

Assessment of anxiety, depression, loneliness and stigmatization in patients with tuberculosis

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Keywords

Stigmatization; Anxiety; Depression; Loneliness; Tuberculosis, pulmonary

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Abstract

Objective: The purpose of this study was to assess anxiety, depression, loneliness, and stigmatization in patients with pulmonary tuberculosis.

Methods: A descriptive and cross sectional study was conducted with 208 out-patients in a state hospital due to PT. A patient identification form, Tuberculosis Patients Stigma Scale (TPSS), Hospital Anxiety and Depression Scale (HAD) and University California of Los Angeles (UCLA) Loneliness Scale were used as data gathering forms. Arithmetic averages, standart deviation (SD), percentage, and correlation were used in statistical analysis.

Results: The prevalence of anxiety (26.0%), depression (60.5%), and loneliness (49.0%) was observed to be among patients with PT. It was found that patients with PT suffered from stigmatization (47.6%).

Conclusion: In conclusion, patients with PT experience high level of depression, moderate-high level of loneliness, mild level of anxiety, and moderate level of stigmatization.

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Introduction

Tuberculosis (TB) is a chronic infectious disease caused by *Mycobacterium tuberculosis*. It is one of the leading causes of morbidity and mortality worldwide.^(1,2) According to World Health Organization (WHO) 2012 estimate, 2 billion people have latent TB, while another 3 million people worldwide die each year due to TB. It remains a major global health problem and a life-threatening disease among millions of people each year and ranks as the second leading cause of death from an infectious disease worldwide, after HIV/AIDS.⁽³⁾

Pulmonary tuberculosis (PT) is a disabling medical condition that may interfere with the sense of confidence both physically and emotionally in social settings. On the other hand, because it is historically known to be contagious and life-threatening, social acceptance of patients with tuberculosis may be compromised widely in society. Negative reactions from others who learn of a TB diagnosis can compound the physical impact of TB disease and the social impact of necessary isolation for patients with PT. TB is a contagious and debilitating disease with many adverse consequences. Various psychosocial conditions including depression, anxiety, feelings of loneliness, feeling stigmatized, and social isolation have been previously reported among these patients. Moreover, in a recent study patients with PT were reported to have higher depression, anxiety, loneliness, stigmatized, and social isolation levels may affect adversely proper anti-tuberculosis treatment compliance.⁽⁴⁻⁶⁾

Tuberculosis is known to be a social illness. In addition, tuberculosis is accepted as a stigmatizing disease as well. There are several studies carried out about diagnosis, treatment and prevention strategies of TB, however, few researches focusing on psychosocial outcomes of the disease such as stigmatizing, depression, anxiety, and loneliness.⁽⁴⁻⁶⁾ This issue is very important for the all health professionals should be aware and can play an important role in the patient's ability to avoid the psychosocial consequences. In regards to how health profession-

als can help patients with TB to prevent negative psychosocial effects from arising, emphasis will be placed on the importance of the encounter between health professionals and patients. The purpose of this study was to assess anxiety, depression, loneliness and stigmatization in patients with pulmonary tuberculosis.

Methods

The study is a descriptive and cross-sectional survey. This study was carried out from October 2014 to February 2015 among patients with PT who presented to tuberculosis clinics of Dr. Suat Seren Tuberculosis and Chest Disease and Surgery Hospital situated in Izmir, Turkey. Izmir is a metropolitan city in the western extremity of Anatolia and the third most populous city in Turkey, after Istanbul and Ankara. It is one of the most westernized city in Turkey. As for, Dr. Suat Seren Tuberculosis and Chest Disease and Surgery Hospital is the first greatest tuberculosis and chest disease hospital in Izmir also this hospital is the fourth greatest tuberculosis and chest disease hospital in Turkey. This hospital has provided health care services with 7 out-patients clinic and 268 in-patient beds which includes nursing and physicians's care, surgery, therapy, laboratory tests, and medical treatment. During the study period, approximately 500 patients applied to the out-patients clinics. According to The Ministry of Health Public Health Agency of Turkey, the prevalence of TB was observed to be 64.0% in 2012.⁽⁷⁾ Odds ratio was used to determine strength of association and was reported with 95% confidence interval. Level of significance for this study was 5%. The minimum required sample size of 208 patients with PT was obtained by using OpenEpi.

Participants were selected according to the following criteria; had been one and over years diagnosis of pulmoner tuberculosis, 18-65 years old, able to speak and read Turkish, to be willing participant. The study purpose, procedural details, the participant's rights and potential benefits and risks of the

study were explained and written consent forms were obtained from them. A patient identification form, Tuberculosis Patients Stigma Scale (TPSS), Hospital Anxiety and Depression Scale (HAD), and University California of Los Angeles-Loneliness Scale (UCLA Loneliness Scale) were used the data gathering. In face-to-face interviews, the patient identification form, TPSS, HAD, and UCLA Loneliness Scale were filled by the first researcher in the outpatients clinics. Each interview took approximately 30 minutes.

The patient identification form

The patient identification form includes social-demographic characteristics (age, gender, marital status, education status, income, insurance) past medical history, and duration of PT.

Tuberculosis Patients Stigma Scale

Tuberculosis Patients Stigma Scale measure the level of self-stigmatization in patients with TB which consisted of 33-item and 4 dimensions. The scale was developed by Sert and Olgun, its original language was Turkish.⁽⁶⁾ The 4 dimensions were perceived stigma, self-perception, family/friends relations, internalized stigma. The response categories were “1=strongly disagree,” “2 = disagree,” “3 = agree,” and “4 = strongly agree” Scores were ranged from 33 to 132. Higher scores indicate a stronger level of self-stigmatization and internalized stigma, a better level of self-perception and family/friends relations. Validity and reliability of the scale were done by using content, construct and criterion validity. Cronbach’s alpha was 0.91, Guttman was 0.829 and Spearman Brown was 0.926 reliability coefficients, item analysis ($p < 0.001$) and test-retest methods ($p < 0.001$). The scale are well-documented, and norm values for a Turkish population are available.⁽⁶⁾ In the present study, alpha coefficient was found 0.74 for the TPSS.

Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression (HAD) rating scale has been established as a much applied and convenient self-rating instrument for anxiety and depression in patients with both somatic and

mental problems, and with equally good sensitivity and specificity as other commonly used self-rating screening instruments. HAD is a 14-item questionnaire, commonly used to screen for symptoms of anxiety and depression. The 14-item can be separated into two 7-item sub-scales for anxiety (HAD-A) and depression (HAD-D). The reliability and validity of Turkish version of the HAD-A and HAD-D are well-documented, and norm values for a general population are available. The scales use a cut off score for anxiety 10/11 and and depression 7/8.⁽⁸⁾ In the current study, alpha coefficient was found 0.89 for the HAD.

University California of Los Angeles - Loneliness Scale

A 20-item scale designed to measure one’s subjective feelings of loneliness as well as feelings of social isolation. Participants rate each item as either O (“I often feel this way”), S (“I sometimes feel this way”), R (“I rarely feel this way”), N (“I never feel this way”). The measure has been revised two times since its first publication; once to create reverse scored items, and once to simplify the wording. The reliability and validity of Turkish version of the University California of Los Angeles (UCLA) Loneliness Scale are well-documented, and norm values for a general population are available.⁽⁹⁾ In the present study, alpha coefficient was found 0.92 for the UCLA Loneliness Scale.

Statistical evaluation of the data was performed via Statistical Package for Social Sciences (SPSS 16.0) soft-ware on computers; social-demographic characteristics and scores of scales were examined using arithmetic averages and standart deviation (SD). Pearson’s correlation analysis was used to examine relationships. Probability values (p) less than 0.05 were considered statistically significant.

This study protocol was approved by the Research Ethics Committee of the Celal Bayar University Faculty of Medicine at Manisa, Turkey, number 100. Participants were informed about the aim and nature of the study. The study was initiated upon receiving the approval and consent form of the planned participants.

Results

The demographic characteristics of the participants

The average age of the participants was 45.5 ± 14.8 (minimum-maximum: 31-60) years, and the most of the study participants were married (62.0%) and male (63.0%). The social-demographic characteristics and the clinical status among patients with pulmonary tuberculosis are shown in the table 1.

Total HAD-A score was 7.80 ± 4.14 (minimum-maximum: 0-17), and total HAD-D score was 8.24 ± 4.30 (minimum-maximum: 0-21). The prevalence of anxiety was 26.0%, and depression was 60.5% (Table 2). Total UCLA Loneliness Scale score is presented in the Table 2. Moderate and high levels of loneliness were reported by 80.2% of the patients. Total TPSS score was found to be 94.90 ± 10.67 (minimum-maximum: 62-122) in the patients with PT. 47.6 percent of the patients perceived moderate level of stigmatization (Table 2).

Relationships among total UCLA Loneliness Scale score, and total HAD-A score and total HAD-D score are presented in the (Table 3). A positive significant correlation was defined between total UCLA Loneliness Scale score and total HAD-A score, total HAD-D score ($p < 0.01$). That is, level of anxiety and depression were affected by level of loneliness, and indicating that higher level of loneliness was associated with higher level of anxiety and depression.

A positive significant correlation was observed between total TPSS score and total HAD-A score, total HAD-D score ($p < 0.05$) indicating that higher perception of stigmatization were associated with higher level of anxiety and depression. Statistical relationships among total TPSS score and total HAD-A score, total HAD-D score are presented in the table 3. A positive significant correlation was observed among total TPSS score and total HAD-A score, total HAD-D score. Relationships among total subscales TPSS scores and total HAD-A score, total HAD-D score were defined to be respectively, Self-perception ($p < 0.01$), Family/friends relations ($p < 0.05$), Internalized stigma ($p < 0.01$). Adverse-

Table 1. The socio-demographic variables among patients with pulmonary tuberculosis and description of clinical status among patients with pulmonary tuberculosis (n=208)

Variables	n(%)
Age	
- 49 years and ↓	105(50.5)
+ 49 years and ↑	103(49.5)
Gender	
Female	77(37.0)
Male	131(63.0)
Marital status	
Married	129(62.0)
Single	79(38.0)
Education status	
Literate	36(17.3)
Primary school	119(57.2)
High school	38(18.2)
University and Postgraduate Education (MSc, PhD)	15(7.2)
Vocation/job	
Government official	13(6.2)
Housewife	48(23.1)
Self-employment	24(11.5)
Worker	33(15.9)
Retired	48(23.1)
Unemployed	35(16.8)
Student	7(3.4)
Income	
Low	119(57.2)
Moderate	2(1.0)
High	87(41.8)
Insurance	
Yes	172(82.7)
No	36(17.3)
Clinical status	
Duration of illness	
< 6 years	120(57.6)
6-10 years	59(28.3)
≥12 years	29(13.9)
Phase of treatment	
Intensive phase	131(63.0)
Continuation phase	77(37.0)
Category of treatment	
New	168(80.8)
Relapse/treatment after failure	34(16.3)
Return after default	6(2.9)
Co-morbid chronic illness	
No	152(73.1)
Yes	56(26.9)
Family member with TB	
Yes	49(23.6)
No	159(76.4)
To be able to say her/his diagnosis to somebody	
Yes	105(50.5)
No	103(49.5)
To be able to accept his/her illness	
Accept	169(81.8)
Refuse	39(18.8)

continue

continuation

Variables	n(%)
Cigarette use	
Yes	65(31.2)
No	143(68.7)
Alcohol use	
Yes	25(12.0)
No	183(87.9)
Interrupting treatment	
Yes	28(13.4)
No	18(86.5)

Table 2. Mean Scores of Hospital Anxiety and Depression Scale; UCLA Loneliness Scale and Tuberculosis Patients Stigma Scale (n=208)

Hospital Anxiety and Depression Scale	Mean± SD	No Risk n(%)	Exist Risk n(%)
HAD-A	7.80±4.14	154(74)	54(26)
HAD-D	8.24±4.30	82(39.5)	126(60.5)
***UCLA Loneliness Scale	n(%)	Mean±SD*	
Low Level Loneliness (20-34)	41(19.7)	44.36 ± 10.29	
Modarate Level Loneliness (35-49)	102(49.0)		
High Level Loneliness (50 and ↑)	65(31.2)		
Total	208(100)		
**TPSS and subscale	Min-Max Score	Mean±SD*	
Perceived stigma	27-50	37.69 ± 5.12	
Self-perception	10-26	18.37 ± 2.85	
Family/friends relations	9-24	17.83 ± 2.94	
Internalized stigma	9-28		
Total TPSS	62-122		

*SD - Standard Deviation; **TPSS - Tuberculosis Patients Stigma Scale; ***UCLA - University California of Los Angeles - Loneliness Scale

ly, there was no significant correlation between Perceived stigma and total HAD-A score, total HAD-D score ($p > 0.05$). According to this findings, Self-perception, Family/friends relations, and Internalized stigma were affected by level of anxiety and depression, but level of anxiety and depression did not affect Perceived stigma. These findings indicated that lower Self-perception, Family/friends relations, and Internalized stigma were associated with higher anxiety and depression.

Statistical relationships among total TPSS score and total UCLA Loneliness Scale score are shown in the table 3. There was no significant correlation between total TPSS score and total UCLA Loneliness Scale score ($p > 0.05$). That is, the perception of stigmatization was not affected by level of loneliness.

Relationships among total subscales TPSS scores and total UCLA Loneliness Scale score were defined to be respectively, Perceived stigma ($p < 0.05$), Family/friends relations ($p < 0.01$) and loneliness, but a positive significant correlation was between Self-perception ($p < 0.01$), Internalized stigma ($p < 0.01$) and level of loneliness. According to this finding, Perceived stigma, Self-perception, Family/friends relations, and Internalized stigma were affected by level of loneliness, and indicating that higher level of loneliness was associated with higher Self-perception, and Internalized stigma. Contrary to, higher Family/friends relations, and Perceived stigma were associated with lower level of loneliness.

Table 3. Relationship between Hospital Anxiety and Depression Scale Scores and UCLA Loneliness Scale Scores. Relationship between Tuberculosis Patients Stigma Scale Scores, Hospital Anxiety and Depression Scale Scores and UCLA Loneliness Scale Scores (n=208)

Hospital Anxiety and Depression Scale	UCLA Loneliness Scale					
	r		p-value			
HAD-A	0.64		0.00**			
HAD-D	0.74		0.00**			
TPSS and subscale	*HAD-A		*****HAD-D		****UCLA Loneliness Scale	
	r	p-value	r	p-value	r	p-value
Perceived stigma	-0.10	0.11	-0.12	0.06	-0.16	0.01**
Self-perception	0.46	0.00**	0.51	0.00**	0.38	0.00**
Family/friends relations	-0.16	0.03*	-0.13	0.04*	-0.20	0.00**
Internalized stigma	0.22	0.00**	0.26	0.00**	0.19	0.00**
TPSS	0.14	0.03*	0.16	0.01*	0.03	0.63

*Significant association (p-value < 0.05); **Significant association (p-value < 0.01); ***TPSS - Tuberculosis Patients Stigma Scale; ****UCLA - University California of Los Angeles - Loneliness Scale; *****Hospital Anxiety and Depression Scale

Discussion

Tuberculosis is a classic example of an infection disease with both medical and social dimensions, characterized by its close relation to poor socioeconomic conditions.⁽¹⁰⁾ The characteristics of the patients in this study give us strong clues about the patient profile of the other TB patients even out of the hospitals. First of all, the study hospital was one of the major reference sanatoriums in Izmir, Turkey (West Anatolian). TB patients especially from the Anatolian region of Turkey were generally known to utilize this hospital. On the other hand, patients from other regions of the country including Istanbul (Northwest Anatolian) and Ankara (Middle Anatolian) where the other sanatoriums are located, were also hospitalized. Supporting this idea, we found that some of the social-demographic characteristics of our patients were similar to other studies.⁽¹¹⁻¹³⁾

The literature indicates that psychiatric comorbidity⁽¹⁴⁾ before and after tuberculosis onset, psychological issues such as stigma, isolation,^(15,16) lack of social support, helplessness, loneliness,^(17,18) and other psychological reactions to the disclosure of the diagnosis⁽¹⁹⁾ as well as medication side effects, all adversely affect the treatment adherence.⁽²⁰⁾ In the present study, the prevalence of anxiety was observed to be mild, the prevalence of depression was observed to be high, and the prevalence of loneliness was found to be moderate-high among patients with PT. We observed that 47.6% of the patients reported to moderate level of stigmatizing.

Anxiety and depression are the most frequently occurring mental disorders in the general population.⁽²⁰⁾ The studies indicate that there is high prevalence of depression and anxiety among TB patients compared to general population which is about 3-17%⁽²¹⁾ and 7% to 82.3%,⁽²²⁾ respectively. Studies conducted in different countries on prevalence of depression and anxiety among TB patients shows that 46.3 % (anxiety), 47.2% (depression) in Pakistan,⁽²⁰⁾ 72.88% (anxiety), 38.98% (depression) in Romania,⁽²³⁾ 40.67% (anxiety), 9.93% (depression)

in Greece,⁽²⁴⁾ 45% (depression) in Nigeria.⁽²⁵⁾ Contrary to, in our study, the prevalence of anxiety and depression were found to be 26.0%, 60.5%, respectively. However, we found that the prevalence of depression was higher but also the prevalence of anxiety was lower than these studies. The variation might be due to the difference in study design, data collection tool, sample size and difference in study participants.

In recent years, a topic of interest in patients with TB has been self-discrimination and isolation. Traditionally it is known that TB patients feel that they are excluded from the population due to concerns mainly related to disease dissemination.^(26,27) In some previous studies, feelings of shame, embarrassment, loneliness or social isolation have been reported among patients with TB.⁽²⁸⁻³⁰⁾ In this study, it was determined that moderate and high levels of loneliness among patients with PT. In addition, anxiety and depression were affected by level of loneliness, and higher level of loneliness was associated with higher anxiety and depression among patient PT. These findings were similar to those by Polat & Ergüney⁽¹⁸⁾ which showed that moderate levels of depression and loneliness among patients with PT. Moreover, it was stated that a positive significant correlation was observed among loneliness, anxiety, and depression.

Today, TB is accepted as a stigmatizing disease and perceptions of patients with TB about their illnesses can be a way of understanding how 'stigmatizing' affects their social lives. In Southeast Asia, presence of TB with AIDS enhanced stigma of TB. Stigmatizing characteristic of the disease can affect the quality of life of the patients. A study from Mexico City showed that 52% of patients discharged from hospital after treatment for TB were not allowed to go home due to the hostility of their families. Hansel et al.⁽²⁹⁾ interviewed with patients with TB and they reported that experiencing social stigma and isolation from friends and family as well as suffering from depression and anxiety due to their disease. Such examples may influence patients' relations with their social settings negatively. This is also

confirmed by Kelly⁽¹⁵⁾ who found in her study trial that patients with tuberculosis claimed feelings of stigmatization, anxiety, depression related to their tuberculosis diagnosis. The studies indicate that there is the prevalence of stigmatizing among patients with TB which is about 27-80%.^(15,31) Studies conducted in Turkish population on the prevalence of stigmatizing among patients with TB show that 53.4%,⁽³²⁾ 52.3%,⁽⁶⁾ 74.4%.⁽³³⁾ In the present study we observed that 47.6% of the patients experienced moderate level of stigmatizing. This finding could be explained due to the meaning of stigmatizing differs from one culture to another.

In this study we found that presence of perceived stigma was highly associated with depression and anxiety. This finding was similar to the studies were conducted in Pakistan and Ethiopia.^(20,34) The patients with PT who have high perceived stigma and low family/friends relations which may predispose them depression and anxiety. In addition, stigma accompanying TB could have a negative impact on the individual and family, which may result in their withdrawal from society because of shame and fear.^(28,31) Moreover, the current study indicated that poor family/friends relations, loneliness, and low self-perception were significantly associated with depression and anxiety. These findings were similar to the other studies.^(18,35-38) The patient with TB effect of stigma can be emotional or psychological such as, stress and anxiety, depression, feeling of loneliness or discrimination and frequently shatters infected person's identity and self-confidence, significantly decreases their ability to manage the disease successfully.^(31,39,40) Lack of (poor) social support and chronic illness may lead to increased psychological distress. Since stigmatization in TB patients may limit their socialization, it may be causes of loneliness. In both conditions, patients would make an effort to avoid conversations and feel distant from others.^(41,42) In contrast, the findings of our study indicated that no significant relationships exist between UCLA loneliness scale and TPSS total scores. This finding could indicate that the most of patients have accepted of illness and their diagnoses have been

clarified to another person. Moreover, a negative significant correlation was defined to be among perceived stigma and loneliness. The patients reported that their loneliness was not affected by stigma. They explained that their loneliness was caused by being hospital, and medical isolation for preventing disease dissemination. But, there was a positive significant correlation among internalized stigma, loneliness, anxiety, and depression. These findings could be explained that stigma and internalized stigma were the major source of depression and anxiety aside, being hospital and medical isolation. However, the results demonstrated that no significant relationships exist between perceived stigma and depression and anxiety. This finding could be explained that, patients did not think stigmatized and they used as a coping method for suppress their anxiety, loneliness, anger, unhappiness and depression.

Conclusion

In conclusion, patients whom PT experience high level of depression, moderate-high level of loneliness, and low level of anxiety. In addition to, anxiety, depression and loneliness were associated with moderate level of stigmatization among patients with PT. Of course, there are some limitations in our study. The results of this study may not generalised the community or those patients with PT who lived in population because of the small sample size and only hospital. However, these findings highlight the benefits of regular screening for depression and anxiety in the medical outpatient clinic particularly TB clinics. Treating depression and anxiety and coping loneliness may help decreasing patients' stigma perceptions and improving overall patient management.

Collaborations

Yılmaz A and Dedeli O declaram que colaboraram com as etapas de concepção do estudo, análise e interpretação dos dados, redação do artigo, revisão crítica relevante do conteúdo intelectual e aprovação final da versão a ser publicada.

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