



Self-evaluations of tuberculosis patients about their illnesses at Ankara Atatürk Sanatorium Training and Research Hospital, Turkey

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Summary Tuberculosis (TB) is one of the leading causes of morbidity and mortality and almost one-third of the world is infected with this disease. In Turkey, it remains an important public health concern. In many of the studies, social aspects of TB are underestimated. In this study, self-evaluations of TB inpatients between the ages of 18 and 65 were assessed between July 29 and August 01, 2002 at Ankara Atatürk Sanatorium Training and Research Hospital, which is one of the major reference hospitals for TB in Turkey. This was a cross-sectional epidemiological study in which the participation rate was 88.2%. Mean age of the total 97 participants was 41.3 (SD = 13.6) and 80.4% of patients were male. Patients expressed "unhappiness and stress (23.7%)" to be the major cause of their illness. From the patients' point of view, the three major difficulties incorporated in their lives due to TB were "financial problems (27.9%)", "loneliness (9.3%)", and "hospitalization (9.3%)". Relationships between the patients and their social environments were also assessed in five categories: "closest friend at work, closest friend in life, parents, children, and spouse".

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Introduction

Tuberculosis (TB) is one of the leading causes of morbidity and mortality and almost one-third of the world is infected with this infection.¹ World Health Organization (WHO) estimated that eight million new TB cases and three million deaths occur due to this infectious disease each year.²

In Turkey, there has been a significant decline in mortality and morbidity patterns of TB in the last

4–5 decades. But, it still remains an important public health issue. Whereas mortality rate due to TB was 262/100 000 in 1945, it decreased to 3.2/100 000 in 1990. Morbidity rates also decreased from 172/100 000 to 36.8/100 000 within the last decades.³

Tuberculosis is known to be a social disease. There are several studies carried out about diagnosis, treatment and prevention strategies of TB, however, researches focusing on social outcomes of the disease like stigmatizing characteristics, gender difference of the disease or "social well being" of patients with TB, etc. are rare.⁴ Women who suffer from TB are often less likely to

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be detected and treated than men and the impact of the disease is strongly felt by their children and families. Biological mechanisms may account for most of this difference, but socioeconomic and cultural factors leading to barriers in accessing health care may cause under-notification in women.⁵

Today, TB is accepted as a stigmatizing disease and the meaning of stigmatizing differs from one culture to another. For example, 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.⁶ 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.⁷ Such examples may influence patients' relations with their social settings negatively. Perceptions of patients with TB about their illnesses can be a way of understanding how 'stigmatizing' affects their social lives.

In this study, self-evaluations of patients with TB in the 18–65 age group were assessed between July 29 and August 01, 2002 at Ankara Atatürk Sanatorium Training and Research Hospital (AASTRH), which is one of the major reference hospitals for TB in Turkey.

Materials and method

In this cross-sectional study, there were 110 TB patients (all of them were inpatients) in the 18–65 age group. The participation rate was 88.2%. The number of patients excluded from the study was 13. Nine of them refused to respond to the questionnaire, three of them were not at the hospital and one of them did not speak Turkish. Data were collected by "face to face interview" method. The questionnaire included 38 questions in mainly three topics (socio-demographic characteristics of inpatients; self-evaluations of patients about their disease; and knowledge and attitudes about TB). The pre-trial of the questionnaire was completed at another state hospital with TB patients.

For each patient, additional data were collected by using the official hospital files. This was done for double-checking some part of the data recorded during the interview such as their medical history about TB.

Ankara Atatürk Sanatorium Training and Research Hospital, which is one of the major reference hospitals for TB in Turkey is located in the capital city of Turkey.

In this study, some opinions of patients about TB and self-evaluations of them about their social relationships were assessed in five different categories (closest friend at work, closest friend in life, parents, children, spouse).

Statistical Package for Social Sciences (SPSS) program-version 11.0 was used for data entry and analysis.

Results

In this study, 97 patients with TB disease were interviewed. Majority of them (73.2%) settled in Ankara, and 26.8% of them were from outside Ankara, especially, from the neighboring cities. Forty-six out of 97 patients with TB (46.0%) were newly diagnosed cases and 89 of them (91.8%) did not have any extra-pulmonary TB.

The majority of the patients were male (80.4%). The mean age of the patients was 41.3 years ($SD = 13.6$, range = 19–79 years) and 67.0% of them were married. Half of the participants (50.6%, 49 patients) were graduates of primary school.

Most of the patients (91.8%) stated that it was their own decision to visit the sanatorium. Only a few of them (8.2%) were referred to the hospital with the guidance of their physicians. Two persons mentioned that they visited the sanatorium because of their parents' emotional pressure.

Only less than 1/4 of the patients (23.7%) stated that they had a regular job. Thirty-two out of 74 unemployed patients mentioned that they had to leave their job because of their illness. However, four patients were dismissed from their job after they were diagnosed with TB. Majority of the participants (99.0%) were covered by a health insurance system and the most frequent health insurance system was green card (62.9%) which is given to poor people by the government to cover their medical expenses.

Patients were asked to state their opinions about some diseases most of which were known to be socially troubling (TB, AIDS, mental diseases, etc.). Majority of the patients stated TB as a socially troubling disease (91.8%); however, the percentage of the participants who thought AIDS as a troubling disease was lower (76.3%). Approximately half of the patients (47.4%) did not accept cancer as a socially troubling disease. One out of two persons (50.5%) had no idea about what leprosy was (Table 1).

Almost one out of five patients (23.7%) believed that "unhappiness and stress" was a predisposing factor of their illnesses. Risk factors such as

Table 1 Opinions of TB patients about some diseases whether they are socially troubling or not (AASTRH, July 29–August 01, 2002) (%).

Disease	Socially troubling disease		
	Yes	No	Do not know
AIDS	76.3	3.1	20.6
Gonorrhoea	49.5	15.5	35.0
Pneumonia	40.2	43.3	16.5
TB	91.8	4.1	4.1
Cancer	42.3	47.4	10.3
Leprosy	46.4	3.1	50.5
Mental disease	48.5	33.0	18.5
Influenza	49.5	43.3	7.2

Table 2 Patients' beliefs about the predisposing factor of their illnesses (AASTRH, July 29–August 01, 2002).

Predisposing factor of their disease	Number	%
Unhappiness and stress	23	23.7
Undernourishment and poverty	15	15.6
Catching the disease from another person	12	12.4
Previous prolonged stay in cold	11	11.3
Smoking, drinking alcohol	5	5.2
Fatigue, working too hard	4	4.1
Having diabetes mellitus	3	3.0
Other*	8	8.2
Have no idea	16	16.5
Total	97	100.0

*Unrequited love, inherited, closed settlements, religious beliefs.

undernourishment, poverty, smoking, alcohol consumption were the other items that patients had emphasized (Table 2).

"Financial problems" were the most frequent difficulty that patients were facing due to TB (27.9%). Symptoms and signs of TB (8.2%) were highlighted less than social and psychological ones (separation from family, isolation, stress, anxiety, etc.) (Table 3).

Patients had more tendencies to change their relations with their children after being told of their diseases (57.7%). Other social categories were arranged in the order of spouse (41.4%), closest friend in life (39.1%), parents (33.8%) and closest friend at work (33.3%) (Table 4).

Five out of 34 patients who have a closest friend at work perceived a change both in their and their

Table 3 Opinions of inpatients about the most important difficulty that they were facing due to TB (AASTRH, July 29–August 01, 2002).

Difficulty due to TB	Number	%
Financial problems	27	27.9
Separation from family	9	9.3
Isolation	9	9.3
Hospitalization	9	9.3
Stress, anxiety and other negative feelings	8	8.2
Symptoms and signs of TB	8	8.2
Concealing the disease	2	2.1
Negative influences on sexual life	1	1.0
There is no significant difficulty	10	10.3
Do not have an idea	14	14.4
Total	97	100.0

friends' behaviors, whereas 52.9% of them did not perceive any change due to either side.

Most of the people, who have a closest friend in life, stated that they did not perceive any changes arising from both themselves and their counterparts (42.0%). The results were similar for the assessment of patients and spouses. Majority of the patients also did not perceive any behavioral change arising from both sides (43.4%). Relations between patients and children were also assessed. Most of the patients stated that there was a unilateral behavioral change arising from the patients themselves (41.1%) (Table 5).

Discussion

In this study, we used "illness" instead of "disease" even though diagnosis of all cases was proved by some TB specific tests, etc. The term "disease" is assumed to be more medical and universal. For example, TB as a disease generally does not change in almost every culture or society. However, "illness", defined as the subjective response of an individual suffering from the symptoms of a disease, is usually affected by backgrounds and emotional characteristics of individuals as well as social, physical, environmental, and cultural values. Being ill usually correlates with perceived changes in bodily appearance, excessive and emotional stress and behavioral changes in relation to others. People generally perceive themselves as being ill, when they find answers to a series of questions such as "what has happened?", "why has

Table 4 Perception of patients with TB about changes in their social relations arising from themselves after being acquainted with their diagnosis (%) (AASTRH, July 29–August 01, 2002).

Changes in social relations after being diagnosed as TB	Closest friend at work (<i>n</i> = 54)	Closest friend in life (<i>n</i> = 87)	Parents (<i>n</i> = 68)	Child/children (<i>n</i> = 71)	Spouse (<i>n</i> = 70)
There is a change	33.3	39.1	33.8	57.7	41.4
There is no change	61.1	58.6	63.2	39.5	54.3
No response	5.6	2.3	3.0	2.8	4.3
Total	100.0	100.0	100.0	100.0	100.0

Table 5 Patients' perceptions about behavioral changes in some social relations after being diagnosed as having TB (AASTRH, July 29–August 01, 2002).

Social relation with	Behavioral Change			
	There is a behavioral change arising from both sides	There is no behavioral change arising from both sides	There is a unilateral behavioral change arising from the patient	There is a unilateral behavioral change arising from the counterpart
	%	%	%	%
Closest friend at work (<i>n</i> = 34 [*])	14.7 (5/34)	52.9 (18/34)	17.6 (6/34)	14.8 (5/34)
Closest friend in life (<i>n</i> = 69 [†])	20.3 (14/69)	42.0 (29/69)	20.3 (14/69)	17.4 (12/69)
Parents (<i>n</i> = 58 [‡])	19.0 (11/58)	48.3 (28/58)	15.5 (9/58)	17.2 (10/58)
Child/children (<i>n</i> = 56 [§])	16.1 (9/56)	37.5 (21/56)	41.1 (23/56)	5.3 (3/56)
Spouse (<i>n</i> = 60 [¶])	25.0 (15/60)	43.4 (26/60)	18.3 (11/60)	13.3 (8/60)

*63 people are non applicable (NA) for this question

†28 people are (NA)

‡39 people are (NA)

§41 people are (NA)

¶37 people are (NA)

it happened?", "why has it happened to me and why now?", "what should I do about it?", etc.⁸

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 the country. 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, where the other sanatorium is located, were also hospitalized. Supporting this idea, we found that some of the socio-demographic characteristics of our patients were similar with others. For example, in one of the Turkish studies, TB was found to be more common among persons with a mean age of 37.5 years (range 20–39) and 85% of patients were male.⁹ In our study, we found that the majority of

the patients were male (80.4%) and the mean age of the patients was 41.3 years (*SD* = 13.6, range = 19–79 years).

About nine in ten patients accepted TB as a socially troubling disease. Remarkably, the percentage of the participants who considered AIDS as a troubling disease was lower (76.6%). In general, AIDS is also a very troubling and a traumatizing disease, but patients may have prioritized TB due to their illnesses.^{10–12} Besides, people may truly have lack of knowledge about AIDS and in Turkey, AIDS currently is not as prevalent as it is in other countries, so people are not very familiar with the disease. There were only 119 reported AIDS cases in Turkey in 1999. Total number of the cases was 983 by the end of 1999 (Table 1).¹³

Attitudes and perceived causes of the disease may affect patients' health-seeking behaviors and treatment delays. In a study conducted in the

Philippines, about two-third of the patients (69%) had been told by someone to have a medical check-up for their symptoms and in many cases a private doctor was the first health care provider who initiated the treatment.¹⁴ In our study, we aimed to learn if it was their self-decision to be treated at the Sanatorium or not. Most of the patients (91.8%) agreed with this idea. However, it was our limitation that we did not ask the initial factor or person that facilitated their health-seeking behavior.

Beliefs of the patients about the underlying factors of their illnesses were evaluated. Almost one out of five patients (23.7%) believed that “sadness, stress” was a predisposing factor for their illnesses. Risk factors such as undernourishment, poverty, smoking, alcohol consumption were the other issues that patients had emphasized. Eight people gave some quite unusual answers; one of which was “unrequited love”. TB is known to be a social disease in Turkish culture for many years. Movies and serials produced in Turkey use the theme of a patient with TB very frequently and “unrequited love” leading to TB is a very common part of this theme. Leading characters in movies who suffer from “unrequited love” usually acquire TB. Patients might have been affected by this detail (Table 2). Similar traditional beliefs were reported in other studies conducted in different parts of the world. For example, in a study from Vietnam, patients stated that they contracted TB because of “hard work”, “too much worrying”, and “the fact that TB is a genetic disease”.¹⁵

“Financial problems” were the most frequent issue that participants had to struggle with due to TB (27.9%) (Table 3). Patients who do not have a regular job and are not covered by a social insurance system may have financial problems. Treatment of TB lasts for at least 6 months, which is indeed a very long time for patients to live without earning their livelihoods. This may be the reason why the patients were suffering from financial problems.

Symptoms and signs due to TB (8.2%) were highlighted less than social and psychological ones. Separation from family, isolation, feelings of stress, anxiety, etc. were the most frequent prioritized perceptions (Table 3). This brings another important social concept “stigma” to mind. Briefly, stigma is a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from an adverse social judgment about a person or a group.⁶ At this point, TB becomes very serious for both the infected individual and others around him/her. Stigmatization can influence patients’ relations with their social settings negatively.⁷ Perceptions

of patients with TB about their illness can be a way of understanding how ‘stigmatizing’ affects their social lives. In this study, we assessed patients’ perceptions about their social relations within their social environment in different categories. For each category, patients mentioned the perception of behavioral change arising either from themselves or their counterparts.

They had more tendencies to change their relations with their children after being told of their diseases (57.7%) (Table 4). Supporting this result, patients perceived a unilateral behavioral change arising from themselves mostly in their relation with their children (41.1%) (Table 5). In our view, this may be because of the responsibility that they feel for their children as a parent and they may have anxiety about their children, because TB is a communicable disease.

There are some limitations about this study. Our study population was not sufficient for evaluating the associations between the variables in detail. A different study design with follow-up components conducted for a longer period may give more detailed and generalizing results. The questionnaire was developed by the research team. Although the pre-trial of the questionnaire was completed, there is a further need to improve it. Another important limitation of our study was the lack of qualitative data. For assessing the perceptions, especially the stigma aspect of TB for our study population, qualitative (focus group discussions, in depth studies, etc) and quantitative studies should be planned collaboratively for future evaluations.

We hopefully think that our study will guide the health staff in prioritizing social care as well as physical and biological care in TB patients.

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