Perceived stigma in fibromyalgia patients and related factors

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Abstract

Aim: Familial and social support is low in fibromyalgia patients. The present study aimed to determine the stigma in fibromyalgia and related factors.

Materials and Methods: The study is an observational, descriptive, cross-sectional study. Between May-December 2020, two groups who applied to an outpatient clinic formed the participants: the first group included patients with Fibromyalgia and the second group consists of healthy controls. The presence of stigma was evaluated using the Stigma Scale for Chronic Illnesses. The Multidimensional Scale of Perceived Social Support, The Distress Tolerance Scale, The Discomfort Intolerance Scale, the Fibromyalgia Impact Questionnairev and Visual Analog Scale were used to determine the related factors.

Results: In this study, which included 92 fibromyalgia and 46 healthy volunteers , stigma was significantly higher in fibromyalgia patients compared to the healthy controls (p = 0.002). A significant relationship was found between stigma and disease impact (p < 0.001). In addition, as the duration and impact of the disease increased, the stigma scores increased and the rates of social support and resilience decreased (p < 0.001).

Conclusion: In fibromyalgia patients, the long duration of the disease, low level of social support and high disease impact can be counted among the factors associated with stigma.

Introduction

Stigma is a vigorous social process characterized by stereotyping, labeling and separation, all occurring in the context of power, leading to loss of status and discrimination [1]. By definition, it can be considered as a negative attitudes and beliefs towards a group of people because of their features.ıIn the literature, stigma has generally been evaluated for different mental and neurological diseases including dementia, Alzheimer's disease or Down syndrome for children. Psychiatric diseases such as schizophrenia, bipolar disorder, and depression also have been particularly studied in terms of both social and self-stigma [5]. Additionally, stigma was evaluated in infectious diseases, mostly for leprosy and AIDS [6]. Especially recently, stigma has become important in our lives with the COVID-19 infection, worldwide [7]. In the first months of the disease, it was necessary to fight against the disease and the stigma in case of both the health workers and the survivors of the disease [8].

Stigma comes from a Greek word meaning to mark; there are also ways to express shame, stigma or mockery, stigma.

It is mostly due to ignorance and education. Stigmatization of people with chronic diseases leads to discrimination in social life. This discrimination may also have effects on the treatment, progression, morbidity and mortality of the disease. When these patients and diseases are approached with prejudice, especially in psychiatric diseases, the patient may refuse treatment and delay rehabilitation. For this reason, it is important to detect the stigma in different chronic diseases and to investigate its effect on the disease [5, 9]. Different types of stigma have been proposed in the literature; public stigma, structural stigma, courtesy stigma, provider-based stigma, and self-stigma (also known as internalized stigma) are classified [9].

Fibromyalgia, is a chronic disease characterized by subjective complaints such as widespread body pain, fatigue, depression, sleep disturbance, abdominal pain, migraine etc. [10]. Fibromyalgia, like other chronic diseases, has different effects on the patient, the treating physician, and her/him family and the environment. [11]. Adressing the stigma and related factors is important in the management, activities of daily living and treatment of fibromyalgia patients. Perceived stigma have been found higher in fibromyalgia patients than rheumatoid arthritis patients and the stigma associated with lower well-being [12]. Fibromyalgia has been a stigmatizing disease that cannot

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be definitively diagnosed, although it has some diagnostic criteria, and sometimes the patient cannot convince the treating doctor or relatives that she has chronic pain, and also psychological predisposition is blamed. Because of the contradictions [13], the aim of the present study was to search for the stigma in Fibromyalgia patients and to research other factors that may be associated with stigma such as social support, distress and discomfort tolerance using various questionnaires.

Materials and Methods

The present study is an observational, descriptive, cross-sectional study conducted between May and December 2020 in an outpatient clinic. Ethical approval for study was obtained from the Ethics Committee of Gaziosmanpaşa Taksim Training and Research Hospital. (22.01.2020 and approval number 2020/13). Signed consent was obtained from all participants. Inclusion criteria of the study in the patient group were: Patients over 18 years old and diagnosed with fibromyalgia according to the revised criteria of the American College of Rheumatology 2016. Exclusion criteria were: Having any diagnosis that may cause secondary fibromyalgia (including any rheumatic diseases such as rheumatoid arthritis, ankylosing spondylitis), anemia, Vitamin D deficiency, any known endocrine, neurological or cardiac disease and usage of antidepressants. Demographic information of the patients and the healthy controls were recorded. In addition, the Stigma Scale in Chronic Illnesses was filled in order to investigate the presence of stigma, the Multidimensional Scale of Perceived Social Support to evaluate the level of social support, and both the Distress Tolerance Scale and the Discomfort Intolarance Scale were filled to determine the levels of resilience. In addition, the Fibromyalgia Impact Questionnaire and Visual Analog Scale (VAS) were filled.

The Stigma Scale in Chronic Illnesses (SSCI)

The Stigma Scale in Chronic Illnessesscale (SSCI) is a questionnaire consisting of 24 questions in total and each question is scored between 1 and 5, measures the stigma levels of patients. The survey was created by Rao et al. in 2009 [14] and Turkish validity and reliability were determined by Karşıdağ et al. [15].

The Multidimensional Scale of Perceived Social Support (MSPSS)

The Multidimensional Scale of Perceived Social Support scale (MSPSS) is a questionnaire consisting of 12 questions in total, which measures the social support levels of the patients. The survey was created by Zimet et al. in 1988 [16] and validity and reliability study for Turkish population made by Eker et al. [17].

The Distress Tolerance Scale (DTS)

This scale is a questionnaire consisting of 15 questions in total, measures the distress level of the patients. The survey was created by Simons et al. in 2005 [18] and Turkish validity and reliability study for Turkish population made by Sargın et al. [19].

The Discomfort Intolerance Scale (DIS)

This scale is a questionnaire consisting of 7 questions in total, measures the level of tolerance of the patients' discomfort. The survey was conducted in 2006 by Schmidt et al. [20] and validity and reliability study for Turkish population conducted by Özdel et al. [21].

Fibromyalgia Impact Questionnaire (FIQ)

This scale is a questionnaire consisting of 26 questions in total and is measures the level of impact of the disease on the patients. Questionnaire created in 1991 by Burckhardt et al. [22] and validity and reliability study for Turkish population made by Sarmer et al. [23].

Visual Analog Scale (VAS)

Fibromyalgia patients were asked to mark progressively between 0 and 10 cm on a straight line, 0 no pain, 10 experienced and severe pain. Then the results were measured with a ruler and indicated in cm. [24].

Sample size

Initially, 5 patients were recruited into each group and their stigma scores were recorded. The effect size of the stigma scores was 0.34 for this pilot sample. Using GPower (ver. 3.1.9.2., Germany) with $\alpha = 0.05$, power $= 0.80$, and an allocation ratio of 2:1, the total sample size was calculated as 138 subjects (92 Fibromyalgia patients and 46 controls).

Statistical analysis

For all statistical analyses SPSS version 24.0 software (IBM Corporation, Armonk NY, USA) was used. The normal distribution of the data was determined by Shapiro-Wilk test. Continuous variables were expressed as mean $\pm$ SD and minimum-maximum, categorical variables as number and percent. The groups were compared using the independent samples t-test for continuous variables and the chi-square test or Fisher's exact test, where applicable, for categorical variables. The Spearman correlation coefficients were used to evaluate the association between the continuous variables. P value < 0.05 was considered statistically significant.

Results

A total of 138 participants; 92 Fibromyalgia patients and 46 healthy controls, were included in the present study.

Demographic information including age, gender, height, weight and body mass index of both Fibromyalgia patients and the healthy controls was shown in Table 1. There were no significant difference between groups for demographic features ($p > 0.05$).

The clinical characteristics and results of the questionnaires were shown in Table 2.

Fibromyalgia patients stated that they were exposed to stigma significantly compared to the healthy controls using SSCI ($p = 0.002$). In addition, it was statistically significant that their social support was less compared to the control group using MSPSS ($p = 0.011$). Another point

Table 1. Demographic features of the patients and healthy controls.

	Fibromyalgia Patients (n = 92)	Healthy Controls (n= 46)	p values
Age, years, (mean ± SD)	33.1 ± 7.8	34.9 ± 13.5	0.281
Gender, female, (n, %)	78, 84.7 %	36, 78.2 %	0.101
Height, cm, (mean ± SD)	153.1 ± 15.5	154.1 ± 12.9	0.764
Weight, kg, (mean ± SD)	76.1 ± 11.8	78.2 ± 13.4	0.314
BMI, kg/m^2, (mean ± SD)	27.3 ± 4.7	27.2 ± 6.6	0.873

cm: centimeters, kg: kilograms, m: meter, BMI: Body Mass Index, significance level p < 0.05.

Table 2. Clinical features of the fibromyalgia patients and the healthy controls.

	Fibromyalgia Patients (n = 92)	Healthy Controls (n= 46)	p value
Duration, months	8.3 ± 7.6		
SSCI	17.3 ± 4.3	4.9 ± 1.7	0.002
MSPSS	19.1 ± 8.2	38 ± 13.5	0.011
DTS	32 ± 5.6	49 ± 10.9	0.032
DIS	5.4 ± 3.6	12.1 ± 4.4	0.021
FIQ	55.3 ± 13.8		
VAS	6.1 ± 2.9		

SSCI: The Stigma Scale in Chronic Illnesses, MSPSS: The Multidimensional Scale of Perceived Social Support, DTS: The Distress Tolerance Scale, DIS: The Discomfort Intolerance Scale, FIQ: Fibromyalgia Impact Questionnaire, VAS: Visual Analog Scale, significance level p < 0.05.

Table 3. Correlation between stigma scores and related factors in fibromyalgia patients.

	SSCI scores	
	rho	p value
MSPSS	-0.452	< .001
DTS	0.361	0.088
DIS	0.539	0.275
FIQ	0.511	< 0.001
VAS	0.871	0.466

SSCI: The Stigma Scale in Chronic Illnesses, MSPSS: The Multidimensional Scale of Perceived Social Support, DTS: The Distress Tolerance Scale, DIS: The Discomfort Intolerance Scale, FIQ: Fibromyalgia Impact Questionnaire, VAS: Visual Analog Scale, significance level p < 0.05.

was that as the duration of the disease increased in the impact of the disease on Fibromyalgia patients was increased and social support decreased significantly (p < 0.001).

While fibromyalgia patients had lower scores on the distress tolerance scale and the discomfort intolerance scale, this situation was significant between fibromyalgia patients and healthy controls (Table 2). Also, no significant correlation was found between VAS values and SSCI scores (p > 0.05) (Table 3).

Discussion

In the present study, perceived stigma in fibromyalgia patients was found significantly higher than the healthy controls. Additionally, social support was significantly lower in fibromyalgia patients. Although lower scores were obtained in tolerance scales compared to healthy controls, no significant difference was found in the fibromyalgia patient group.

The presence of stigma has been shown in different diseases. Valery et al. have shown stigma in mental health professionals treating schizophrenia in a systematic review [25] and weight stigma was shown in obese patients in a meta-analysis by Emmer et al [26]. Stigma was also shown in healthcare workers after the COVID-19 pandemic [27]. In the present study we found higher stigma scores using SSCI in fibromyalgia patients compared to the healthy controls.

In a recent study life satisfaction, psychological well-being and quality of life negatively correlated with stigma in healthcare workers during the pandemic [28]. Another study found a relationship between stigma and education level in cancer patients [29]. HIV-related stigma was also associated with poor adherence to therapy and psychological stress [30]. In another study searching stigma in tuberculosis patients, increasing the education of the patient about the disease and the function of the patients' relatives were shown among the precautions that can be taken against stigma in tuberculosis [31]. In epilepsy patients, having epilepsy related deformities, other chronic illnesses and a longer duration of antiepileptic drug use were shown as related factors for stigma [32]. In our study, we found a negative significant correlation between stigma scores and social support in fibromyalgia patients. We also found a positive significant correlation between disease duration and stigma levels.

There are few studies investigating the presence of stigma in fibromyalgia patients. A study conducted by Alboom et al. compared fibromyalgia patients with rheumatoid arthritis and found higher stigmatization in fibromyalgia patients [12]. Another study by Armentor conducted interviews with fibromyalgia patients and found disbelief and lack of understanding about the disease [33]. Quintner also stated that studies addressing the stigmatization of fibromyalgia patients are poor [13].The primary limi-

tation of our study was the absence of the third group with another chronic pain condition. We only compared fibromyalgia patients and healthy controls. In addition, we did not evaluate how stigma perception changed in fibromyalgia patients after treatment. Thirdly, we did not compare the stigma perception of patients who were aware of their disease and those who were unaware of their disease. After the diagnosis was confirmed how stigma was changed should be investigated in further studies.

Conclusion

In conclusion, the present study shows that stigma increases significantly as the level of social support decreases in fibromyalgia patients. In addition, as the duration of the disease increases, stigma scores increase significantly. Future studies should evaluate the effect of treatment on stigma and disease impact of fibromyalgia patients.

Ethics approval

Ethical approval for this study was obtained from the Ethics Committee of Gaziosmanpaşa Taksim Training and Research Hospital (22.01.2020 and approval number 2020/13).The study was designed to be compatible with the latest updated version of the Declaration of Helsinki.

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