

Stigma Associated with Tuberculosis Disease in Republic of Macedonia – Results from a Cross-Sectional Study

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Abstract

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BACKGROUND: Stigma and discrimination are interrelated and are breaking the fundamental human rights. Both are associated with tuberculosis (TB) disease since ever and have negative influence on activities aimed at TB prevention, treatment and control, both at individual, community and societal level.

AIM: To determine the magnitude of TB stigma in Republic of Macedonia, identify root causes and detect main determinants associated with it.

MATERIAL AND METHODS: Cross-sectional study was performed on 315 TB patients registered in the period Jul, 2012-Jun, 2013, using selected module from World Health Survey questionnaire. Self-reported data is collected through face to face interview conducted by trained directly observed treatment (DOT) nurses in the patients' home.

RESULTS: 16.7% TB patients have not received any assistance when diagnosed with TB and 8.4% were treated badly by a member of the family or close friends because of the disease, consequences ranging from living the patient completely, refusal to talk or telling other people that the person is infected. An odd for such behavior were higher if the patient is male, married, have no formal education or have completed only primary school, is unemployed and lives in rural area.

CONCLUSION: Understanding the origins of TB stigma is integral to reducing its impact on health. Our survey has provided a baseline on the magnitude of existent stigma associated with TB disease and has identified main determinants that trigger stigmatizing behavior.

Introduction

Stigma is defined as a “*negative social label that identifies people as deviant, not because their behavior violates norms but because they have personal or social characteristics that lead people to exclude them*” [1]. It can be associated with an array of individual characteristics, such as skin color, behavior, social status etc and is completely subjective and arbitrary [2]. It goes hand-in-hand with discrimination, which defined as “*distinction among individuals in similar situations based on race, gender, religion, political affiliation, moral and cultural values and religious philosophical beliefs, association with ethnic minority or personal antipathy*” [3] and exists in absence of legislation that prevents it, or legislation that is not enforced or is implemented inappropriately [4], leading to violation of other human rights as the right to health, to dignity, privacy, rule of law and liberty from inhuman and degrading action or

punishment [5, 6].

Stigma and discrimination are associated with TB disease since ever and have negative influence on activities aimed at TB prevention, treatment and control, both at individual, community and societal level and exist in all countries and different societal establishments, representing a significant barrier in prevention and continuity of treatment [7]. Stigma associated with tuberculosis disease is multi layered and is associated with the social status, additional vulnerability of the groups (such as immigrants or prisoners) and is particularly present among individuals with dual TB and HIV infection [8]. Erroneous images of TB patients presented in media are further fueling stigma and discrimination [9]. The degree of stigma is variable and dependant on the cultural and societal environment and is highest in societies with deeply rooted gender differences, socially unacceptable sexual behavior etc [10].

Following the independence in 1991, Republic of Macedonia (RM) has embarked upon numerous reforms and has faced numerous challenges in all sectors of the society, in the transition towards development of parliamentary democracy in parallel with efforts to preserve social values based on democracy, citizen's participation and right to private property [11]. In its efforts for accession to European Union, RM is also signatory of Stabilization and Association Agreement [12] and is obliged to provide compatibility of country's laws with EU laws, including the human rights and non-discrimination.

Although TB is on constant decrease in the country over the past decade, with incidence of 17.2/100.000 in 2012 that classifies RM as low incidence country [13], TB is clustered in certain ethnic groups, with highest rates notified in the north-west part of the country, in male population with ratio of 1.5:1 – 1.3:1 in the period 2007-2013 and most affected is age group 25-54. While there is no scientific evidence on the magnitude of TB stigma, these numbers and everyday practice indicate that it is present in the population, regardless of ethnicity or region where they reside. TB stigma is present in RM since ever, transferring the fear and shame of the disease through generations. By the mid 20th century, entire families were dying of TB, due to reasons well known in the literature, such as lack of drugs, poverty, wars and the fear among population is still present [TB Stigma reduction program 2007-2011, Ministry of Health].

Data on stigma and other social determinants of health is not routinely collected, neither monitored, therefore the implicit need to study them in national context. Education on TB is an integral part of the terms of reference of health professionals included in TB control, aimed at increasing public awareness and reducing stigma, but this education is not at satisfactory level for various reasons, ranging from lack of personnel, inadequate patronage service, lack of motivation and inadequate environment as well as inadequate organization of services and collaboration with other services [TB Stigma reduction program 2007-2011, Ministry of Health].

The objective of this survey is to determine the magnitude of TB stigma in Republic of Macedonia, identify root causes and detect main determinants associated with it.

Materials and Methods

This cross-sectional study was conducted in the period March – December, 2013, on a cohort of TB patients registered TB cases in the period July, 2012 – June, 2013. Informed consent was an integral part of the questionnaire and was obtained from each survey participant. The study was granted ethical approval by Doctors Chamber in March, 2013.

Data is collected with selected module on stigma from the World Health Survey questionnaire [14], modified to provide data for survey objectives, in accordance with guidelines for developing countries [15]. The instrument is designed to collect broad range of data associated with everyday functioning of households, such as demographic data, economic activity, consumption of goods and services, living conditions, lifestyle, health status and access to health services of household members.

Social determinants are assessed by collected data on gender, place of residence (urban-rural), educational and employment status, ethnicity and the region where the patient lives. Stigma is assessed with three questions on assistance received since the patient was diagnosed with TB, the type of assistance received and conduct of family members and friends since the diagnosis. Face-to-face interview was performed by 20 trained DOT nurses who visit TB patients 3 times/week; all data on variables is based on self-reported information.

The instrument has been pre-tested on 10% of the sample, with appropriate corrections following feedback from the pre-test, mainly additional explanations for better understanding of questions. The instrument has been also translated into Albanian language, as to allow for interviewing ethnic minorities in RM into their mother tongue.

Data has been analyzed with IBM SPSS Statistics, version 19.0 (IBM Corporation, Somers, NY, USA), using descriptive statistics to calculate frequencies and mean values. Percentages are used to express values and chi-square test to analyse differences between cases and controls for categorical variables. Multiple logistic regression was used to assess the relationship between stigma as single categorical response and age, gender, place of residence, region, educational and employment status as categorical explanatory variables [16, 17].

Results

The total study population is 315 respondents who were diagnosed with tuberculosis in the period Jul, 2012 – June, 2013, which corresponds to high 96% of all registered TB cases in the period under study. Socio-demographic characteristics of study population are presented in Table 1.

Respondents are represented in all 8 regions, as per statistical division of the country, most of them interviewed in the North-West region, 47.6% in Skopje region, 14.9% in Polog, South-West 8.4%, South-East and North-East with 7.4% and 7.2%, respectively, Pelagonija 5.9%, East 5.3% and the lowest number in Vardar region (3.2%), which corresponds to distribution of TB patients registered in the period Jul, 2012 – June, 2013, as the main inclusion criterion.

Table 1: Demographic characteristics of study population (n=315).

| | TB Cases (# and %) |
|---------------------------------|--------------------|
| Region | |
| Skopje | 149 (47.3%) |
| Polog | 47 (14.9%) |
| South-West | 27 (8.5%) |
| South-East | 23 (7.3%) |
| North-East | 22 (7%) |
| Pelagonija | 20 (6.3%) |
| East | 16 (5.1%) |
| Vardar | 11 (3.5%) |
| Place of residence | |
| Urban | 160 (50.9%) |
| Rural | 155 (49.1%) |
| Gender | |
| Female | 116 (36.8%) |
| Male | 199 (63.2%) |
| Mean age of respondents | 45.17 |
| Mean HH¹ size | 4.66 |
| Ethnicity | |
| Macedonian | 118 (37.4%) |
| Albanian | 160 (50.8%) |
| Roma | 24 (7.6%) |
| Turkish | 13 (4.2%) |
| Education | |
| No formal education | 8 (2.6%) |
| Unfinished primary school | 32 (10.1%) |
| Completed primary school | 129 (41.7%) |
| Completed high school | 122 (39.5%) |
| 2-years university education | 5 (1.6%) |
| Completed university education | 14 (4.5%) |
| Employment status | |
| Public administration | 23 (7.3%) |
| Self-employed | 28 (9%) |
| Employer | 35 (11.1%) |
| Unemployed | 228 (72.4%) |
| NGO | 1 (0.3%) |

¹HH = household.

Distribution of respondents by place of residence is quite proportional with 50.9% living in urban and 49.1% in rural areas. Dominant are male TB cases (63.2%) with mean age of 45.17 years \pm 15.7 SD who live in households of average 4.66 members. By ethnicity, most of TB cases are Albanians (50.8%) or Macedonians (37.4%), followed by Roma (7.6%) and Turkish ethnicity (4.2%).

By education, most of the TB patients have completed primary school (41.7%) or high school (39.5%), 10.1% have never finished primary school and 2.6% are without formal education. Only 1.6% and 4.5% TB patients have 2-years or complete university education, respectively.

Stigma

Stigma is assessed through 3 questions on behavior of family members and friends after the patient was diagnosed with TB. Distribution of answers is presented in Table 2.

Two thirds of TB patients have received some kind of assistance from members of the family or friends. However, 16.7% have provided negative answer to this question and 8.1% don't know. 24 TB patients (8.4%) were treated badly (i.e. have experienced severe behavior) by a member of the family or close friends when he/she has informed them that is diagnosed with TB disease. Of those who were treated badly, in 1.9% cases the family member or a friend left the TB patient, 4.3% refused to talk to them, 3.1% have told others that the person has TB, although high 84.4% did not notice any change in their family or friends behavior.

Table 2: Distribution of answers on question for assessing stigma associated with TB¹ disease.

| | TB Cases (# and %) |
|---|--------------------|
| Have someone, for example member of your family or a friend has provided any assistance since you were diagnosed with TB? (n=234) | |
| Yes | 176 (75.2%) |
| No | 39 (16.7%) |
| I don't know | 19 (8.1%) |
| Have someone, for example member of your family or a friend has treated you badly because he/she knew you have TB? (n=283) | |
| Yes | 24 (8.4%) |
| No | 241 (85.1%) |
| I don't know | 18 (6.3%) |
| How did this person treat you since he/she knew that you have TB? (n=256) | |
| Has left me | 5 (1.9%) |
| Refused to talk to me | 11 (4.3%) |
| Has told everyone that I have TB | 8 (3.1%) |
| No change | 216 (84.4%) |
| Other | 14 (5.4%) |

¹TB=tuberculosis.

Multivariate logistic regression shows that probability to be treated badly if a family member or a friend knows about the disease is almost three times higher if the patient is male and married, and has no formal education or has completed only primary school, compared to TB patients with university education as a reference group. Stigma is also likely to be 2, 1 or 4 times higher if the TB patient is of Albanian, Turkish or Roma ethnicity, respectively, compared to Macedonians as a reference group. Another determinant associated with stigma is unemployment with 5 times higher probability for TB patient to be treated badly and is more than 6 times higher if the patient lives in rural area – Table 3.

Table 3: Adjusted odds ratios for socio-demographic characteristics associated with TB¹ stigma.

| Social determinant | OR ² | 95% CI ³ | | p-value |
|------------------------------|-----------------|---------------------|--------|---------|
| | | Lower | Upper | |
| Gender | | | | |
| Female* | 1 | | | |
| Male | 2.717 | 1.220 | 6.053 | 0.048 |
| Marital status | | | | |
| Not married* | | | | 0.014 |
| Married | 3.188 | 1.927 | 10.962 | 0.014 |
| Separated | 1.512 | 0.081 | 28.140 | 0.066 |
| Divorced | 1.914 | 0.201 | 18.192 | 0.781 |
| Widowed | 2.592 | 0.470 | 14.307 | 0.572 |
| Education status | | | | |
| University education* | | | | 0.043 |
| No formal education | 1.163 | 1.013 | 2.035 | 0.043 |
| Uncompleted primary school | 1.114 | 1.013 | 2.001 | 0.015 |
| Completed primary school | 0.269 | 0.041 | 1.780 | 0.050 |
| High school | 0.220 | 0.036 | 1.364 | 0.173 |
| 2-years university education | 0.113 | 0.006 | 2.152 | 0.104 |
| Ethnicity | | | | |
| Macedonian* | | | | 0.022 |
| Albanian | 2.440 | 1.024 | 5.812 | 0.022 |
| Turkish | 1.124 | 1.107 | 7.353 | 0.044 |
| Roma | 4.168 | 1.948 | 18.319 | 0.014 |
| Employment status | | | | |
| Public administration* | 1 | | | |
| NGO ⁴ | 2.351 | 0.148 | 37.414 | 0.187 |
| Self-employed | 1.952 | 0.125 | 30.520 | 0.545 |
| Employer | 6.739 | 0.528 | 85.964 | 0.634 |
| Unemployed | 5.234 | 1.837 | 8.228 | 0.029 |
| Place of residence | | | | |
| Urban | 1 | | | |
| Rural | 6.30 | 2.97 | 13.35 | 0.015 |

*reference group; ¹TB = tuberculosis disease; ²OR = Odds ratio; ³CI = Confidence interval; ⁴NGO=Non-governmental organisation

Discussion

Our survey has described the degree of stigma associated with TB disease in a cohort of TB

patients registered in one year period and has identified the basic social determinants associated with the stigma. Although majority of TB patients have received some kind of assistance from members of the family or friends, there is a certain portion of individuals that have experienced severe behavior when a family member or a close friend found out that they have the disease, such as living the person, refusal to talk to them, telling others that the person has TB, all of which is indicative of existence of undeniable degree of stigma that needs further exploration of underlying reasons. Our findings are consistent with existing literature [18-21], that have measured various degree of stigma. It has to be noted, though, that literature on stigma in the neighboring countries is scarce and limited, therefore comparison is mainly with other countries, not very similar to Macedonia.

Due to its association with disease at interpersonal level that affect health outside of the ease with which an individual can access medical services [22], stigma is shaped and promulgated by institutional and community norms and interpersonal attitudes, and is therefore an important social determinant of health [23]. Our survey has identified gender, marital status, education and employment status as social determinants that determine stigma and should be taken into consideration when designing programs and interventions for target groups, findings similar to the survey done in Kosovo in 2009, identifying as most vulnerable patients without education background and from villages [24]. Place of residence is also important, rural population having 6 times higher odds of being stigmatized, a finding that is consistent with a study on TB and HIV stigma in Ethiopia [25]. Ethnicity is also associated with stigma and implies the necessity for provision of culturally appropriate and sensitive services, as well as awareness campaign that will take into consideration cultural and other characteristics of the particular ethnicity separately. Findings are similar with the survey that explored peculiarities of TB disease in war affected areas of Former Yugoslavia that has identified TB stigma as rooted in the society [26], in addition to TB knowledge survey that has identified the necessity of educational programs that will improve health seeking behavior and prevent delays in diagnostics related to stigma [27].

In conclusion, understanding the origins of TB stigma is integral to reducing its impact on health [28]. Our survey has documented certain degree of stigma associated with TB disease, shaped by specific social determinants, such as education, place of residence and employment status. Recognition of stigma associated with TB disease and its magnitude is not important only for the TB disease, but also for achievement of broader public health goals. In an ideal world, individuals should be free to seek and receive appropriate and high quality treatment when diagnosed with TB that will allow not only treatment of

the diseased person, but also control and spread of the disease through implementation of appropriate public health measures. People living with TB should experience full compassion, assistance and support from their environment. Such an example would contribute for raising awareness in the general population, openness to preventive measures and success in efforts for treatment and care at individual level, leading to further containment of TB disease in Republic of Macedonia.

Author's contribution

DGN and FT were responsible for study design, survey logistics, recruitment of interviewers, and supervision of all research phases and preparation of final report. The authors alone are responsible for the content of this report.

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