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Original Article

Anticipated Stigma and Related Factors in Patients with Chronic Diseases

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ABSTRACT

Objective: The aim of this study was to investigate the anticipated stigma and related factors in patients with chronic diseases, who were under treatment in in-patient clinics.

Methods: The data of this descriptive study were collected from a total of 195 individuals with chronic diseases between May and August 2022. The patient information form, the Anticipated Stigma Scale for Chronic Illnesses, the Barthel Index for Activities of Daily Living, and the Beck Depression Scale were used for data analysis.

Results: The mean age of the 195 participants was 51.8 (±17.6) years and the mean duration of disease diagnosis was 75.4 (±102.1) months. The total stigma scale score was 1.92 (±0.6), and the highest score obtained from the sub-dimensions belonged to work life, which was 2.5 ± 1.0. The mean stigma score was compared according to socio-demographic characteristics and revealed no significant difference ($P > .05$). It was observed that the stigma score of the patients with affected economic ($P = .044$), social ($P = .006$), and private ($P = .001$) lives was significantly higher. Furthermore, a negative correlation was determined with the mean Barthel Index score ($P = .023$), and a positive correlation was observed with the depression scale score ($P < .001$).

Conclusion: It was observed that the stigma score was highest in the work-life sub-dimension and that the level of stigma was related to both physical sufficiency and psycho-social wellness of the patients with chronic disease. Therefore, it has been considered that both the physical and pyschosocial health of the patients is of high importance in providing holistic care.

Keywords: Chronic illness, anticipated stigma, activities of daily living, depression

Introduction

The word stigma was first defined by Goffman as "undesired difference" and "a qualification which devalues and falls the individual out of favor," in 1963.[1] In other words, the individuals blame themselves for the diseases they have and feel worthless and different from other people.[2] Enacted stigma may be defined as the discrimination that really exists and that is performed by other people, whereas anticipated stigma may be defined as the belief of the patients that they are going to be discriminated in the absence of a real imposition.[3] It has been reported in many of the chronic diseases that anticipated stigma, rather than imposed stigma, caused a higher stress level and psychological load and impaired the quality of life.[4-7] This is due to the fact that patients believe that all adverse events they experience are related to the disease they have and that they are exposed to discrimination, although they are not. Furthermore, these individuals feel that they will meet many negative events and discriminations in their future lives.[8] Therefore, anticipated stigma may lead to a negative attitude of the patient developing against his/her own disease, insufficient benefit from the health care system, non-compliance to therapy, impaired self-control, and increased psychiatric problems in patients with chronic disease.[9,10] From the moment of diagnosis, concepts such as adaptation to the disease, self-management, and self-efficacy are emphasized for individuals with chronic disease[11] because chronic diseases cannot be eliminated with short-term treatment and require long-term care. Therefore, it is essential for the patient to adapt to the disease and to have good self-management in disease management. However, if patients believe they will be discriminated against because of their diagnosis (expected stigma), their health-seeking behaviors and disease management will be adversely affected.[12] This situation can be compared to a vicious circle, in which deterioration in physical

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health can cause psychosocial influence, and psychosocial influence can worsen physical health. Therefore, holistic care should be offered to patients.[13] Henderson (1978),[14] one of the nursing theorists, states that the individual is a component of physical, social, emotional, and intellectual needs and that any disruption in one of them will affect the other. Therefore, the nurse should not only focus on the patient's physical health but should provide holistic care to the patient. Since stigma contributes to psychiatric comorbidity and worsens the quality of life in chronic diseases, it should be emphasized that it is an important issue to be evaluated.[15] In our country, the number of studies on the anticipated stigma in chronic diseases is limited and the subject is rather new, because the validity study of "Anticipated Stigma Scale for Chronic Illnesses," which may be performed for all types of chronic illnesses and which evaluates stigma in many different aspects, has only recently been conducted.[16] In this thesis study conducted by Tünerir (2019), patients' diagnoses were mostly composed of neurological diseases, and no different types of diseases such as oncological or respiratory diseases were included. The aim of our study was to investigate the anticipated stigma level and related factors in patients with varying chronic diseases hospitalized in in-patient clinics.

Research Questions

1. What is the level of "expected stigma" in individuals with chronic disease?
2. What are the factors associated with expected stigma in individuals with chronic disease?

Methods

Study Design and Participants

The data of this descriptive, cross-sectional study were collected between May and August 2022 via face-to-face interviews. The sample size was determined by considering a similar study.[8] As a result of the power analysis using the G*Power 3.1 program, with 95% power, 5% margin of error, and $d = 0.31$ effect size, a total of at least 136 samples were found to be sufficient. However, considering that there may be losses, 20% of sample was added, and the study sample was determined as 164. The sample of this study consisted of a total of 195 patients hospitalized in the inpatient services of a university hospital due to various chronic diseases, and more patients than the specified sample number were reached. A total of 195 patients hospitalized in the in-patient clinics of a university hospital due to various chronic diseases constituted the sample of this study (Figure 1). The inclusion criteria were the presence of a chronic disease diagnosed for a minimum of 3 months, age of 18 or older, ability to read and write, absence of a communication problem, and presence of the will to participate in the study.

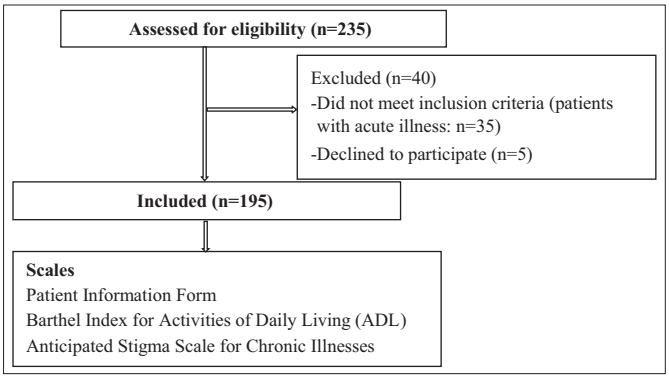

Figure 1. Sample selection and study flow diagram.

Measures

The Patient Information Form, the Anticipated Stigma Scale for Chronic Illnesses, the Barthel Index for Activities of Daily Living (ADL), and the Beck Depression Scale were used for the data analysis.

Patient Information Form

The form was developed by the investigators in order to evaluate the sociodemographic (age, gender, educational status, etc.) and disease-related (diagnosis, duration of diagnosis, etc.) information and included 14 questions [9,10,17,18]

Barthel Index for Activities of Daily Living

The Barthel index scale was first developed by Mahoney and Barthel in 1965 and included 10 items.[19] The scale questions feeding status, cleaning, self-care and dressing ability, defecation control, urination control, mobility status of the patients such as toilet visit, transfer from the bed to wheel-chair, walking or dependence on wheel-chair, and the ability to climb stairs. It measures the level of these activities performed by the patients independently, alone, and without any verbal or physical help. The Turkish validity and reliability study of the scale was conducted by Küçükdeveci et al (2000)[20], and the score to be obtained varies between 0 and 100 and Cronbach's alpha internal consistency coefficient was reported as 0.93. Higher scores indicate a better independence level for daily activities of the patient. In this study, Cronbach's alpha value was found to be 0.90.

Anticipated Stigma Scale for Chronic Illnesses

The scale was developed by Earnshaw et al[17] in order to measure the stigma level expected by patients with chronic diseases from their surroundings. The scale was prepared with 3 sub-dimensions as the anticipated stigma level measured in people including family and friends, colleagues, and healthcare providers and included 12 items. The mean scores were calculated independently for each sub-dimension and a total of 3 stigma levels were obtained. The mean scores of all items were calculated to obtain the total stigma level. Higher scores revealed higher levels of stigma. The Turkish validity and reliability study was conducted by Tünerir (2019)[16], and the Cronbach alpha coefficient was reported as 0.85. In this study, the Cronbach alpha coefficient of the scale was determined as 0.80.

Beck Depression Inventory

The scale with a total item count of 21 was developed by Beck et al.[21] and the Turkish adaptation was conducted by Hisli et al[22] The scale measures the severity of depressive mood. The score to be obtained varies between 0 and 63, and higher scores indicate depressive mood. In Turkish population, the cut-off point was reported to be 17, and Cronbach`s alpha coefficient was 0.90[23] In this study, the Cronbach alpha coefficient of the scale was determined as 0.90.

Statistical Analysis

The International Business Machines Statistical Package for Social Sciences Statistics 22 (IBM SPSS, Armonk, NY, USA) program package was used for the statistical analysis. The compliance of the data to the normal distribution was evaluated using the Kolmogorov–Smirnov test. It was determined that the data did not fit the normal distribution, and nonparametric tests were used. First, descriptive statistics of the data were presented (mean, standard deviation, frequency). The Kruskal–Wallis test was used to evaluate more than 2 groups, and the Mann–Whitney *U* test was used to determine the group that caused the difference. Spearman's rank correlation coefficient was used to examine the correlation between scales. Significance was accepted at a *P*-level of $<.05$.

Ethical Consideration

Ethical approval was obtained from the Ondokuz Mayıs University Ethical Committee of Clinical Research (Date: April 13, 2022, Ethical No: 2022/186) and institutional consent was obtained from the institute of the study, prior to data collection. Written informed consents of the patients were obtained prior to the study.

Results

The mean age of the 195 participants was 51.8 (±17.6) years and the mean duration of disease diagnosis was 75.4 (±102.1) months. More than half of the patients were female (59.0%) and primary/secondary school graduates (63.1%). The vast majority of the patients with chronic diagnosis had oncological (30.8%) and neurological (26.2%) diseases. The mostly affected aspects of life were social (71.3%), economic (70.3%), and private lives (59.5%) (Table 1).

It was accepted that the patients who scored 3 or more points on the stigma scale according to the histogram felt stigmatized. Accordingly, 36.9% of the patients had stigma (Table 2).

The total score of the Barthel Index (ADL) was 83.4 (±22.5), and the depression scale score was 19.0 (±10.0). The total stigma scale score was 1.92 (±0.6), and the highest score obtained from the sub-dimensions belonged to work life, which was 2.5 ± 1.0 (Table 3).

The mean stigma score was compared according to the sociodemographic characteristics, which revealed no significant difference ($P > .05$). The relationships between the clinical and psychosocial characteristics were investigated and it was observed that the stigma score of the patients with affected economic ($P = .044$), social ($P = .006$), and private ($P = .001$) lives was significantly higher. Those with respiratory system disease had the highest stigma score. In addition, the stigma score of those with respiratory system disease was significantly higher than the score of individuals with neurological and oncological diseases ($P = .009$). Furthermore, it was observed that the stigma score negatively correlated to the mean Barthel index score ($P = .023$), and positively correlated to the mean depression scale score ($P < .001$) (Table 4).

Discussion

Anticipated stigma expresses the feelings of shame, self-blaming, and discrimination perceived due to the disease/diagnosis the patient has. Stigma causes an additional burden to the patients while they are dealing with the disability caused by the chronic disease. Stigma impairs the psychosocial well-being and quality of life of the patients, reduces compliance to the disease, and increases the rate of psychiatric comorbidities such as anxiety and depression.

In this study comprising individuals with many different chronic diseases, the mean stigma level score was observed to be minimal to moderate. Similar outcomes were observed in the study of Tünerir (2019); however, the mean score was relatively higher.[16] This may be due to many reasons; however, disease diagnosis can be counted as the main factor. Our study did not include those with a diagnosis of rheumatological disease, and Tünerir's (2019) study does not include those with a diagnosis of neurological and oncological diseases. In some of the studies conducted in different countries, the stigma score was relatively higher,[6,24] and in some others, it was relatively lower,[17] and some were similar to ours.[7,10] Many factors may have contributed to this difference in the stigma score. These include sociodemographic (age, gender, educational status, employment status, etc.), clinical (age of onset, duration of onset symptom burden, comorbidity, drugs used, etc.), and psychosocial factors (psychological well-being, perceived social support, meanings attributed to diseases by society, the effect of the disease on social life, etc.).

Although there are differences between studies with regard to stigma scores, it is important to emphasize one common feature. The anticipated stigma score in work life was highest among all, which was similar in all studies. It has been reported in many studies that this feeling of the patients is not meaningless, and many individuals have

Table 1. Sociodemographic and Clinical Characteristics of Patients (N = 195)

	n	%
Age (mean ± SD)	51.82 ± 17.65	
Duration of diagnosis (month) (mean ± SD)	75.48 ± 102.11	
Gender		
Female	115	59
Male	80	41
Education		
Primary/secondary school	123	63.1
High school	37	19
University and higher	35	17.9
Employment		
Employee	30	15.4
Homemaker	69	35.4
Student	10	5.1
Retired	67	34.4
Unemployed	19	9.7
Marital status		
Married	138	70.8
Single	38	19.5
Divorced/widow	19	9.7
Income		
Good	29	14.9
Moderate	143	73.3
Bad	23	11.8
Diagnosis		
Respiratory system disease	13	6.7
Cardiovascular system disease	20	10.3
Neurological system disease	51	26.2
Endocrine system disease	29	14.9
Nephrological disease	13	6.7
Oncological disease	60	30.8
Other (gastrointestinal, immune system)	9	4.6
Barthel ADL Index		
Total dependency (0-20)	5	2.6
Severe dependency (21-61)	27	13.8
Moderate dependency (62-90)	70	35.9
Slight dependency (91-99)	23	11.8
Independent (100)	70	35.9
Has the disease negatively affected your economic life?		
Yes	137	70.3
No	58	29.7
Has the disease negatively affected your social life?		
Yes	139	71.3
No	56	28.7
Has the disease negatively affected your private life?		
Yes	116	59.5
No	79	40.5

ADL, activities of daily living; SD, standard deviation

Table 2. Frequencies of Stigma Scale Items and Total Score (N = 195)

Item no	Items	>3 points* n (%)
Friends and family		
1	A friend or family member will think that your illness is your fault	47 (24.1)
2	A friend or family member will not think as highly of you	39 (20.0)
3	A friend or family member will blame you for not getting better	49 (25.1)
4	A friend or family member will be angry with you	23 (12.8)
Work colleagues		
5	Someone at work will think that you cannot fulfill your work responsibilities	115 (58.9)
6	Your employer will assign a challenging project to someone else	99 (50.7)
7	Someone at work will discriminate against you	121 (62.1)
8	Your employer will not promote you	116 (59.5)
Healthcare workers		
9	A healthcare worker will blame you for not getting better	39 (20.0)
10	A healthcare worker will be frustrated with you	29 (14.9)
11	A healthcare worker will give you poor care	19 (10.8)
12	A healthcare worker will think that you are a bad patient	43 (22.1)
Stigma scale total		**72 (36.9)**

*According to the histogram of the total score of the scale, those who score 2 points or less are considered to have no stigma, and those who score above 3 points are considered to have stigma. This means that the patients chose one of the options maybe (3), probably (4), and most likely (5) for each item.

experienced occupational and economic problems following the diagnoses they had.[18,25-27]

Previous studies have reported that individuals with chronic diseases are mostly exposed to discrimination in their work life.[28-32] This discrimination by society is defined as enacted stigma. Therefore, they think individuals who have witnessed this discrimination will also be exposed to it. In this case, the expected level of stigma in work life is high. Interestingly, in our current study, although most patients were not actively working (retired and homemakers), the expected stigma in business life was high. This may be related to previous negative experiences of the patients. For example, if he had problems in work life before retiring, the stigma on this issue would be high. In addition to all of this, the economic and psychosocial lives of individuals whose work lives are affected are directly affected. In our study, a higher stigma score was obtained which reflected the impaired economic life of the patients, which supported these findings. Treatments for chronic diseases are costly, and economic problems affect the patient and his family.[33,34] When the burden of stigma is added to the burden of the disease, the patients' quality of life is adversely affected. Therefore, patients with diagnosed chronic diseases should be questioned if they experience problems with their occupational lives, and they should be supported by communicating with the related department when necessary.

Table 3. The Mean Scores of the Functional Scales of the Patients

Scales	Mean ± SD	Min-Max
Barthel ADL Index	83.41 ± 22.58	0-100
Depression	19.08 ± 10.07	0-55
Stigma_family	1.70 ± 0.97	1-5
Stigma_work	2.57 ± 1.05	1-5
Stigma_healthcare	1.49 ± 0.72	1-3.75
Stigma_total	1.92 ± 0.61	1-4.17

ADL, activity of daily life; SD, standard deviation.

Table 4. Comparison of Patients' Mean Stigma Score According to Sociodemographic, Psychosocial, and Clinical Characteristics

Characteristic	Mean ± SD	*P**
Age		.065
Gender		
Female	1.92 ± 0.59	.778
Male	1.91 ± 0.64	
Education		
Primary/secondary school	1.93 ± 0.55	.079
High school	1.77 ± 0.73	
University and higher	2.04 ± 0.65	
Marital status		
Married	1.95 ± 0.62	.082
Single	1.73 ± 0.55	
Divorced/widow	2.09 ± 0.56	
Has the disease negatively affected your economic life?		
Yes	1.98 ± 0.62	**.044**
No	1.77 ± 0.57	
Has the disease negatively affected your social life?		
Yes	2.00 ± 0.64	**.006**
No	1.71 ± 0.48	
Has the disease negatively affected your private life?		
Yes	2.05 ± 0.64	**.001**
No	1.73 ± 0.52	
Diagnosis		
Respiratory system disease	2.53 ± 0.72	**.009**
Cardiovascular system disease	1.87 ± 0.44	
Neurological system disease	1.79 ± 0.56	
Endocrine system disease	1.87 ± 0.63	
Nephrological disease	2.05 ± 0.54	
Oncological disease	1.84 ± 0.59	
Other (gastrointestinal, immune system)	2.36 ± 0.68	
Barthel Index (ADL)		**.023**
Beck Depression Inventory		**<.001**

*For correlation analysis for continuous variables, Mann–Whitney *U* and Kruskal–Wallis analysis were used for other variables.
ADL, activity of daily life; SD, standard deviation.

It was observed that stigma scores differed according to the diagnosis of the diseases in different individuals. Interestingly, the stigma score was observed to be highest in individuals with respiratory system diseases. It has been reported in the literature that the stigma level is affected by factors such as disease progression, concealment and etiology, destructive effect of the disease, perception of the disease, and esthetic concerns.[35] Symptoms such as dyspnea, severe cough and expectoration in respiratory system diseases, and use of assisted respiratory equipment/medications make the disease apparent and eliminate the potential to conceal it. In addition to its apparency, the effect of the disease on daily life may be the factor that increases the score of stigma as well. Furthermore, recent studies have reported that the diagnosis of smoking-related diseases leads to an increase in the self-blaming of an individual and to a related increase in the stigma level.[10,36]

Chronic diseases may negatively affect both physical and the psychological health of individuals to a significant extent. Daily life activities (83.41 ± 22.58) and depression (19.08 ± 10.07) scale scores reveal

that the patients had moderate physical dependence and moderate depressive mood. Additionally, it was determined in our study that both factors were related to anticipated stigma.

Individuals with a decreased physical independence due to illness become dependent on others and may encounter problems such as losing their job and being limited in their social life. In addition, the thought of being a burden to others can be experienced intensely, and this can increase the expected stigma.[37,38] Individuals physically dependent on others may experience both imposed and expected stigma simultaneously, and both are correlated. However, mental health is as important as physical health in terms of stigma, and the contribution of depression to stigma in our study supports this situation. There is a 2-way relationship between depression and stigma.[39,40] As depression increases, individuals focus on their deficiencies, perceive themselves negatively, and isolate themselves from society more because of their illness. Similarly, increased stigma can accelerate the onset of depression and negatively affect treatment behavior.[41] Physical insufficiency is considered as the first step during caregiving to patients with chronic diseases, and mental health is generally underestimated. Considering many studies reporting the relation of depression with stigma,[9,42-44] the mental health of the patient should not be disregarded, because chronic diseases have bio-psychosocial effects, and therefore, the patient should be considered in a holistic manner. In our present study, the majority of the patients mentioned that their social, economic, and private lives had been negatively affected due to their diseases, and it was observed that these patients had higher stigma scores.

In conclusion, it was observed that the anticipated stigma level in chronic diseases was related to the diagnosis the individual had and to the diagnosis-related physical disability and psychosocial exposure, rather than the sociodemographic characteristics. In light of these data, both physical and psychosocial health of the patient should be considered in a holistic manner and a holistic management should be carried out.

Study Limitation

The limitations of this study were the inclusion of individuals with different types of chronic diseases, unequal distribution of the diagnoses, non-inclusion of patients in all internal disease clinics (patients with rheumatological diseases could not be included since the rheumatology clinics were closed), and the study was a single-center study. The presence of many diseases in this study can be considered a limitation because the diagnoses of the diseases were gathered under the general heading. For example, diseases such as epilepsy, multiple sclerosis (MS), and stroke could not be discussed in detail. These diseases were included only under the heading of neurological disorders. However, the level of stigma in each condition is different. Therefore, it is recommended to consider this situation in future studies. Furthermore, it should not be forgotten that patients may have been noncommittal about being objective during the face-to-face interviews. Therefore, further studies should be conducted, providing a more proper environment for the patients.

Ethics Committee Approval: Ethics committee approval was received for this study from the ethics committee of Ondokuz Mayıs University (date: April 13, 2022, number: 2022/186).

Informed Consent: Written informed consent was obtained from patients with multiple sclerosiswho participated in this study.

Peer-review: Externally peer-reviewed.

Declaration of Interests: The author declare that they have no competing interest.

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