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Social Acceptance for Patients with Pulmonary Tuberculosis from Their Own Perspective in Rafsanjan, Iran: A Cross Sectional Study

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ABSTRACT

Introduction: Social acceptance is defined as the support by social network for patients via family, friends and colleagues that often reason the better management and prognosis. If the social acceptance is significantly low in patients with chronic diseases like tuberculosis, an appropriate plan can raise the level of knowledge and the culture of the community to enhance the level of patient and community's acceptance. The authors aim to evaluate social acceptance and related factors in these patients in Rafsanjan.

Methods: This was analytical cross-sectional study. It was conducted on 29 pulmonary TB (tuberculosis) patients who had referred to Rafsanjan city health center in Iran in 2014. They were selected by census method. The Marlou-Crown questionnaire was completed by patients, and the scores were calculated based on the questionnaire key using SPSS 16. T-test, Fisher and chi-square tests were used for evaluation, and the significance level was considered .05.

Results: Results showed that the frequency social acceptance among patients was moderate to high (62%) and moderate to low (38%). Fifteen patients(52%) were male and 14 (48%) were female whose age range was 8 to 90. Among the variables of age, sex, education, place of residence, nationality and family history of patients, the relationship between age، nationality, positive family history of TB and social acceptance was significant (P-value <0.05).

Conclusion: This study concludes that older patients, those with a family history of TB, and migrant patients have higher social acceptance

Keywords: Behavior, Disease, Social Stigma, Tuberculosis

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Introduction

Tuberculosis (TB) is an infectious and sometimes fatal disease induced by various species of Mycobacterium (1). It usually affects respiratory system, but can affect other organs as well. Tuberculosis is an airborne disease transmitted from sneeze and cough of the infected patients. (2). This disease accounts for a large part of chronic and pandemic diseases in developing countries. It remains one of the ten causes of death worldwide, especially in low-income countries (3). According to WHO in 2018 (4), TB population in the world was 10 million, of which about 3 million were either undiagnosed or unreported, and 1.5 million died. Moreover, TB has become a fetal disease among infectious diseases. In 2018, the estimated incidence of tuberculosis in Iran was 13 (confidence level of 8.5 to 14) or 14 (confidence level of 10 to 17) per 100,000 population. Mortality rate was estimated to be 950 (88 to 1000 confidence level) or 1.2 people (confidence level 1/1 to 1.2) per 100,000 population in this year (5). According to the TB distribution map in the Eastern Mediterranean, Iran is located in the middle region. Afghanistan has many immigrants to Iran due to the common border in the east of Iran and the lack of a health community organization because of the civil war. Social acceptance is the help and support offered to a person by social network, which is often associated with improving one's awareness. This network includes family, neighbors, friends and colleagues. Lack of social acceptance is believed to be a barrier to the acceptance of drugs and care by individuals. The suffering from disease is exacerbated by social segregation and isolation. For patients, the hypothesis of sharing the diagnosis of tuberculosis with close friends and family is rooted in the fact that they have to be able to fight the disease. But, some people are surprised when people around them or the community avoid them. This strengthens prejudice and discourages the patient from accepting treatment. Because of this fear, some patients hide the disease as a way to maintain social acceptance (6-8). Therefore, they consider hiding the diagnosis as a solution to prevent exclusion from society. On the other hand, if people are away from society, they may suffer from emotional deprivation and numbness. By being present in society, however, they will feel better about each other and learn to solve and deal with problems (9).

Tuberculosis, like other chronic diseases, affects individuals and its quality. It causes psychological problems and inter and intra psychic relationships. Lack of treatment and the patient's cooperation or poor insight cause illness's incidence and even threaten the patient's health. Consequently, the cost and burden of treatment increases and decreases the patient's quality of life. Awareness and knowledge of the patient and his family about the disease, different treatment methods and options, diet changes and daily activities lead to more cooperation and therapeutic alliance. As a result, the patient can fight the disease (10, 11). On the other hand, according to the patient's mental assumption and background about TB, he/she is afraid of the negative attitude of society towards him/ herself. This leads to the failure of the treatment process. Therefore, educational programs are offered around the world to improve the general and negative attitude of society about tuberculosis and reduce social sensitivity about this disease (10). In other words, whenever society's attitude towards tuberculosis is negative, it has an adverse effect on the patients' social relationships, their moral and ethical concerns. Accordingly, the disease control is challenged (12).

The results of extensively studies show that social stigma is a prominent topic about TB population. This perception and belief is so strength that even the patient avoids expressing their anti-tuberculosis drugs in the community context (13, 14). Sometimes, it has been observed that the patient avoids treatment protocols , even if it leads to loss or near of life (14). Due to the importance of this issue and in order to prevent the low quality of life of tuberculosis patients due to low social acceptance of patients and also a few research has been done in this field in Iran, so of the aim of this study was to determine the social acceptance of patients with

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pulmonary tuberculosis from their point of view in Rafsanjan city in 2017-2018.

Methods

This analytical cross sectional study was performed on pulmonary tuberculosis patients with medical records in Rafsanjan city (Iran) health center during 2017-2018. After approving the plan and obtaining permission from the Research Council of Rafsanjan University of Medical Sciences, with code number 810 thesis, also, explaining the research to the participating patients and obtaining their informed consent, 29 patients (Iranian and foreign) with pulmonary TB were included in the study. Sampling was by census method. Demographic data and patients' information was collected by a questionnaire and checklist that was prepared. The inventory demographic characteristics which include the patient's record code, sex, age, education, place of residence, occupation, marital status, family history and nationality of the patient. This questionnaire was completed by patients under the supervision of a physician and a psychiatrist at the counseling center. The Marlowe-Crown Social Acceptance Scale is one of the most authoritative measures of social acceptance. This test has 33 phrases and the subject must choose one of the yes or no options to determine his agreement or disagreement with each of its phrases (15).

Subjects' answers are matched by the scale key, and the sum of the answers corresponding to the scale key determines the overall result for each individual.

In this article, we proceeded exactly based on the structure of this test, so that we can confirm the final results of the test with the validity of this test.They completed the Marlou-Crown social response score questionnaire, and the scores were calculated based on the questionnaire key by using SPSS software version 16. In order to further align the statistical analysis with the design of our study, we carefully included all the variables related to TB patients that can, one by one, affect the rate of social acceptance. It separated the qualitative and quantitative variables, and based on the statistical articles, We considered the most valid tests for the small sample size.

Statistical analysis

T-test, Fisher and chi-square tests were used for evaluation, and the significance level was P-value <0.05 (16). The Marlou-Crown Social Response Score Questionnaire is a 33-item social acceptance scale in which a subject chooses to agree or disagree with any of its statements by choosing one of the yes or no options (15). To determine each person's score, the answers were measured with the scale key. Scores from 0 to 8 indicated a possible lack of social acceptance of the people and as a result the risk of exclusion from society. Scores 9 to 19 showed the average social acceptance of patients' behavior and social behavior policy. Scores from 20 to 33 showed that the actual behaviors of individuals were highly compatible with the culture of the community, which led to high social acceptance. Ethical confidentiality requirements are considered and guaranteed due to the anonymous and voluntary nature of the participants.

Inclusion and exclusion criteria

All participants in this study included patients of both sexes with informed consent and tuberculosis who had a disease information record in the health center. Also patients who could not speak Persian or communicate and were reluctant to participate in this study were excluded from the study.

Results

In this study, among 29 pulmonary TB patients, 15 (51%) were male and 14 (49%) were female. Frequency of moderate to high and low social acceptance among patients was 62% and 38% respectively. The frequency distribution of other patients' variables is shown in Table 1. The mean age of patients was 57.93 years with a range of changes from 8 to 90 years and a standard deviation of 23.57. The results showed that the mean age of individuals with low social acceptance was 54.18± 24.91 and the mean age of individuals with moderate to high social acceptance was 60.22± 23.13 (P = 0.036). Table 2 shows the results of the relationship between

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gender, nationality, family history of TB, education and patients' place of residence with their social acceptance. There was a statistically significant difference between patients' social acceptance and nationality with Fisher's exact test (P = 0.021). Out of 15 Iranian patients, 9 (60%) had low social acceptance and 6 (86%) had moderate to high social acceptance. Out of 14 Afghan patients, 2 (14%) had low social acceptance and 12 patients (86%) had moderate to high social acceptance. Among 10 patients with a family history of TB, one patient (10%) had low social acceptance and 9 (90%) had moderate to high social acceptance, and among 19 patients without a family history of TB, 10 patients (53%) with low acceptance and 9 (47%) had moderate to high social acceptance (P value = 0.044). There was no statistically significant relationship between gender and patients' place of residence with their social acceptance (Table 2).

Table 1. Frequency distribution of the studied variables in pulmonary TB patients (n=29)

Variable		Frequency (n/%)	Total
Sex	Male	15 (51)	100
	Female	14 (49)	
Nationality	Iranian	15 (52)	100
	Afghan	14 (48)	
Family history of TB	Yes	6 (21)	100
	No	23 (79)	
Place of residence	City	16 (55)	100
	Village	13 (45)	
Education	Illiterate	9 (31)	100
	Elementary School	5 (17)	
	Secondary School	4 (14)	
	High school Diploma	8 (28)	
	Academic	3 (10)	
Social acceptance	Low	11 (38)38	100
	Moderate to high	18 (62)	
		62	

Table 2. Frequency of social acceptance of TB patients according to different variables (n=29)

Variable	Social acceptance		p-value
	Low (%)	Moderate to high (%)	
Sex			
Male	7 (47)	8 (53)	0.45
Female	4 (29)	10 (71)	
Nationality			
Iranian	9 (60)	6 (40)	0.021
Afghan	2 (14)	12 (86)	
Family history of TB			
Yes	1 (10)	9 (90)	0.044
No	10 (53)	9 (47)	
Place of residence			
City	5 (31)	11 (69)	0.47
Village	6 (46)	7 (54)	
Education			
Illiterate	1 (10)	9 (90)	0.9
Elementary School	2 (20)	3 (60)	
Secondary School	3 (75)	1 (25)	
High school Diploma	4 (67)	2 (33)	
Academic	1 (25)	3 (75)	

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Discussion

About 1.5 million deaths from tuberculosis occur worldwide each year and it is tenth of disease burden in world. Tuberculosis has still a hudge stigma and prejudice about patients in the community(7, 17). In addition, patients' self-stigma about disease, which is supported by current social values, may lead to decline of self-esteem: "How do people see me?" As a TB person or as a human being?" Therefore, a negative attitude towards TB patients makes it difficult to accept and control , treatment and follow up the disease (14). On the other hand, social stratification triggers discrimination in individuals in society and affects social acceptance. Also, this social stratification leads to dehumanization and damages or brunt human dignity and excludes the individual from society. On the contrary, society rejects the TB patients and the patients are unprotected ,neglected or misdiagnosed.

According to the results , 62% of the patients had moderate to high social acceptance and 38% had low social acceptance. In a study conducted by Eyanoer et al. in Indonesia, 23.8% of TB patients had low social acceptance, 45.2% had high social acceptance, and 31% had very high social acceptance (18). High social acceptance in TB patients shows that these patients can adapt and coincide well to current living situation and organizational norms. Social acceptance depends on the temperament, character and personality of the individual and can be influenced by the education,sex, training and information given to them about the disease. People who are more adaptable to problems, challenges and crisis have higher social acceptance and people who have poor coping mechanisms, low resiliency and low education have less acceptance. Also, family support, self-actualization and self-esteem affect people's social acceptance (18). In a study by Lacerda et al. (19), the social stigma stemmed from a lack of public ,community knowledge and information about TB. Therefore, education plays an crucial role in the awareness of patients and families, and provides the opportunity to eliminate stigma and prejudices (20).

In the present study, the mean age of individuals with low social acceptance was 54.18± 24.91 and the mean age of individuals with moderate to high social acceptance was 60.22±23.13, which was statistically significant. However, Moya *et al.* did not find a significant relationship between age and social acceptance of TB patients (13). In a study conducted by Kibrisli *et al.* entitled high social anxiety and poor quality of life in patients with pulmonary tuberculosis in Turkey, no significant difference was observed between age, sex and level of education between both healthy and TB groups (21). One of the reasons for the difference between our study and other studies is the sample size and the degree of group cohesion, unanimity and group size that exists in a community between individuals, which is certainly related to cultural issues.

The results of the present study showed that between patients' gender and social acceptance, 53% of men and 71% of women had moderate to high social acceptance, which was not significant using the Fisher exact's test . In the study of Kibrisli *et al.*, Women had more social anxiety than men, but it was not significant. They cited the fear of spreading the disease as a critical factor in women's anxiety about men. Fear of further social exclusion is other cause, too (21). Factors such as personality, society flexibility,theory of mind , social skills or problem-solving methods affect social acceptance. Due to the small number of the studied population, no significant relationship was obtained. People with TB are usually from low-income communities and have received less environmental education on communication skills and problem-solving techniques. An effective factor is the mood of the people during the clinical interview and completing the questionnaire, which can be effective as a result of the study.

According to the results of the present study, no significant relationship was found between education level and social acceptance of TB patients. Moya *et al.* (13) did not find a significant relationship between the level of education of individuals and social stigma. Of course, better education and growing and developing of the

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level of knowledge , as a result, social acceptance of individuals increases. In the present study, most patients were illiterate and only 10% had an academic level education.

Nearly, half of the patients in the present study were Afghans population and the level of social acceptance was significant in relation to nationality. Social acceptance was moderate to high in Afghan society (86%) and in Iranian patients (40%). In a study, Chinese and Vietnamese immigrant patients who immigrated to the United States had lower social acceptance rates than nonimmigrant patients (22). However, Afghan citizens, given that they have lived in Iran for many years, have some similarities to Iranian citizens and their culture in some social and cultural items. People who migrate from a weaker society to a higher society are usually expected to be less accepted due to cultural and racial , language differences and even health conditions., such as Chinese immigrants in the United States or Afghan immigrants in Iran or Turkish immigrants in Germany It is inconsistent with the present study, perhaps due to the neglect of the consequences of the disease and the high life expectancy of Afghan refugees. In some countries, such as Iran, the race and socio-economic status of immigrants have stigma effect and causes additional stigma in association with the disease.

Family history of TB showed a significant relationship with social acceptance of patients in the present study . Ninety percent of patients had a family history of TB and 47% of those without it had moderate to high social acceptance. It seems that social acceptance in patients with a family history is strengthened by gaining experiences from family members. Also, empathy among family members or caregivers, theory of mind, humanistic or altruistic beliefs or attitudes and helping or care to improve can increase a person's social acceptance. Stubborn people have more control over life events and see them as opportunities for improvement instead of solving problems. They also evaluate stressful events as positive and controllable, which first reduces negative outlook on life and increases life expectancy, and ultimately increases mental health (23). According to the traits of personality and efficient and mature coping defense mechanisms, a suitable response to stress is given. People with high resiliency and those who act rationally in solving problems are more resistant to stress and more competent. In contrast, those who have poor coping mechanisms and low resilience were fragile or frustrated people (24).

A Russian study found that proper interaction between family members and caregivers in the hospital with people with tuberculosis could have a positive effect on their coping mechanisms (25).

Patients who are afraid of being alone and have their own psychological needs and are influenced by their peers. This issue has a significant impact on the acceptance of treatment and their independence and autonomy (26, 27)

According to the results , 69% of urban people and 54% of rural people with tuberculosis had moderate to high social acceptance, which was not statistically significant. In a study conducted in Mexico (13), there was no significant relationship between place of residence and the social acceptance of patients. Of course, in smaller urban communities, people are more connected to each other, so they are aware of each other's living conditions and it affects social acceptance.

Limitations of study were few infected people, and on the other hand, for moral reasons, it was impossible to reach these loved ones directly.

Conclusion

This study concludes that older patients, those with a family history of TB have higher social acceptance. It can also be stated that the fear of spreading the disease as an important factor in women's anxiety about men. Fear of further social exclusion is also the cause. Although in cross-sectional studies the patient's opinion is asked at some point in time, and over time the patient's condition and responses may be different, but nevertheless social acceptance in TB patients to this disease in the central region of Iran is related to age, nationality or social stratification and family history of patients.

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Conflict of interest

The authors declare no conflict of interest.

Authors' contribution

RB, MBM and ZSHSH designed the study; MBM conducted the experimental work; HBA analyzed the data; RB and MS wrote the manuscript.

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