Tuberculosis related stigma and delay in seeking care after the onset of symptoms associated with tuberculosis

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ABSTRACT

Aim To determine association between tuberculosis (TB) related stigma and delay in seeking a treatment after the onset of symptoms associated with tuberculosis.

Methods This prospective study was carried out in the „Podhrastovi“ University Clinic of Lung Diseases and Tuberculosis and Health facilities for lung diseases and tuberculosis in the Sarajevo area. The sample consisted of 300 tuberculosis patients. Between patients who consider TB a stigmatizing disease and patients who did not consider TB a stigmatizing disease distribution of patient delay was compared.

Results Of the total of 300 patients 79 (26.3%) considered TB a socially stigmatizing disease. Among them 43 (54.4%) were females and 36 (45.6%) males. Among patients in the age group 18-24 years, nine (50%) considered TB a socially stigmatizing disease compared to seven (12.3%) among patients in the age group 65-75 years. Among patients with university degree, nine (64.3%) and among patients that had no education, one (9.1%) declared TB as a socially stigmatizing disease. The average time interval from the appearance of first symptoms of tuberculosis until the first visit to a health care facility for those who consider TB a stigmatizing disease was 6.41 weeks and for those who did not consider it a stigmatizing disease the average time interval was 4.99 weeks.

Conclusion Study results revealed high stigma-generating attitudes towards tuberculosis. Perceived TB related stigma had no strong impact on patient delay in seeking care for TB symptoms.

Key words: community norms, tuberculosis, health-seeking behaviour
INTRODUCTION

Tuberculosis (TB) is highly stigmatized disease (1). Tuberculosis-related stigma has an enormous impact on sufferers (2). That impact is felt at home, in the workplace and in the community (3). When tuberculosis is stigmatized, the fear of social and economic consequences following diagnosis can affect willingness of individuals at-risk to undergo TB screening and to seek medical care after the onset of symptoms associated with TB (4). The structure of community’s beliefs and norms about the disease and the resulting stigma can, therefore, substantially impact health. By delaying seeking care, these people may develop more serious symptoms, meaning that they will be more difficult to treat; and as they remain infectious for a longer period of time, they are more likely to transmit the disease to others (5).

Understanding the origins of TB stigma is integral to reducing its impact on health. Using surveys, focus groups, and unstructured and focused interviews, a number of studies have explored the causes of TB stigma (6-8). Although there is geographic and cultural variation in the explanations for why TB is stigmatized, most authors identify the perceived risk of transmission from TB-infected individuals to susceptible community members as a leading cause of stigmatization (9-12). Tuberculosis is also stigmatized because it is closely associated with HIV, poverty, low social class, malnutrition, or disreputable behavior (13).

The perception of TB as a stigmatizing disease seemed to differ according to cultural context, whereas the social TB stigma can have important implications on health seeking behavior and the affected person’s well-being (14).

Therefore, the aim of this study was to determine association between social stigma and delay in seeking treatment after the onset of symptoms associated with TB.

PATIENTS AND METHODS

A prospective study was conducted in the period 2008-2011. Adults (≥ 18 years) with diagnosed TB were enrolled from the health care centres for lung diseases and tuberculosis in the Sarajevo area and the “Podhrastovi” University Clinic of Lung Diseases and Tuberculosis. The sample consisted of 150 acid-fast bacillus (AFB) smear positive and 150 AFB smear negative tuberculosis patients. The study was approved by the Ethics Committee of the Medical School of Sarajevo University, and an informed consent was taken from the patients for participation in research and review of their medical records.

Physicians conducted the interviews using a structured questionnaire. The questionnaire elicited information about demographics, socio-economic status, education level, care seeking and TB stigma from the patient perspective. Information from the medical records available at health care centres (especial results of sputum microscopy, radiological and other investigations) was also abstracted. Those data were used to supplement information obtained from patients’ interviews.

A case of sputum smear positive pulmonary tuberculosis involves a patient with at least two initial positive sputum smears, or one sputum smear positive plus radio-graphic abnormalities consistent with active pulmonary tuberculosis as determined by a clinician; or one sputum specimen positive plus culture specimen positive for Mycobacterium tuberculosis. A sputum smear negative pulmonary tuberculosis case was defined as a patient diagnosed with pulmonary tuberculosis by a clinician, who did not meet the above criteria for smear-positive disease.

Social-stigma (social consequences of a person with tuberculosis) refers to consequences of patients’ discrimination by society and other people’s antagonistic practices or attitudes.

Patient delay, defined as the period (in weeks) from onset of the first symptom(s) possibly related to pulmonary TB to the date when the patient first contacted qualified primary health care services as a result of the symptoms, was the focus of interest. Patients were asked to recall the duration of their symptoms and when they first visited a doctor. Delay was calculated as the time between these two points. In order to determine the effect of TB stigma on the length of the delay, TB stigma was correlated with the categories of the delay.

The chi-square test was applied to analyse the categorical variables. Statistical significance was considered when $p<0.05$. The standard deviation (SD) and 95% confidence intervals (CI) were calculated. The correlation among individual perception of TB such as social stigmatization of the disease and patient delay was calculated...
and verified by means of the Pearson Correlation with the display of the relevant probabilities that were obtained based on a Sig. 2-tailed test.

RESULTS

A total of 300 tuberculosis patients were included in the study. Among them 150 (50%) had sputum smear positive for pulmonary tuberculosis and in 150 (50%) it was negative.

The participants included 152 (50.7%) males and 148 (49.3%) females. The largest number of participants, 57 (19%) was between 65 and 75 years of age, followed by persons in the age group 55-64 years, 52 (17.3%) and >75 years, 51 (17.0%). Both groups included mostly persons with secondary school qualifications. One hundred and four (69.3%) among AFB-positive patients and 116 (77.3%) among AFB-negative patients completed secondary school.

Of the total of 300 AFB-positive / AFB-negative patients 79 (26.3%) considered TB a socially stigmatizing disease (95% CI=0.21-0.32, p<0.05). Among 150 AFB-negative patients 31 (20.7%) (95% CI=0.14-0.28, p<0.05) declared that TB is socially stigmatizing disease. Among 150 AFB-positive patients 48 (32%) declared that TB is socially stigmatizing disease (95% CI=0.25-0.40, p<0.05) (Figure 1).

Of the total of 79 patients, who considered TB as a stigmatizing disease, 48 (60.8%) were AFB-positive and 31 (39.2%) AFB-negative. Among 152 males and 148 females 36 (23.7%) and 43 (29.1%), respectively, considered TB a socially stigmatizing disease (95% CI=0.17-0.31, and 95% CI=0.22-0.37, respectively).

Of 75 AFB-negative males and 75 AFB-negative females 17 (22.6%) and 14 (18.7%), respectively, considered TB a socially stigmatizing disease (95% CI=0.14-0.34 and 95% CI=0.11-0.29). Of 75 AFB-negative females 14 (18.7%) considered TB a socially stigmatizing disease (95% CI=0.11-0.29).

Of 77 AFB-positive males and 73 AFB-positive females 19 (24.7%) and 29 (39.7%) respectively, considered TB a socially stigmatizing disease (95% CI=0.15-0.36 and 95% CI=0.28-0.52, respectively). Of 73 AFB-positive females, 29 (39.7%) considered TB a socially stigmatizing disease (95% CI=0.28-0.52) (Figure 2).

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The percentage of patients (AFB-positive/AFB-negative), who stated that TB is socially stigmatizing disease was higher in younger age groups (18-24 years of age), nine (50%), than in the age group above 75 years, 8 (15.7%); in the age groups 65-75 and 55-64 years there were 7 (12.3%) and 14 (26.9%), respectively.

The data indicate that among patients with university degree 9 (64.3%) and among patients that had no education, one (9.1%) declared that TB is a socially stigmatizing disease.

The average time interval from the appearance of the first symptoms of tuberculosis until the first visit health care facility was 5.4 weeks (5.3 weeks by AFB-negative and 5.4 weeks by AFB-positive patients).
Patients who considered TB a socially stigmatizing disease had a longer delay in seeking care for TB symptoms (6.41 weeks by AFB-positive/AFB negative patients, 6.77 weeks by AFB-negative patients, 6.17 weeks by AFB-positive patients) than the average delay in seeking care for TB symptoms for total number patients and average delay in seeking care for TB symptoms for those who did not consider TB a socially stigmatizing disease (4.99 weeks by AFB-positive/AFB negative patients, 4.97 weeks by AFB-negative patients, 5.02 weeks by AFB-positive patients) (Figure 3).

Based on review of the published literature gender was considered as a potential factor associated with TB stigma (21). In our study the perception of TB as a stigmatizing disease differed by gender and it was greater in females than in males. Numerous studies have shown that females are somewhat more likely to perceive TB as a stigmatizing disease (6,22). Qualitative studies have reported that TB stigma more adversely affects females than males, primarily because of their sensitivity to social interaction (23). A study conducted among patients with TB in Thailand showed that being female was not associated with perceived stigma (24).

TB stigma is felt more strongly in certain subpopulations, including people with lower education levels and higher age (1,25). Our study showed quite opposite results.

Tuberculosis-related stigma is perceived to increase time intervals from onset of symptoms to seeking care (26). In population with a relatively short median patient delay in seeking care for TB symptoms the impact of TB stigma translates into a minimal change in delay time. The impact of stigma would likely be greater in population where median delay times in seeking care for TB symptoms are much longer (27).

In our study the median time interval from onset of symptoms to seeking care was 5.4 weeks and was close to lower bound of the range (10-119 days) reported in other studies (27). Patients who considered TB as a socially stigmatizing disease had a longer patient delay in seeking care for TB symptoms than those that did not. The association between patients’ perception of TB as a socially stigmatizing disease and length of patients delay in seeking care for TB symptoms was statistically significant but weak. Similar results were obtained in the study conducted in Thailand where this association was not observed. In Thailand median patient delay in seeking care for TB symptoms in study population of 26 days corresponds to a maximum four days decrease in delay time (27). The study conducted in Camero-

Figure 3. The perception of tuberculosis as a stigmatizing disease and status of patient delay

TB, tuberculosis

The results of Pearson’s correlation (-0.170) and Sig. 2-tailed test (0.003) indicated a statistically significant but weak association between patient perception of TB as a socially stigmatizing disease and length of the period from onset of first symptom(s) possibly related to pulmonary TB to the date when the patient first contacted health care service.

DISCUSSION

This study investigated the prevalence of perceived TB related stigma and its impact on health seeking behaviors. The results revealed high stigma-generating attitudes towards tuberculosis. In the study the percentage of the patients considering TB as a stigmatizing disease, 26.3 %, is far higher than the percentage reported in Croatia (less than 10%) (15), and it is below that found in Pakistan (48.2%) (16) and in a study of TB-negative Mexican Americans at-risk, where half of the participants believed that someone with TB would experience social isolation (17).

Worldwide studies use qualitative instruments (e.g., in-depth interviews and focus groups) to gauge the degree to which TB is seen as stigmatized in a community. Considerable geographic variability exists in the perceived prevalence of TB stigma, with 27% to 80% of individuals at-risk reporting that TB is stigmatized in their communities (18–20).

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on found that perceived TB stigma was a significant predictor of delays in seeking care for TB symptoms of more than four weeks (28). Similar results were shown in a study conducted in Afghanistan where a high level of social stigma was an independent explanatory factor for increased risk of patient delay in seeking care for TB symptoms (29). A multi-country study by the World Health Organization in the eastern Mediterranean region reported that increased stigma was associated with decreased patient delay in seeking care for TB symptoms in Somalia (30).

Although a great deal of research in public health is based on a trend to increase focus on social determinants of health, including TB-related stigma, there are few studies about this problem conducted in Europe. Geographically, most studies involved Asia/Pacific Islands or Africa/Middle East. More studies in Eastern Europe can be expected in the future.

In conclusion, the results of this study illustrate that TB-related stigma is a barrier to health-seeking and access to health care. Our findings provide information that is important for the future development of individual and structural stigma reduction interventions in order to ensure that persons affected by tuberculosis receive crucial preventive, diagnostic and treatment services that are free of stigma and discrimination. An important challenge for future research on TB related stigma is to better assess the impact of TB stigma on completion rates of tuberculosis treatment.

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**TRANSPARENCY DECLARATION**

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**REFERENCES**

Stigmatizacija oboljelih od tuberkuloze i odloženo javljanje pacijenata liječniku nakon pojave simptoma ove bolesti

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SAŽETAK

Cilj Utvrditi postojanje povezanosti između pacijentovog posmatranja TB-a kao stigmatizirane bolesti i njegovog odloženog javljanja liječniku nakon pojave simptoma ove bolesti.

Metode Rad predstavlja prospektivnu studiju provedenu na Klinici za plućne bolesti i tuberkulozu “Podhrastovi” Univerziteta u Sarajevu, te dispanzera za plućne bolesti i tuberkulozu na području Sarajeva. Uzorak je činilo 300 pacijenata oboljelih od tuberkuloze. Izvršena je komparacija dužine trajanja pacijentovog odlaganja posjete liječniku između pacijenata koji su TB smatralo stigmatizirano, a onih u kojima bolest nije smatrana stigmatiziranoj.

Rezultati Od ukupno 300 pacijenata, 79 (26,3%) su TB smatralo stigmatizirano. Među njima je bio 43 (54,4%) žena i 36 (45,6%) muškaraca. Među pacijentima koji su pripadali starosnoj grupi od 18 do 24 godine, njih 9 (50%) je TB smatralo stigmatizirano, u poređenju sa 7 (12,3%) pacijenata unutar starosne grupe od 65 do 75 godina koji nisu. Među pacijentima s fakultetskim obrazovanjem, njih 9 (64,3%), a među pacijentima bez škole, ukupno 1 (9,1%), izjasnilo se da je TB stigmatiziran.

Zaključak Rezultati studije pokazuju da je tuberkuloza stigmatizirana bolest. Pacijentovo sagledavanje TB-a kao stigmatizirane bolesti nema snažan utjecaj na njegovu brzinu javljanja liječniku nakon pojave simptoma bolesti.

Ključne riječi: društvene norme, tuberkuloza, traženje ljekarske pomoći