

Cultural attitudes of society towards tuberculosis patients: A qualitative study

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Abstract

Objective: To evaluate the view on tuberculosis of individuals living in an urban setting.

Methods: This qualitative study was conducted between April and May in 2015 in the Balçova region of İzmir, Turkey, and comprised healthy adults who did not have tuberculosis. Data was collected via information form of socio-demographic features and a semi-structured questionnaire. Focus group interviews were conducted. Data collection was terminated when data reached saturation point. Data was analysed using content analysis.

Results: Data analysis of 26 subjects in all revealed three main themes; information about tuberculosis, perceptions, attitudes and behaviour regarding tuberculosis or tuberculosis patients and stigmatisation and its causes.

Conclusion: Findings showed that participants didn't have sufficient information about tuberculosis, had prejudices and fears about the disease and patients, and isolated them.

Keywords: Cultural approach, Tuberculosis, Qualitative study. (JPMA 68: 1060; 2018)

Introduction

Social determinants of health likely to be effective in organisations and interpersonal relationships can have an influence on individuals receiving health care. Stigmatisation is a social determinant shaped by social norms and individuals' attitudes.¹

Underlying stigmatisation is prejudices, which cause society to have a negative attitude towards infectious diseases, its victims, and to isolate them.² Some conditions such as a disability or a disease leads society or organisations to discriminate against individuals with these conditions, which results in stigmatisation, creating the feeling of guilt and embarrassment. Persistence of this situation has a negative impact on individuals' attempts to seek solutions to their problems and cause them to feel worthless, isolate themselves from society and prevent them from getting their treatment regularly (Figure-1).^{2,3}

Tuberculosis (TB) is a common disease, which is an important factor causing stigmatisation of TB patients and affecting care and treatment of the patients. It was called the 'consuming disease' since it caused weight-loss and death, 'white death' or 'white plaque' since it caused paleness and death, 'captain of death' since it caused many deaths, and 'contaminating disease' as the affected individuals were called guilty people.⁴

Two marked stigmatising features of TB are that it has a bad reputation of a contaminating disease and that TB patients are isolated by society.⁵ The leading cause of stigmatisation is that TB is an infectious disease. This creates the perception of hunger and poverty, reminds people of human immunodeficiency virus (HIV) due to the similarity, especially in places with a high incidence of HIV, and is believed to be given by God due to acts deserving punishment.^{1,3}

Stigmatisation of TB has several negative effects on individuals suffering from this disease. In a review about stigmatisation of TB patients, three main themes were embarrassment, isolation and fear.⁶ Embarrassment results from the fact that TB is considered a bad disease and that the patients hide their disease from their families, friends and society.^{7,8} Isolation can be in the form of diminished communication with society and withdrawing. People avoid visiting and eating with the patients, prevent their children from playing with the patients' children, and may even hate the patients since they fear about the transmission of the disease.⁶ "This is a very bad disease and we don't want to eat or drink with TB patients..."⁹ Sources of fear are thought to be behind high risk of divorces and unemployment and even death. The statements "I was terrified. I've seen many patients dying from this disease" can show the extent of fear in patients diagnosed with TB.¹⁰ Moreover, it was determined that men were especially afraid of losing their masculinity due to TB.¹¹

The rate of stigmatisation over TB varies from 27% to 80% worldwide.¹² This rate changes especially between

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genders.¹³ Stigmatisation is felt more by women, which is attributed to their being more sensitive in their social interactions.¹⁴ In a study on TB patients in Bosnia, a higher rate of the young patients felt stigmatisation than the old ones and stigmatisation was found to cause delays in seeking treatment.¹² A study from Turkey revealed that TB patients experienced problems with their relationships with people around and felt stigmatised and were isolated by society.¹⁵ Another study showed that the patients did not share information about their disease since they were afraid of being isolated.¹⁵ Outcomes of stigmatisation can isolate the patients from society. TB patients have been reported to experience problems with their neighbours and friends and at work.¹⁶

Because TB has social dimensions, the patients remain in the background, cannot talk about their diseases in society, and are exposed to stigmatisation and labelling. The current study was planned to evaluate attitudes of society towards TB patients in Turkey.

Subjects and Method

This qualitative study was conducted between April and May 2015, and comprised healthy individuals living in Balcova region of Izmir, Turkey. Approval was obtained from the ethics committee of Non-Interventional Research of Medical School at Dokuz Eylül University. Verbal informed consent was taken from all the participants. Criterion sampling was used and interviews were conducted with healthy subjects who did not have TB. The subjects were at least 18 years of age, living in Izmir, and volunteered to participate in the study. Since the study was qualitative, no sample size calculation was made and the data was collected until the point of saturation was reached. Data was gathered with information form of socio-demographic features and a semi-structured questionnaire, both created by the researchers and composed of questions directed to elicit people's views about TB, and were evaluated by three experts.

Focus group interviews were conducted and data was collected by two researchers, of whom one was an observer and the other was a moderator. The interviews were voice-recorded, and were continued until a new concept or an expression did not emerge. In other words, data collection ended when collected data reached a satisfactory point. Obtained data was

analysed with content analysis. The analysis was composed of five steps; coding data, determining themes, arranging codes and themes, description of findings and interpretation of findings.¹⁷ Voice recordings of the interviews were listened two times and confirmed that they were complete and free of error by two researchers. Data obtained through voice recordings was transcribed verbatim and emerging main themes and subthemes were documented.

Results

There were 26 subjects in all across 4 focus groups. As a result of the content analysis, three main themes appeared; information about TB, perceptions, attitudes and behaviour concerning TB patients and TB, stigmatisation and its causes (Figure-2). Information about TB involved three subthemes, i.e. causes of TB, prevention and treatment. The participants reported that they did not have adequate knowledge about development of TB and got their knowledge about the disease from people around them. "...I don't believe that people do not know factors creating an appropriate environment for growth of the bacterium. Under what conditions this bacterium grows, what factors should exist for its growth and what course it follows before changing into a disease affecting society should be known..." (TU, Male, 45 years).

The participants said that TB is caused by such factors as

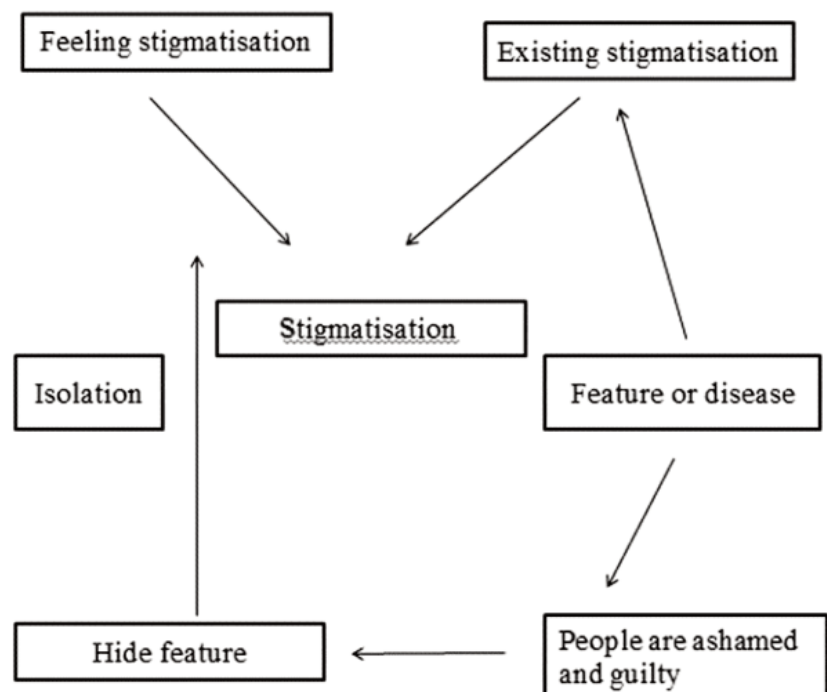


Figure-1: Stigmatisation and effects.

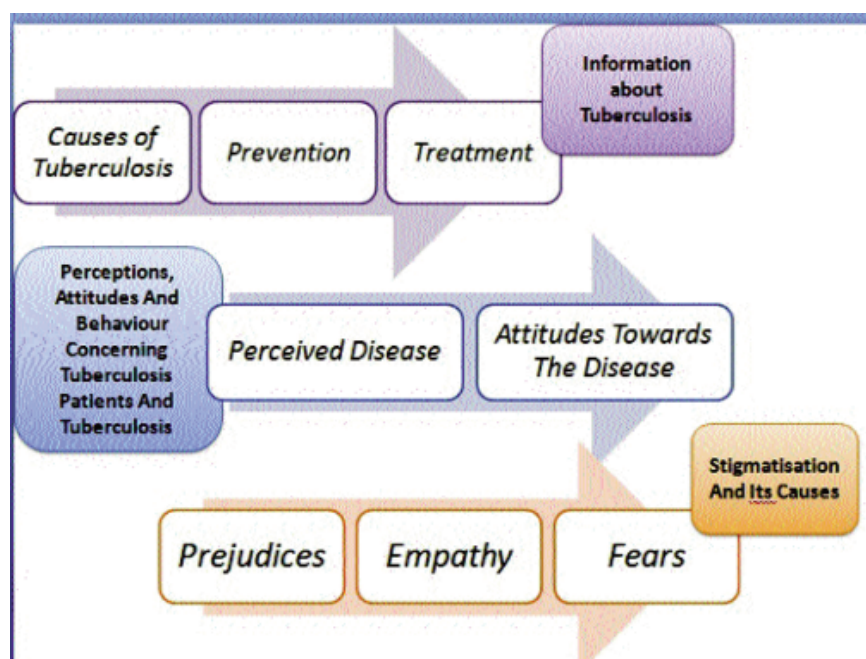


Figure-2: Themes and subthemes for cultural attitudes of society towards tuberculosis patients.

insufficient nutrition/food intake, lack of care, wars, poor economic/living conditions, high immigration rates, increased number of Syrian people in the country, pangs of love, insufficiency of natural food, smoking and drug abuse and impairment of the immune system. "... Consumption refers to tuberculosis, doesn't it? It used to appear in the poor rather than in the rich, didn't it? Insufficient food... lack of care..." (SE, Female, 32 years).

"...I've heard it is spreading now. The number of Syrian people unable to receive care has increased..." (NE, Female, 56 years).

The participants emphasised that good nutrition, living under good hygienic conditions and not getting cold were effective in prevention of TB. They also noted that isolation of TB patients and adoption of hygiene and sanitation principles could prevent transmission of the disease. "...You should use water and soap for prevention..." (GÜ, Female, 53 years).

"... People used to tell, 'you shouldn't get cold or you might catch tuberculosis' ..." (EL, Female, 44 years).

The participants pointed out the importance of taking medication, staying in a sanatorium and in a place full of oxygen, receiving special care and having good nutrition. "...I know that it requires special therapy and that there are medications which have to be taken ..." (AS, Female, 38 years).

"...The patients used to be isolated ..." (EL, Female 44 years).

The theme perceptions, attitudes and behaviour concerning TB patients and TB was divided into two subthemes: 'perceived disease' and 'attitudes towards the disease'. The participants emphasised that TB used to be common, was a disease of the poor, was caused by a microorganism, was infectious, afflicted physically weak individuals and frequently appeared in individuals smoking and using drugs. "... It used to be very common ..." (AS, Female, 38 years).

"...My son caught tuberculosis. He stayed in hospital and received treatment. Therefore, I think this disease is connected with smoking, stress and drugs. It's an infectious disease..." (NÜ, Female, 42 years).

The participants had negative attitudes towards TB. However, they said the degree of their closeness with the person with this disease was effective in their behaviour. "My father had tuberculosis, but I did not take any measures to protect myself and we even used the same plate to eat ..." (BA, Female, 33 years).

The participants noted that they kept away from TB patients. They also added that they did not stay in the same place, eat with them, use the same plates, kiss them, hug them, work in the same place or employ them. "When I meet a tuberculosis patient, I feel worried in case he/she comes closer to me ..." (D?, Female, 22 years).

"When tuberculosis patients died, people threw out their plates or burry and cover them with limestone ..." (EM, Female, 26 years).

The theme stigmatisation and its causes was divided into the subthemes prejudices, empathy and fears. The participants admitted that their attitudes were affected by their prejudices. They attributed their prejudices to their lack of knowledge about the disease and their fears about what they had heard about it. "...One should act in accordance with scientific knowledge. I'll search for it tonight and change my behaviour if it's wrong ..." (GÜ, Male, 31 years).

"...Our behaviour is affected by our prejudices. People want to keep away from patients with even the most unimportant illnesses. In other words, they put barriers

even if those illnesses are not infectious ..." (SE, Male, 19 years).

Some participants underlined the necessity not to stigmatise TB patients and the role of empathy concerning this issue. "...I may also suffer from tuberculosis ...they should not be isolated ..." (SE, Female, 32 years).

"...If tuberculosis patients are allowed to socialise by their doctors, their isolation by society is not reasonable ..." (GÜ, Female, 53 years).

"...When the patients tell people about their disease, they can be isolated by society. For this reason, I prefer not to talk about it. However, I can tell a close friend of mine. Still, it isn't right to tell everybody about it and to attract attention to it ..." (MÜ, Male, 59 years).

While some participants argued that the public should know who has TB, others objected to this idea. "... The patients themselves tell about it if they want. People should not gossip about them." (NE, Male, 56 years).

"The public doesn't have to learn about it." (BU, Male, 24 years).

"The public should know it so that they can take measures." (AS, Female, 38 years).

The participants noted that they were afraid of TB patients since the disease is infectious.

"What makes me scared is tuberculosis; a very long, poor disease outlook. It is not death which causes fear." (F?, Female, 28 years).

"...It is because the disease has had a bad reputation. Since people were afraid of them, the patients were kept in bell jar-like places..." (MÜ, Male, 59 years).

Discussion

In the present study, attitudes towards TB in a healthy adult population living in an urban area in Izmir, Turkey, were evaluated.

According to the results, the participants thought that TB is an infectious, lethal disease. This finding may suggest that they will make a greater attempt to receive health care when they contract the disease. However, it may indicate their fear and prejudices concerning the disease. To prevent transmission of TB, the participants recommended that the patients should be isolated, stay in sanatoriums and use their own plates to eat and that people should not hug and kiss them and should be careful with hygiene conditions. This is also evidence for fear and prejudices of society regarding TB. In a similar

study from China, prejudices, stigmatisation and lack of knowledge of society concerning TB were shown to cause delays in treatment of the disease and a decrease in attempts to keep the disease under control.¹⁸ In addition, in a study on a healthy population in India, the majority of the participants thought that TB was a dangerous, infectious disease and claimed that the patients should be kept in hospitals in order to prevent transmission of the disease.¹⁹ Researchers reported that underlying stigmatisation over TB was fear of infection, which led to delays in diagnosis and treatment of the disease and diminished control over the disease.¹ Therefore, public attempts to reduce fears, prejudices and stigmatisation concerning TB should be increased. They can make great contributions to bringing the disease under control.

The present study revealed that the participants lacked sufficient empathy for TB patients and that their prejudices and fears were predictive of stigmatisation. Former studies also showed that rates of people with prejudices about TB patients were high and that especially uneducated people were more likely to be prejudiced.^{20,21} The reason for fears concerning this disease was reported to be its transmission from person to person. This fear was proven to affect beliefs, attitudes, acts and behaviour playing a role in interactions with the patients.²² It is also evident in the results of the present study that the participants wanted to avoid contact with TB patients and to limit their relationships with them and wanted them to receive treatment away from society. It can be suggested that increased attempts to diminish prejudices and fears of society improve relationships between the patients and society and reduce stigmatisation over the disease.

In the current study, the participants associated TB with conditions weakening the immune system like poor living conditions, immigrations, wars, insufficient nutrition, pangs of love and substance abuse. Consistent with this finding, the former studies underlined that society linked the disease with lower socio-economic status, poverty, HIV and poor hygiene and that the patients were embarrassed with their disease, did not share information about it with other people, isolated themselves from society and experienced fear of death.^{6,18} Researchers, reported that considering TB as an infectious, very serious disease requiring a long treatment created negative attitudes and behaviour in society concerning the patients.²³ These negative attitudes and behaviour cause isolation of the patients from society and delays the diagnosis of the disease and affect adherence to treatment and involvement in social relationships. This can be attributed to lack of knowledge about the disease

and low health literacy in society. Therefore, health care authorities, especially public health workers should design health education campaigns about routes of transmission and contribute to awareness of society about the disease and acceptance of the patients by society and diminish stigmatisation over the patients.

Conclusion

The participants did not have knowledge about TB and considered the disease as infectious and fatal, had prejudices and fears about the disease and its patients, and thus preferred isolating them. For these reasons, healthcare providers should offer information about routes of transmission, ways of prevention, prognosis and treatment of the disease. They should develop strategies directed towards increasing involvement of the patients in social life and stopping their isolation, decrease morbidity and mortality due to this disease by maintaining screenings for the patients.

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