Research Article

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Stigmatisation of tuberculosis patients

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ABSTRACT

Background: Stigma is an important barrier to tuberculosis diagnosis and treatment. This research has been conducted to determine the status of the stigmatisation of tuberculosis patients.

Methods: Descriptive study. This research population consisted of 129 patients with tuberculosis who have been undergoing a treatment in Ankara. This study was conducted between 03.09.2012 and 31.01.2013. The data have been collected using the "socio-demographic questionnaire" and "Stigma scale for patients with tuberculosis". Evaluation of data has been carried out using numbers, percentages and t test, one-way analysis of variance and Tukey tests.

Results: 50.4% of the patients who participated in our research were females and 60.5% had pulmonary tuberculosis. In this study, the mean score of the patients in the general scale was $\overline{X} = 69.6 \pm 12.6$, and stigma levels of more than half of the patients (53.4%) were determined to be high. The highest average score of the patients in the scale was at the "Felt stigma" sub-dimension ($\overline{X} = 29.9 \pm 6.3$), while the lowest average score was at the "Family/friend Relationship" sub-dimension ($\overline{X} = 11.3 \pm 3.8$).

Conclusions: The healthcare institutions and authorities dealing with tuberculosis can perform practices that reduce the stigma levels of the patients and the society by making use of the conclusions of this research.

Keywords: Tuberculosis, Stigma, Nursing

INTRODUCTION

Stigma is considered to be a social process that gives a mark or attribute to individuals and is characterised by exclusion, rejection, blame or devaluation. Goffman defined stigma as an "attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted, discounted one". Considering the literature, it can be clearly seen that patient groups with AIDS and tuberculosis suffer more intensely from stigma.

Most studies identify the perceived contagiousness of TB as a leading cause of stigmatisation, although there are various reasons as to why TB is stigmatised.²⁻⁴ Among different reasons is the fact that tuberculosis is a disease transmitted through the air, which people do not know

much about and its treatment. It also has a bad reputation from the past.^{3,4} A number of studies show that the stigma may result in delays in the diagnosis and lead to depression or cause the patients to discontinue the treatment process, conceal their diagnoses and withdraw from society.²⁻⁵ In addition, the patients are accused by their families and those around them of contacting the disease because they have not taken good care of themselves. This situation places a huge strain on the patients and affects the treatment adversely. Stigmatisation of the tuberculosis patients by society is one of the most important obstacles to eliminating this disease.

There are many studies on the stigmatisation of TB patients worldwide. However, only one study is available on the stigma in our country.

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The results to be obtained from this study will guide the education and counselling of the patients and society. This research has been conducted to determine the status of the stigmatisation of tuberculosis patients registered at the tuberculosis dispensaries in the province of Ankara.

METHODS

The research population comprises 468 patients, who have been under treatment at Ankara Central Tuberculosis dispensaries No.1, 2, 3, 4, 5, 6 and 7, which are located within the boundaries of the Ankara metropolitan municipality. This study was conducted between 03.09.2012 and 31.01.2013. The patients, who came to the dispensaries between the dates specified, were included in the research. In total, 129 tuberculosis patients participated in the research. The data have been collected using the "General information form" and "Stigma Scale for Patients with Tuberculosis (SSPT)". The General information form consists of 18 questions that determine family history of tuberculosis and affect stigmatisation of patients, including age, sex, education, employment, social security, smoking and alcohol use.

"SSPT" has been developed by Havva Sert. 12 It is a Likert-type scale containing a total of 33 negative and positive expressions that aim at measuring the stigma level of tuberculosis patients, which includes four "Agree", "Disagree", "Strongly agree", "Strongly disagree". In the scale, the opinions of the patients regarding the stigma are graded as "4" for strongly agree, "3" for agree, "2" for disagree and "1" for strongly disagree. Questions 2, 4, 17, 18, 19, 22, 23, 25, 26, 27, 28, 30 and 31 are graded reversely. The scale is composed of four sub-dimensions: "Felt stigma, Selfperception, family-friend relationship, internalized stigma". The higher the scores received in the scale, the higher the stigma levels of the patients. While the lowest score that can be received from the scale is 33, the highest score is 132. The Cronbach's alpha coefficient has been found to be 0.91. Cronbach's alpha coefficient of this study, however, has been determined to be 0.88.

Statistical analysis

SPSS version 15 was used for the evaluation of the data obtained from the study. Frequency and percentage values were used for the presentation of the categorical variables (qualitative variables). The scores (quantitative variable) obtained from the scale were presented with the mean and standard deviation values. First of all, research was conducted regarding whether the parametric test conditions (number of subjects and investigating the compliance with the normal distribution) were satisfied, comparing the scale scores according to a variety of qualitative variables. For variables satisfying parametric test conditions, Student's t test was performed to compare two groups; one-way analysis of variance (ANOVA) was performed to compare three or more groups; and Kruskal Wallis H test was performed for variables not satisfying

parametric test conditions. Tukey's multiple comparison test was used in order to determine from which groups the disparities stemmed as a result of the analysis of variance, and Mann-Whitney U-test with Bonferroni correction was used for Kruskal Wallis H test. The significance level was accepted to be P <0.05 in all statistical analyses. Patients with psychiatric diagnoses, those under 18 and those who were treated for tuberculosis for less than fifteen days were not included within the scope of the research.

RESULTS

Socio-demographic characteristics of TB patients are given in Table 1.

Table 1: Socio-demographic characteristics of TB patients.

Socio-demographic variables	N	%			
Sex					
Male	64	49.6			
Female	65	50.4			
Age groups					
18-24	20	15.5			
25-44	49	38.0			
45-64	47	36.4			
65 and above	13	10.1			
Marital status					
Single	32	24.8			
Married	87	67.4			
Widow	10	7.8			
Education status					
Graduate of elementary school	62	48.1			
Graduate of secondary school	41	31.8			
Graduate of higher education	26	20.2			
Work status					
Yes	52	40.3			
No	77	59.7			
Profession					
Housewife	42	32.6			
Civil servant	15	11.6			
Worker	27	20.9			
Self-employed	21	16.3			
Retired	17	13.2			
Student	7	5.4			
Type of tuberculosis					
Pulmonary	78	60.5			
Extrapulmonary	45	34.9			
Pulmonary and extrapulmonary	4	4.7			
Can tell everyone of his/her tuberculosis					
Yes	71	55.0			
No	58	45.0			
Family type					
Nuclear family	92	71.3			
· · · · · · · · · · · · · · · · · · ·	23	17.8			
Extended family	23	17.0			

50.4% of the patients were determined to be females, 67.4% were married, 48.1% were graduates of elementary school and 59.7% were unemployed. In addition, 60.5% of the patients participating in the study hid their pulmonary tuberculosis, while 45% concealed their TB from others around them (Table 1).

Comparing the SSPT scores with the marital status of the patients, a significant difference (P <0.05) was determined at the "Family/friend relationship" sub-dimension, and the multiple comparison showed that scores of the married and widowed patients were higher than the single patients.

A significant difference was determined between the civil servant and self-employed, civil servant and the retired, and worker and self-employed patients at the SSPT "Self-perception" sub-dimension. The mean stigma scores of the self-employed patients were found to be higher compared with the civil servant and worker patients at the SSPT "Self-perception" sub-dimension.

When the average total scores the patients received in this study from of the general SSPT were analysed, a significant difference (P < 0.05) was determined between the housewife, civil servant, worker and self-employed patients. The mean score of the self-employed patients out of the general SSPT was determined to be significantly higher than the stigma score of the housewife, civil servant and worker patients.

In Table 2, average total score of SSPT and mean scores of the SSPT sub-dimensions are given. While the average total score received by the patients from the scale was \overline{X} = 69.6 ± 12.6, the mean highest score obtained from the sub-dimensions was \overline{X} = 29.9 ± 6.3 at the "Felt stigma" dimension and the mean lowest score was \overline{X} = 11.3 ± 3.8 at the "Family/friend relationship" sub-dimension.

Table 2: Average total score of SSPT and mean scores of SSPT sub-dimensions of the TB patients.

Subscales	Min.	Max.	σ	SD
Felt stigma	13	49	29.9	6.3
Self-perception	7	25	13.3	3.8
Family/friend relationship	6	20	11.3	3.8
Internalised stigma	7	25	14.1	4.5
Total	33	102	69.6	12.6

When the mean scores the patients received for each question at the "Felt stigma sub-dimension" of SSPT were analysed, the patients were found to receive the highest score ($\overline{x} = 2.73 \pm 0.93$) from the question, "people are afraid of getting married with someone who has tuberculosis".

At the "Family/friend relationship sub-dimension" of SSPT, the patients were determined to receive the highest score ($\bar{x} = 2.19 \pm 0.97$) from the question "if I tell my

friends that I have tuberculosis, my relationship with them will be adversely affected" on the scale.

DISCUSSION

As tuberculosis is an infectious disease transmitted by the air, it is a major public health problem with physical as well as social, psychological and social effects. Many TB patients are ostracised and face stigmatisation due to the lack of knowledge of tuberculosis, fear and prejudice and the fact that the disease is contagious and its treatment takes a long time. This situation affects the patients' quality of life and treatment process adversely. In other words, the patients concerned are stigmatised, which causes them to discontinue the treatment and lose self-esteem, and leads to depression and delays in the diagnosis process. To this end, the present study aims at determining the status of the stigma of tuberculosis patients.

In this study, the mean total score of the patients in the SSPT was $\mathbf{X} = 69.6 \pm 12.6$, and the stigma levels of more than half of the patients (53.4%) were determined to be high (Table 2). The relevant reasons for this result were discussed using various studies on the subject. The discussion took place in light of the socio-demographic variables, the overall scale and sub-titles of the scale.

Socio-demographic variables

In this study, 38% of the patients participating in the research were in the 25-44 age group (Table 1). When we look at the distribution of tuberculosis patients according to age groups in Turkey in 2006, we see that a large percentage (39.74%) were 25-44, and that this number decreased over time until 2009, when it reached 36.1%. This decrease in the percentage observed in the young adult age group shows that the tuberculosis control services are effective, but not yet successful enough in Turkey. The increase in the age group of the TB patients and the fall of the incidence rate below twenty out of one hundred thousand indicate that the country is successful in the control of tuberculosis. 14

In this study, 67.4% of the patients were determined to be married, while 71.3% had a nuclear family (Table 1). Comparing the SSPT scores with the marital status of the patients, a significant difference (P <0.05) was determined between the marital status and the SSPT "Family/friend relationship" sub-dimension. The multiple comparison analysis also showed that the "Family/friend relationship" sub-dimension scores of the married and widowed patients were higher. We can argue that the higher stigma scores of the married and widowed patients stem from the fear of infecting his/her spouse and children with the disease or of being abandoned by his/her spouse. However, in a study conducted in India, the stigma scores of the unmarried women were found to be higher. 15 Furthermore, it was observed in research carried out on 2123 tuberculosis patients in India by Dhingra and Khan (2009) that the families hesitated to disclose their daughters' disease - taking into account the possibility that they cannot get married - and ensure they were treated. We can interpret the reason for this situation as the reduction in the expectation of marriage of young women due to tuberculosis. When other studies conducted among different patient groups are analysed, gender, age, education level, marital status, duration of disease and economic conditions appear to affect the stigma. ^{2,8,16-18}

Of the patients participating in the study, 48.1% were identified to be elementary school graduates (Table 1). A significant difference was not found between the educational status of the participants and the stigma scores. In many studies, level of education of the tuberculosis patients was determined to be low. 19-21 Courthwright and Turner (2010) concluded in their study that the effect of stigma was higher on the patients with low level of education. The higher the level of education, the more the knowledge increases; the more the knowledge, the less the stigma scores, as the stigma stems from prejudices and lack of information.²² In a study conducted in Nigeria, the educational status was found to be decisive for the experience of stigmatisation.² In the study conducted by Kipp et al. (2011) in southern Thailand, the level of education of the patients was associated with stigma.²³

In total, 45% of the patients participating in the study were determined to hide from the people around them that they suffered from tuberculosis (Table 1). The reason for this may be the tendency of the patients to hide their diseases for fear of being ostracised from and stigmatised by society. The fear of stigma can sometimes adversely affect the treatment process and social life of the patients.⁵ As noted earlier, there are not enough studies on this subject in Turkey. In a study conducted in Delhi, the patients were observed to suffer from a high level of labelling at the community level, which led 60% of them to hide their diseases from their friends and neighbours. The patients can be stigmatised not only by society but by the family members as well. Atre et al. (2011) identified in their study conducted in India that the patients hid their disease from the people around them for fear of experiencing marital problems and loss of social status.

Further discussion will be presented under the titles of SSPT in general and sub-dimensions of SSPT.

Stigma scale for patients with tuberculosis (SSPT)

When the average total scores the patients received in this study from the general SSPT were analysed, a significant difference was determined between the housewife, civil servant, worker and self-employed patients. The mean score of the self-employed patients from the general SSPT was determined to be significantly higher than the stigma score of the housewife, civil servant and worker patients. The scores of the self-employed patients were

found to be high at the SSPT "Self-Perception" subdimension. The same reasons apply here as well. The self-employed individual is likely to experience a loss of revenue as he/she will not be able to practise his/her profession due to the disease. In our culture, men are obliged to provide for the family and if the diseased individual is a man, it may be unavoidable for him to experience stigma with the added pressure of having to provide for the family. The scale consists of four subdimensions. These are "Felt stigma, self-perception, family/friend relationship, internalised stigma" subdimensions.

Felt stigma sub-dimension

The Felt Stigma refers to the shame the patient feels for having the stigmatised disease and the fear he/she feels of being stigmatised.²⁴ In fact, 45% of the patients participating in this study replied "No" to the question "Can you tell everyone that you have tuberculosis?" This clearly indicates that they tend to hide their disease, and perhaps because of the fear of being stigmatised (Table 1).

The patients in the study scored above the average, which is $X = 29.9 \pm 6.3$, at the "Felt stigma" sub-dimension (Table 2). The fact that the patients achieved a score above the average at the "Felt stigma" sub-dimension indicates that they fear being stigmatised by society due to this disease. In the study conducted by Sert (2010), it was stated that the patients got a score of \bar{x} =3 4.76 ± 8.39 at the "Felt stigma" sub-dimension. The reason why these patients received higher scores at the "Felt stigma" sub-dimension than the patients in the study may be because the relevant study was conducted in a clinical setting and the patients were newly diagnosed with the disease and in the initial phase of treatment. In Turkey, patients with tuberculosis are generally referred to the dispensaries after their treatment begins at the hospital following their hospitalisation.

The patients are observed to receive the highest score (\overline{X}) = 2.73 ± 0.93) at this sub-dimension from the question "People do not want to marry someone with tuberculosis". That the patients received the highest score from this question at the SSPT "Felt stigma" subdimension may mean that they think people refrain from marrying someone with tuberculosis. In the study conducted by Thomas et al. (2008) in Malawi and India, findings similar to those of the study were obtained, which clearly showed that women with tuberculosis were more worried and concerned about their disease. Likewise, in another study conducted in Pakistan, Nepal and Bangladesh, the expectation of marriage of patients was found to reduce due to the fact that tuberculosis requires long-term treatment and it is contagious. In the same study, it was also stressed that the expectation lessened in that region as great attention was paid to a bride being healthy.²⁵

Self-perception sub-dimension

"Self-perception" sub-dimension relates to the individuals' recognising themselves. It stems from the attitudes, emotions and similar intrinsic states of the individuals as well as their behaviours and the conditions in which these behaviours are displayed.²⁶

By appraising self-perception in relation to the disease, we can determine that it is associated with how the patient feels to be a tuberculosis patient, whether he/she suffers loneliness and blames himself/herself, that is to say, whether he/she has formed a connection between his/her disease and himself/herself and how he/she is affected by this relationship.

The patients participating in the study achieved an average score of $\overline{X} = 13.3 \pm 3.8$ at the "Self-perception" sub-dimension (Table 2).

A significant difference was noted between the civil servant and self-employed, civil servant and the retired and worker and self-employed patients at the SSPT "Selfperception" sub-dimension. The mean stigma scores of the self-employed patients were found to be higher compared with the civil servant and worker patients at the SSPT "Self-perception" sub-dimension. This is mainly associated with the fact that civil servants and workers have job security and do not suffer from loss of income once they notify the institution they work for about their disease in a medical report. If the employer is the patient himself/herself, as in the case of self-employment, and cannot work due to his/her disease, he/she both faces financial difficulties and experiences fear of stigma. These individuals may experience self-accusation, shame and loneliness as they cannot provide for their family.

The mean stigma scores of the retired patients were found to be higher compared with the civil servant patients at the SSPT "Self-perception" sub-dimension. If we assess these two groups in terms of age factor, the abovementioned result is estimated to arise from old age problems, loss of status, decreased productivity of the retired patients and their place in society, a significant decrease in their monthly income, tuberculosis and other diseases they might have.

Family/friend relationship sub-dimension

The SSPT Family/friend relationship sub-dimension covers the attitudes and behaviours of the family and friends towards the person suffering from tuberculosis. It is associated with any changes in the behaviours or attitudes of the patient's family and friends towards the patient once they learn about his/her disease. The patients participating in the study were observed to achieve an average score of $\overline{X} = 11.3 \pm 3.8$ at the "Family/friend relationship" sub-dimension (Table 2).

At the "Self-perception sub-dimension" of SSPT, the patients were found to receive the highest score ($\overline{x}=2.19\pm0.97$) from the question "if I tell my friends that I have tuberculosis, my relationship with them will be adversely affected". In the study, the disease has been identified as affecting relationships with family and friends. In a study conducted in China, the majority of respondents stated that they were worried that their social relations would be adversely affected due to their disease.²⁸ In a study conducted by WHO (2013) in seven Eastern Mediterranean countries (Yemen, Somalia, Iraq, Iran, the Syrian Arab Republic, Pakistan and Egypt), it was found that the stigma adversely affected family and friend relationships by 90% in Pakistan.²⁹

Internalised stigma

Internalised stigma refers to the adoption of the stigmatising views of the community by the individual patient. The internalised stigma covers emotions, thoughts, beliefs and fears experienced by the individuals in their private spaces, and their beliefs that they are dangerous to others or incapable of managing their own lives.³⁰ According to Corrigan, the internalised stigma is the adoption of the negative stereotypes by the patient, who thus withdraws himself/herself from society due to negative emotions such as worthlessness and shame.³¹ Internalised stigma causes harm to the patients by exacerbating the symptoms of the disease and delaying the recovery process.³² The patient exposed to stigmatisation may internalise the stigma and isolate himself/herself from society over time by evaluating himself/herself and others unfavourably.³³

The patients participating in the study were observed to get an average score of $\overline{x} = 14.1 \pm 4.5$ at the "Internalised stigma" sub-dimension (Table 2).

CONCLUSIONS

This research has been conducted descriptively to determine the stigma level of the tuberculosis patients and the factors affecting that level. In conclusion, more than half of the tuberculosis patients (53.4%) got scores above the average and their level of stigma was found to be high. In this context, it is recommended that society as a whole, mainly the patient, patient's family and risk groups, should be educated on tuberculosis.

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