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Research Article

Investigation of Participation in Patients with Rheumatic Diseases: A Comparative Study

Romatizmal Hastalarda Katılımın Araştırılması: Karşılaştırmalı Bir Çalışma

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ABSTRACT

Purpose: The study aimed to determine participation and the factors affecting it in patients with rheumatic diseases and to compare them with healthy individuals of the same age. **Material and Methods:** Two hundred twenty-four patients (155 female, 69 male) with rheumatic diseases (the mean age: 50.14±12.28 years) and 166 healthy (108 female, 58 male) individuals (the mean age: 48.04±13.48 years) were included in the study. The Participation Scale was used to examine participation. **Results:** 111 patients with Ankylosing Spondylitis (AS), 62 Rheumatoid Arthritis (RA), 14 Familial Mediterranean Fever (FMF) and 13 Sjögren's and 25 other rheumatic diseases were included in the study. Participation score was significant in favor of healthy individuals (z=-6.56, p=0.00). The lowest participation scoring was in patients with RA (15.32±2.38 points). A significant negative correlation was found between participation and education level. **Conclusion:** According to the results of this study, the participation rate of patients with rheumatic disease was lower than the healthy ones. Furthermore, patients with RA had the lowest participation score and participation increased as education level increased. This study demonstrates the significance of planning rheumatic disease rehabilitation programs to enhance participation and assessing participation prior to these initiatives.

Keywords: Participation; Patients; Rheumatic Disease

ÖZ

Amaç: Çalışmanın amacı romatizmal hastalığı olan hastalarda katılımı ve etkileyen faktörleri belirlemek ve aynı yaştaki sağlıklı bireylerle karşılaştırmaktır. **Gereç ve Yöntem:** Çalışmaya romatizmal hastalığı olan 224 hasta (155 kadın, 69 erkek) (ortalama yaş: 50,14±12,28 yıl) ve 166 sağlıklı (108 kadın, 58 erkek) birey (ortalama yaş: 48,04±13,48 yıl) dâhil edildi. Katılımı incelemek için Katılım Ölçeği kullanıldı. **Sonuçlar:** Çalışmaya 111 Ankilozan Spondilit (AS), 62 Romatoid Artrit (RA), 14 ailesel akdeniz ateşi (AAA), 13 Sjögren ve 25 diğer romatizmal hastalık hastası dâhil edildi. Katılım puanı sağlıklı bireyler lehine anlamlı bulundu (z=-6.56, p=0.00). En düşük katılım puanı RA hastalarındaydı (15,32±2,38 puan). Katılım ile eğitim düzeyi arasında anlamlı negatif bir ilişki bulundu. **Tartışma:** Bu çalışmanın sonuçlarına göre romatizmal hastalığı olan hastaların katılım oranı sağlıklı olanlara göre daha düşüktü. Ayrıca RA'lı hastaların katılım puanı en düşüktü ve eğitim düzeyi arttıkça katılım da artmaktaydı. Bu çalışma romatizmal hastalıklara yönelik rehabilitasyon programları öncesinde katılımın değerlendirilmesi ve bu programların katılımı arttıracak şekilde planlanması önemli olduğunu göstermektedir.

Anahtar Kelimeler: Katılım; Hasta; Romatizmal Hastalıklar

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Rheumatic diseases are one of the chronic diseases that are characterized by pain and joint inflammation, most often including diseases such as Ankylosing Spondylitis (AS) and Rheumatoid Arthritis (RA), and negatively affect the quality of life (Cano-García et al., 2021). Quality of life is a broad concept defined by the World Health Organization (WHO) (2001) that reflects the culture and value system in which individuals live and includes goals, expectations, standards and concerns (Cano-García et al., 2021; Wysocka-skurska et al., 2016). Participation is necessary to meet the basic needs of individuals and is an important determinant of quality of life (Fekete et al., 2019). Because chronic illnesses can affect health or impair functionality, they may make it more difficult to participate in society. Participation can be viewed as engaging in socially beneficial activities, such as having a paid job, leisure time activities, and positive interpersonal interactions (Halvorsen et al., 2021) and is an important part of rehabilitation for individuals with musculoskeletal diseases such as RA (Björk et al., 2020).

Participation is defined by WHO in the International Classification of Functioning, Disability and Health (ICF) as an individual's involvement in a life situation and expresses the societal perspective on functioning (Perenboom and Chorus, 2003) but the concept of it is difficult to define. This broad definition increases the difficulty of assessing participation as it includes different aspects and areas that are both generic and disease-specific (Björk et al., 2020; Whiteneck and Dijkers, 2009). There are several measures aimed at assessing participation, both objectively measuring the frequency of self-reported behavior and offering the community to assess subjective experiences of self-reported restrictions in this regard (Whiteneck and Dijkers, 2009). One of the most recent participation measures based on the ICF's involvement areas is the Participation Scale (P-Scale) (Altuntaş et al., 2021). ICF divides this into 9 sub-areas such as learning and applying knowledge, home life, communication, mobility, personal care, interpersonal interactions, school and work, community, civic and social life (World Health Organization, 2001), and the P-Scale covers eight of the nine areas and also it assesses the impact on social participation (Van Brakel, 2008). The P-Scale measures the perceived limitations of individuals based on “comparison with peers”. Thus, it enables the individual to compare himself/herself with a peer who is in a similar sociocultural, economic and demographic situation as well as illness and disability (Van Brakel et al., 2006).

People with chronic diseases are less likely to engage in paid employment and volunteer activities, according to research on engagement in chronic diseases with a variety of diagnoses. (Scharn et al., 2019). A study examining the participation of patients with rheumatic diseases such as RA and AS in social activities showed that participation in social activities was low in these patients and the scores were similar according to the diagnosis (Cano-García et al., 2021). Although participation in social activities has been examined with these patients in the literature, participation has not been examined. Therefore, the study aimed to determine participation and the factors affecting it in patients with rheumatic diseases and to compare them with age-matched healthy individuals.

MATERIAL AND METHODS

Study Design

This study is an observational, comparative study of a series of patients with rheumatic diseases (AS, RA, Familial Mediterranean Fever (FMF), scleroderma, gout, systemic lupus erythematosus (SLE)). The Rheumatology department at the hospital conducted the study.. The Clinical Research Ethics Committee approved the study.

Patients

224 patients (155 female, 69 male, 50.14±12.28 years) with a diagnosis of any rheumatic disease followed by a rheumatologist in the Rheumatology Outpatient Clinic of the hospital were included in the study. In addition, 166 healthy (108 female, 58 male) individuals (48.04±13.48 years) were included to compare with patients. An informed consent was obtained from individuals who agreed to participate in the study, stating the scope and purpose of the study according to the Declaration of Helsinki. The study included all patient seen in the hospital's outpatient rheumatology clinic. During the study period, 229 patients were excluded from the study because they did not meet the inclusion criteria. The inclusion criteria were as follows: Diagnosed with rheumatic diseases according to the latest ACR/EULAR criteria, over 18 years old, volunteer, and consent to participate in the study. We excluded the patients who were diagnosed with any non-rheumatic disease, having orthopedic, neurological, psychiatric, cardiovascular, or oncological comorbidities and did not give consent to participate in the study.

Study protocol

All patients who met the inclusion criteria were included in the study. All patients are followed prospectively every 3-6 months, usually in the rheumatology clinic, according to a predetermined protocol for systematic data collection. The rheumatologist invited patients to participate in the study, collected signed informed

consent documents, and recorded the variables in the clinical protocol. The physiotherapist collected all evaluations.

Assessments

After the patients were evaluated by a rheumatologist, age, gender, body mass index (BMI), employment status, income level, years of education, and duration of diagnosis were recorded in the demographic and health-related information form. The Participation Scale (P-Scale) was used to examine participation.

P-Scale consists of 18 items. The scale has Turkish validity and reliability (Altuntaş et al., 2021). It is asked whether the person perceives their participation levels as equal to their "peers" in each of the situations defined by the scale items. If the person thinks that the level of participation is lower than their peers or that there is a possible restriction in participation, they are also asked to indicate how much of a problem this is in their daily life. The score that the individual gets from each item can be "no problem" = 1, "Small" = 2, "Medium" = 3, "Large" = 5 or 0 (zero) if the individual does not consider his/her participation less than his peers. The values attributed to each item are added together to obtain the total score. The P-Scale total score ranges from

0 (zero) to 90; 0 = "no restriction on participation" and 90 = "complete restriction on participation" (Altuntaş et al., 2021, Van Brakel et al., 2006).

Statistical Analysis

Statistical analyses were performed using SPSS version-22 (IBM SPSS Statistics; IBM Corporation, Armonk, NY, USA) software. Descriptive statistics of the data using mean and standard deviation for numerical variables; qualitative variables were given using percentages. Kolmogorov-Smirnov test was used to evaluate the distribution of variables before the test selection. Independent Samples T test was used for data normal distribution and Mann Whitney-U test was used for data non-normally distribution to compare the values. Linear regression analysis was used to identify factors affecting participation. The statistical significance level was assumed as $p < 0.05$.

RESULTS

111 patients with AS, 62 patients with RA, 13 patients with FMF and 13 patients with Sjögren's and 25 other rheumatic diseases (psoriatic arthritis, scleroderma, gout, lupus, Behcet's disease, polimyalgia romatica, takayasu arteritis) were included in the study. The demographic and health related data of the patients were shown in Table 1. The lowest participation scoring was in patients with RA (15.32±2.38 points, Table 1). According to the results of the study, the participation score of patients with rheumatic diseases was 11.75±11.88; score of the healthy individuals was 5.22±6.26.

Table 1. Demographic, health related values and participation scores of individuals

	Patients X±SD (n=224)	**Healthy X±SD (n=166)**	**z**	**p**
Age (year)	50.14±12.28	48.04±13.48	-2.34	0.67
BMI (kg/m²)	27.08±4.99	25.21±2.88	-3.78	0.08
Duration (months)	127.90±116.75	-		
	n (%)	**n (%)**		
Gender				
Female	155 (69.2)	108 (65.06)	-1.23	0.07
Male	69 (30.8)	58 (34.93)	-0.56	0.45
Education level			-	-
Illiterate	8 (3.6)	2		
Literate	2 (0.9)	0		
Primary school	96 (42.9)	48		
Middle school	24 (10.7)	28		
High school	52 (23.2)	53		
University	41 (18.3)	33		
Master degree	1 (0.4)	2		
Employment status			-	-
Employee	100 (44.6)	76 (45.79)		
Unemployee	124 (55.4)	90 (54.21)		

Continued (Table 1)

Income level				**-**	**-**
High	**19 (8.5)**		**57 (34.3)**		
Middle	**122 (54.5)**		**61 (36.7)**		
Low	**83 (37.1)**		**48 (28.9)**		
Participation scores by disease	**Min-max**	**X±SD**			
Ankylosing Spondylitis (n:111)	0-83	9.77±10.81	-	-	-
Romatoid Arthritis (n:62)	0-53	15.32±12.83	-	-	-
Sjogren (n:13)	0-32	11.62±11.40	-	-	-
Familial Mediaterrenean Fever (n:13)	0-40	9.92±12.72	-	-	-
Other diseases (n:25)	0-53	12.76±13.70	-	-	-

X±SD: Mean±Standard Deviation, kg:kilogram, m:meter, z: Mann Whitney U test, p<0.05

Participation score was found to be significant in favor of healthy individuals (z=-6.56, p=0.00, Table 2). In addition, it was found to be significant in favor of the healthy group in all items of the participation scale, except for the tenth, fourteenth and fifteenth items by item comparison (p=0.00, Table 2).

Table 2. Comparison groups according to participation

	Patients with rheumatic disease (n:224) X±SD	**Healthy (n:166) X±SD**	**z**	**p**
Participation Score	11.75±11.89	5.22±6.26	-6.566	0.00
Item 1	1.70±1.99	0.63±1.47	-6.619	0.00
Item 2	1.63±1.98	0.41±1.06	-7.202	0.00
Item 3	0.95±1.61	0.60±1.28	-2.792	0.00
Item 4	0.56±1.12	0.17±0.58	-4.267	0.00
Item 5	0.62±1.17	0.20±0.46	-3.557	0.00
Item 6	0.67±1.19	0.31±0.64	-2.843	0.00
Item 7	0.60±1.08	0.23±0.58	-3.466	0.00
Item 8	0.08±0.49	0.33±1.00	-2.889	0.00
Item 9	1.26±1.83	0.58±1.29	-4.465	0.00
Item 10	0.07±0.43	0.07±0.37	-0.090	0.92
Item 11	0.67±1.13	0.16±0.41	-5.267	0.00
Item 12	0.28± 1.00	0.02±0.13	-3.000	0.00
Item 13	0.51±1.01	0.02±0.13	-6.869	0.00
Item 14	0.43±1.06	0.39±0.89	-0.317	0.75
Item 15	0.43±1.09	0.77±1.48	-2.149	0.32
Item 16	0.28±0.77	0.01±0.08	-5.239	0.00
Item 17	0.47±1.11	0.17±0.54	-2.658	0.00
Item 18	0.56±1.17	0.19±0.53	-2.866	0.00

X±SD: Mean±Standard Deviation

When the variables were considered one by one, the model formed by gender, age, BMI, diagnosis, disease duration, education level, employment status and income level was entered into multiple linear regression analysis with participation. As a result of the analysis, it was determined that education level had an independent effect on participation (p=0.01). Accordingly, a significant negative correlation was found between participation and education level (Table 3).

Table 3. Investigation the relationship between participation and variables

	Unstandardized beta	Standardized coefficients beta	p*
Constant	8.49	-	0.26
Disease	.324	.069	0.30
Disease duration	.007	.067	0.31
BMI	.222	.093	0.17
Gender	-.857	-.033	0.62
Age	.047	.048	0.54
Education level	-1.529	-1.172	0.01
Marital status	.359	.054	-
Employment status	2.97	.125	0.101
Income level	-1.78	-.092	0.161

*BMI: body mass index, *p<0.05*

DISCUSSION

The aim of this study was to investigate the participation of individuals with rheumatic diseases with various diagnoses, to determine the factors affecting this, and to compare patients with healthy individuals. To the best of our knowledge, this was the first study to examine participation in patients with rheumatic diseases. According to results of this
study, the participation rate of patients with rheumatic disease was lower than the healthy ones. Furthermore, patients with RA had the lowest participation score. Although patients with RA, scleroderma, gout, polimyalgia romatica have mild participation restrictions, the patients did not have serious restriction in total. The most important factor affecting participation was the education level.

Participation is one of the most important parts of rehabilitation (Piškur et al., 2014). There is a growing consensus on the provision of scientific documentation and solutions for patients experiencing "restrictions" in participation (Goodley et al., 2012; Javanmard et al., 2021). Studies have reported that individuals with low education are more likely to have a chronic illness and are also less likely to participate in society than individuals with higher education (Scharn et al., 2019, van Rijn et al., 2014; Broese van Groenou and De Boer, 2016). In the recent study, it was observed that the participation of individuals with rheumatic disease was low when compared to the healthy ones, and the level of education had a negative effect on participation. The patient group with the lowest participation was RA. Because RA causes chronic pain and disability, it has adverse effects on patients' ability to perform certain activities of daily living (ADL) and participate in life situation or socio-economic status (Gikaro et al., 2022). Patients who had their engagement in employment, household economy, visiting inside or outdoors, social activities, respect, taking care of oneself, helping others, meeting new people, or learning new things examined individually said that they fell short of their healthy peers in these areas. However, they were same in issues of life partner, household work and family discussion. As the majority of the patients were married in our study, we believe that their involvement in these concerns is related to this. Families are more likely to participate in these scenarios because they have a designated area for their family to live. (Fakere and Ayoola, 2018).

Lower participation rates have generally been linked to lower levels of education and occupational class, however this may vary between research and populations (Reinikainen et al., 2018; Demarest et al., 2013). Higher education levels lead to higher employment rates and thus higher participation in society (OECD, 2009). Poor socioeconomic status, such as a low level of education, is frequently linked to more severe cases of numerous diseases, including RA. (Pincus and Callahan, 1994; Pincus et al., 2004; Bengtsson et al., 2005). The level of education of the patient has been linked in the literature to both beneficial and negative impacts on the course of RA. Low levels of education have been linked to severe clinical conditions and disabilities, according to certain reports. (Gamal et al., 2021, López-Castillo et al., 2014). In the current study, it was found that the factor associated with participation was

education level as expected and increase in education level also increased participation. The majority of individuals with rheumatic diseases in our study had low education level like primary school graduates (42.9%).

The strength of our study was that we included all rheumatic diseases, including rare diseases. One of our possible limitation was that our study was a cross-sectional study. Future studies should follow up on this issue. Another limitation of our study was that we could not evaluate participation within the disease because the numbers of rheumatic diseases were different from each other. Future studies may compare participation by disease and also examine different health-related factors such as sedimentation rate or disease activity etc. that may affect participation.

As a result, the participation of patients with rheumatological conditions is lower than their healthy peers, and education level has a significant role in participation. Due to the low participation rate, patients should be enrolled in rehabilitation programs for their health and well-being. Furthermore, it is imperative to conduct follow-up research and implement strategies to enhance the participation of these patients in society. This study suggests the importance of evaluating participation before starting rehabilitation programs in individuals with rheumatic diseases, and recommending that programs be planned in a way that will increase participation.

Ethical Approval

The Antalya Training and Research Hospital Clinical Ethical Commitee approved this study. (Protocol number: 2023-036).

Authors' Contribution

Data collection and intervention process was carried out by the SYC, OKK, SY, DSK. The conception, design, control, analysis and interpretation, literature review, manuscript writing and critical appraisal processes were carried out jointly by SYC, OKK, SY, DSK, AA.

Conflicts of Interest Statement

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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