The interview comprimised socio-demographic questions, disease and complaint duration, comorbidities and drugs. Disease-spesific instruments were; Bath Ankylosing Spondylitis Disease Activity Index (BASDAI)and Bath Ankylosing Spondylitis Functional Index (BASFI). The function was assessed by the BASFI containing 10 questions, each to be rated on a visual analogue scale (VAS; 0-10), on perceived limitations in daily activities. The final score ranges from 0 to 10, and higher values indicate worse physical function.[12] The BASDAI consists of six questions focusing on fatigue (one item), axial pain (one item), peripheral pain (one item), enthesopathy (one item), and morning stiffness (two items). Each question was scored on a VAS. The BASDAI score (0-10) was calculated as the mean value of the first four items and the last two items referring to morning stiffness. A higher score indicates higher disease activity. Three levels of disase activity were defined: a score ≤4 meant mildly active disase, a score of 4-6 indicated moderate disase activity, and a score of >6 defined severe disase activity.[13,14] The Ankylosing Spondylitis Quality of Life (ASQoL) questionnaire was used for the assessment of disease-related quality of life in patients with AS and consists of 18 yes/no questions. [15,16] Depression was evaluated using the Beck Depression Inventory (BDI) which consisted of 21 items and is widely used in measuring depression symptom levels. Responses are ranging from 0 to3, with 3 representing the most severe symptoms .[17,18]

The patients completed a self-administered questionnaire that included The Brief Illness Perception Questionnaire(BIPQ), a standardized instrument developed in order to evaluate cognitive and emotional representations .[19] The BIPQ consists of 9-items, used to measure illness perceptions. All of the items except the causal question are rated from 0 to 10 response scale, higher scores reflect more negative perceptions. Five of the items assess cognitive illness representations: perceived consequences, timeline (acute-chronic), amount of perceived personal control, treatment control and identity (symptoms). Two of the items assess emotional representations: i.e. concern about the illness, emotional representation. One item assesses illness comprehensibility. The last item assesses causal perceptions by asking patients to list the three most likely causes for their illness. The instrument was translated into Turkish and validated [20] and has been used in many illness populations and has also widely used many countries. [20,21-25]

Statistics

The data was examined from the normal distribution by Kolmogorov- Smirnov test. Descriptive data were presented as mean±standard deviation (SD) or median(minimum-maximum) as necessary to the normal distribution of the parameters.

Kruskal-Wallis test was used to examine the differences in illness perception, regarding the therapy, educational level. Spearman/ Pearson correlation was used to establish the relationship between variables.

The data were analyzed using the Standard SPSS for Windows, Version 17. The level of significance was set to 0.05.

Ethics

The study protocol was reviewed and approved by the local ethics board of Ankara Yıldırım Beyazıt University. Informed consent was obtained from each participant and the study was performed according to the 1964 Declaration of Helsinki.

Results

A total of 67 patients (46 men and 21 women) were included in the study. A total of 13 (19.40%) AS patients used anti-TNF agents; 29(43.30%) used non-steroidal anti-inflammatory drugs (NSAIDs), 25 (37.30%) used sulfasalazin and NSAIDs. Most of the patients were self employed (37.30 %) or housewife (26.90%). Table 1 shows the socio-demographic and disease characteristics of 67 AS patients.

Disease duration (4.5 years) in the AS group was two times shorter than the duration of complaints (8.5 years). 1.50% of AS patients were still employed. 7.50% of patients had peripheral arthritis. In the AS group 22.40% of patients had comorbidities. More than half had never smoked, 3.00% of them were ex-smokers. Educational level did not affect B-IPQ, ASQoL, BASFI, BASDAI and depression scores (p=0.551, p=0.283, p=0.952, p=0.379, p= 0.070, respectively). Smoking and drugs used also did not affect B-IPQ scores (p=0.791, p=0.410) (Table 1).

Table 1. Characteristics of the patients

Characteristics	Mean±SD	Median (min-max)
Age	37.90±10.50	66.00(18.00-70.00)
Body Mass Index (kg/ m^2)	30.60± 6	29.70 (18.90-48.90)
Education (years)	9.70± 3.60	12.00 (5.00- 18.50)
Duration of complaints (years)	8.50± 6.90	7.00 (0.50-40.00)
Duration of diagnosis (years)	4.50± 5.90	2.00 (0-35.00)
Functional index (BASFI 0-10)	4.20± 2.40	4.60 (0-9.30)
Disease activity index (BASDAI 0-10)	4.90± 2.10	4.80 (0-10.00)
Quality of Life (ASQoL)	10.10± 4.50	11.00 (0-18.00)
Pain (VAS, 0-10)	5.60± 2.50	6.00 (0-10.00)
Beck Depression Scale (BDS)	16.90± 9.40	16.00 (0.37.00)
Brief Ilness Perception Questionnaire (B-IPQ)	7.10± 1.40	7.20 (3.50-10.00)

SD- standart deviation

Descriptive statistics pertinent to 8 items comprised by the BIPQ questionnaire showed that; in general, patients with AS tended to view their illness as a chronic disease (timeline) and they understood it well (understanding). They mostly perceived AS as a disease with mild-modarate serious consequences, so that they were concerned about it, and emotionally affected. They experienced many AS- related symptoms which can be well controlled with appropriate treatment (treatment control) but they felt that they have little control over the disease (personal control) (Table 2).

Table 2. Descriptive statistics for the 8 items of the BIPQ completed by patients with AS

BIPQ items*	**Median (interquartile range)**
Consequences	7.00 (0-10.00)
Timeline	10.00 (0-10.00)
Personal control	5.00 (0-10.00)
Treatment control	8.00 (0-10.00)
Identity	8.00 (0-10.00)
Concern	8.00 (0-10.00)
Emotional response	8.00 (0-10.00)
Comprehensibility	10.00 (0-10.00)

*According to Broadbent et al.[19]

According to the patients' beliefs, the main causes of AS were; heredity (n=14, 20.90%), stress (n=9, 13.40%) and hard working (n=8, 11.90%). Most of the patients had no idea about the cause of the disease (n=26, 38.80%). ASQoL was positively correlated with

BIPQ, BASDAI, BASFI and depression (p=0.001, r=0.410; p<0.001, r=0.686; p<0.001, r=0.687; p<0.001, r=0.589; respectively).

The correlations between illness perception rating and disease-spesific instruments, Beck Depression and ASQoL were demonstrated in Table 3. 'Consequences' was the most relevant item with the quality of life and the other instruments.

Table 3. The relationship between the BIPQ items and ASQoL, disease-spesific instruments, BDI

BIPQ items*	Correlation coefficient / –Statistical significance	BASDAI	BASFI	BDI	ASQoL	VAS
Consequences	Spearman rho	0.581	0.480	0.490	0.607	0.385
	p	**<0.001**	**<0.001**	**<0.001**	**<0.001**	**0.001**
Timeline	Spearman rho	-0.171	0.001	0.060	-0.060	-0.194
	p	>0.050	>0.050	>0.050	>0.050	>0.050
Personal control	Spearman rho	-0.090	-0.106	-0.010	-0.124	-0.162
	p	>0.050	>0.050	>0.050	>0.050	>0.050
Treatment control	Spearman rho	-0.120	-0.050	0.120	-0.190	-0.010
	p	>0.050	>0.050	>0.050	>0.050	>0.050
Identity	Spearman rho	0.466	0.410	0.382	0.483	0.406
	p	**<0.001**	**0.001**	**0.001**	**<0.001**	**0.001**
Concern	Spearman rho	0.334	0,155	0.107	0.270	0.143
	p	**<0.010**	>0.050	>0.050	<0.050	>0.050
Emotional response	Spearman rho	0.363	0.401	0.390	0.432	0.170
	p	**0.003**	**0.001**	**0.001**	**<0.001**	0.170
Understanding	Spearman rho	-0.175	0.010	-0.161	-0.170	-0.194
	p	>0.050	>0.050	>0.050	>0.050	>0.050

p= the level of significance, p values in bold refers to the linear relationship between the 2 parameters

Discussion

Chronic diseases negatively affect the quality of life.[26-28] Recently, the primary target in the treatment of chronic diseases has been 'increasing the quality of life'. In the treatment and follow up of patients with AS, it is important to take the physical, psychological, emotional aspects of the patient into account to detect their quality of life in addition to clinical and laboratory findings.[29,30]

The results of the present study demonstrated that ASQoL was mostly associated with functional status and disease activity. On the other hand, 23.40% patients with AS had such comorbidities as hypothyroidism, coronary artery disease, asthma which influence not only the functional limitation but also their quality of life. Few studies in literature have found that; when disease activity increases, functional impairment increases and quality of life decreases.[27,31,32] Our study is consistent with the literature, the higher scores of BASDAI, BASFI correlates with lower QoL. Bostan et al reported that physical domains of QoL related more strongly to functional loss, whereas psychosocial domains correlated best with disease activity levels.[27]

In our study, most patients with AS were middle-aged men. According to general medical practice, the literature indicates that the quality of life decreases with increasing age.[33,34] Ozkan et al. showed that quality of life decreases as the age increases in patients with AS.[35] In our study, age was not associated with QoL, disease activity, functional status or perception. A large number of our patients' educational level was higher than secondary school and only 1.50% were employed. According to our study, factors that we have previously thought were indeed important factors as education level and medication do not have significant influence on BIPQ domains.

In rheumatic diseases, patients usually experience impaired psychological status.[36] While chronic pain may lead to depression, depression may itself increase pain perception. [37] In studies with AS, patients' symptoms of depression was found 14.80-55.50% .[10,38,39] Our results have shown that one third of the patients had moderate-severe depression and there was positive correlation between BDI and QoL. Likely, Baysal et al. suggested that higher HADS-depression scores meant a poorer functional outcome and reduced quality of life.[38]

Lower illness perceptions may cause decreased strength to cope with a rheumatic disease and affect the medical treatment and rehabilitation program in patients with AS.[10] Higher scores indicate more negative perceptions. This study showed that quality of life was affected by consequences, identity and emotional response of illness perception and demonstrated that more negative perceptions have reduced health-related quality of life in AS. At the same time, these items of illness perception was associated with depressive symptoms, disease activity and functionality. Differently, Hypantis et al found that AS patients' physical QoL was associated with illness concern and emotional response and emotional response scores correlated with depression scores.[10]As a contradictory result, most of our patients had no idea about the cause of the disease, however they felt that they understood their illness well.

The BIPQ was developed to provide a very short and simple measure of illness perceptions for clinical use. [19] In contrast to the more traditional method of constructing dimensions by forming subscales from multiple statements rated on Likert scales, the BIPQ uses one single item on a scale from 0 to 10 to assess each dimension.[40] This short scale has advantages in terms of higher number of participants, especially in clinical settings and when repeated follow-up assessments are needed. Stronger illness identity, stronger emotional representations were mild to moderately associated with depression, low quality of life, lower funtional status and higher disease activity while consequences were moderately to strongly associated with them. No perceived personal control nor treatment control were associated with quality of life.

This study has some limitations. One of these limitations is its cross-sectional design. Other important limitation is not having a control group. The generalizability of our findings is also limited because of the relatively small sample size and also, most of the participants were men. There is a need for further research with larger samples and long term follow-up to replicate the findings of this study.

This study elucidated that; disease activity, functional limitation, depression and illness perception were significantly associated with QoL and that lower illness perceptions have negative impacts on patients' functions, daily activities, quality of life. So illness perceptions directly affect the subjective health in patients with AS and should be considered in clinical practice. Health care providers might lead the patients to improve their levels of awareness about their disease.

In conclusion, significant association was found between QoL and illness perceptions. Taking into account the assessment of illness perception of patients with AS in routine clinical practice, may contribute to the optimization of treatment outcomes. Psychotherapeutic approaches in addition to conventional therapy might work to improve the patient's QoL in AS. Further study is needed to examine the effect of illness perception on treatment outcome in chronic rheumatologic diseases.

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