Assessment of TB stigma among patients attending chest hospital in Suez Canal University area, Egypt

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Abstract

Background: TB stigmatization is a complex process involving institutions, communities, and inter- and intra-personal attitudes. While it has been recognized as an important social determinant of health and health disparities, the difficulties in identifying, characterizing, measuring, and tracking changes in stigmatization over time have made it challenging to justify devoting resource intensive interventions to the problem.

Objectives: To identify the magnitude and the burden of TB stigma on patient and effect of TB stigma on treatment adherence.

Methods: The data were collected between August and December 2014, recruiting all patients who had commenced treatment for up to a month. All patients were subjected to personal detailed interview according to a predesigned questionnaire after taking informed consent of the patients.

Results: A total of 53 patients consented to participate. The mean age ± SD was 43 ± 14.1 years. Out of the total number, 22.6% were illiterate and 77.4% were literate. As regards occupation, 69.8% were independent and 30.2% were dependent. The stigma prevalence among TB patients was found to be 41.5%. Stigma is more prevalent among the younger age group (43.5 %), males (43.9 %) and among married patients (46.7%). There was an immense stigma observed among urban residence (57.7 %), current smokers (60.0 %) and those who had two or less rooms in their house (66.7 %) and this was found to have a statistically significant difference (P<0.05). The majority of patients (67.9%) take treatment regularly.

Conclusion: TB stigma has been raised as a potential barrier to home and work-based direct observational therapy (DOT). Perceived TB stigma had no effect on treatment regularity. Health education programs should be conducted to reduce TB stigma and improve patients' compliance.

Key words : TB stigma, prevalence , treatment adherence

Introduction

Tuberculosis (TB) is believed to be nearly as old as human history. Traces of it in Egyptian mummies date back to about 7000 years ago, when it was described as phthisis by Hippocrates(1). It was declared a public health emergency in the African Region in 2005 and has since continued to be a major cause of disability and death(2). About 9.4 million new cases of tuberculosis were diagnosed in 2009 alone and 1.7 million people reportedly died from the disease in the same year, translating to about 4700 deaths per day (2). About one-third of the world's population (estimated to be about 1.75 billion) is infected with the tubercle bacillus(3). As much as 75% of individuals with TB are within the economically productive age group of 15 to 54 years. This significantly impairs socioeconomic development, thereby perpetuating the poverty cycle (4).

The social determinants of health refer to the institutional, community, and interpersonal factors that affect health outside of the ease with which an individual can access medical services (5). Stigma, which is shaped and promulgated by institutional and community norms and interpersonal attitudes, is a social determinant of health(6). Stigma is a process that begins when a particular trait or characteristic of an individual or group is identified as being undesirable or disvalued(7). The stigmatized individual often internalizes this sense of disvalue and adopts a set of self-regarding attitudes about the marked characteristic including shame, disgust, and guilt (8). These attitudes produce a set of behaviors that include hiding the stigmatized trait, withdrawing from interpersonal relationships, or increasing risky behavior (9-10).

Stigmatization is conceptually distinct from discrimination, another social determinant of health in that the primary goal of discrimination is exclusion, not necessarily for the target to feel ashamed or guilty(11-12). Stigmatized individuals can, however, suffer discrimination and status loss at the hands of the broader community, whose norms have caused them to be perceived as undesirable (7-13). Stigmatization is a complex process involving institutions, communities, inter- and intra-personal attitudes. While it has been recognized as an important social determinant of health and health disparities, the difficulties in identifying, characterizing, measuring, and tracking changes in stigmatization over time have made it challenging to justify devoting resource intensive interventions to the problem(6-14). One exception is human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) research, where the interactions among stigma, HIV risk behaviors, and HIV associated outcomes have been fairly well characterized(15-16).

Substantially less study has been conducted on the mechanisms through which stigma impacts the health of individuals at risk for or infected with TB. From its introduction in 1994, DOTS has been the backbone of TB control around the world. With its focus on passive case detection, availability of diagnostic techniques, and directly observed therapy to minimize drug resistant TB, DOTS has

been criticized as a treatment guideline and biomedical strategy that does not account for social factors related to TB control rather than a comprehensive control plan (17-18).

Delay in presentation to a health facility is an important concern as it contributes to delays in initiating TB treatment. This can result in greater morbidity and mortality for the patient and increased transmission of Mycobacterium tuberculosis in the community(19-20). There is a large body of literature on factors associated with delay in seeking care for TB symptoms. These can be broadly grouped into access to care, personal characteristics, socioeconomic, clinical, TB knowledge or beliefs, and social support or psychosocial factors(21). One psychosocial factor of interest is health-related stigma, often defined as a social process "characterized by exclusion, rejection, blame, or devaluation resulting from experience or reasonable anticipation of an adverse social judgment" because of a particular health condition (22). Some studies have suggested that TB stigma could lead to delays in patients seeking appropriate medical care (19-23).

Aim of the study

To highlight the importance of psychosocial factor on TB stigma, aiming to improve the quality of care for TB patients.

Objectives

To identify the magnitude and the burden of TB stigma on patients received TB treatment and to determine socio demographics factors associated with TB stigma.

Methodology

This was a cross sectional study conducted at two government health institutions providing TB services in the Suez Canal area. The treatment regimens used throughout the country are based on the World Health Organization's (WHO) Directly Observed Treatment, ShortCourse (DOTS) strategy. The data were collected between August and December 2014, recruiting allpatients who had commenced treatment for up to a month. All patients were subjected to personal detailed interview according to a predesigned questionnaire after taking informed consent of the patients. Before conducting the study, the questionnaire was pre-tested and evaluated for proper conduct of the study.

The information was elicited from TB patients regarding 'problems faced in their homes, neighbours' attitudes and friends. Questionnaire included questions regarding data on socioeconomic issues and awareness of TB and the nature of their disclosure of their disease to family members. The information was also elicited regarding behavioral changes such as maintaining appropriate personal distance and avoiding close contact in activities with family members, neighbours, friends and other fellow employees.

The data were entered, cleaned and analyzed using SPSS software version 18.0. Descriptive statistics like frequency distribution and percentage calculation was made for most of the variables. Chi square test and proportion tests were used to assess significance. A value of $p < 0.05$ was taken as significant.

Ethical Considerations

The study subjects were explained the purpose of study and assured privacy. Confidentiality and anonymity were maintained according to the regulations mandated by Research Ethics Committee of Faculty of Medicine Suez Canal University (no.2357).
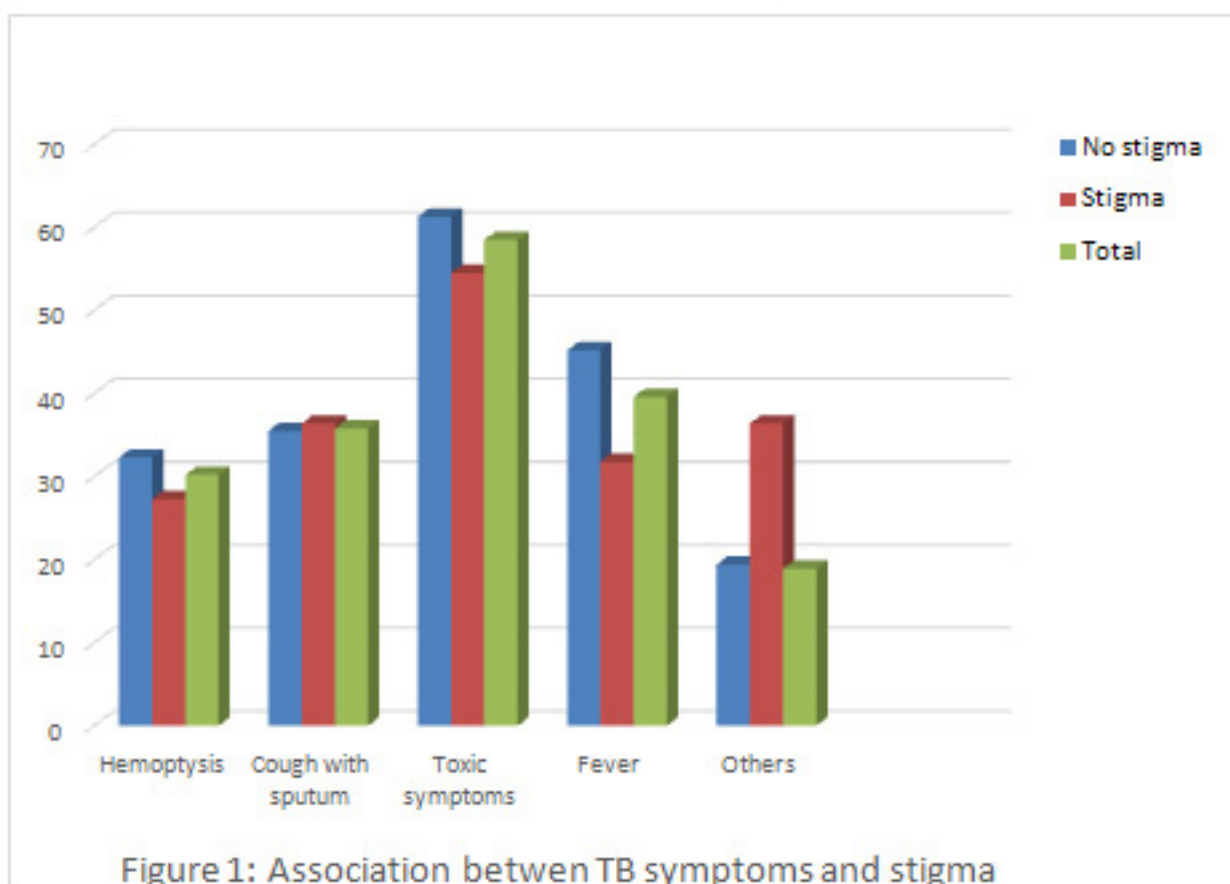
Result

Table 1: Distribution of the study group according to Socio-demographic characteristics

Socio-demographic characteristics	No.	%
Age (yrs)		
< 30	14	26.4
30-50	20	37.7
> 50	19	35.8
Mean ± SD		43 ± 14.1
Education		
Illiterate	12	22.6
Read & write	17	32.2
Primary & preparatory	12	22.6
Secondary, technical, University	12	22.6
Occupation		
Independent	40	75.5
Dependent	13	24.5
Occupational type (n= 40)		
Professional	1	1.9
Intermediate	6	11.3
Skilled	3	5.7
Semiskilled	7	13.2
Unskilled	23	43.4
Smoking habits		
Non-smoker	33	62.3
Smoker	20	37.7
Mean ± SD of cigarettes numbers /day		18.24 ± 17.1
Mean ± SD of smoking duration (years)		21.50 ± 12.1

A total of 53 patients consented to participate. The socio-demographic profile of TB patients is presented in Table 1. The mean age ± SD was 43 ± 14.1 years. Out of the total number, 22.6% were illiterate and 77.4% were literate. As regards occupation, 69.8% were independent and 30.2% were dependent. There were more male cases (77.4 %) than female (22.6%). Approximately half of the cases were married (56.6 %) and the majority had appropriate family income (64.2%).

Clinical profile	No.	%
Presence of chronic disease		
Yes	15	28.3
No	38	71.7
TB		
Pulmonary	43	81.1
Extra-pulmonary	10	18.9
Investigations		
Sputum	53	100
(+) result	40	75.5
(-) result	13	24.5
Chest X-ray	30	56.6
Blood	21	39.6
Family investigations		
Yes	20	37.7
No	33	62.3
Take TT regularly		
Yes	36	67.9
No	17	32.1
TT duration (months)		
< 1	19	35.8
1-6	24	45.3
>6	10	18.9

Table 2: Clinical profile of the study population

Figure 1: Association between TB symptoms and stigma

Table 3: Prevalence of TB stigma

Stigma	N	%
Experienced	22	41.5
Not- Experienced	31	58.5
Total	53	100

Table 4: Association of risk factors and TB stigma

Variables	TB stigma				X²	P-value
	No (n= 31)		Yes (n= 22)			
	N	%	N	%		
Age						
≤ 40	13	56.5	10	43.5	0.06	> 0.05
> 40	18	60.0	12	40.0		
Gender						
Male	23	56.1	18	43.9	0.42	> 0.05
Female	8	66.7	4	33.3		
Residence						
Urban	11	42.3	15	57.7	5.5	
Rural	20	74.1	7	25.9		< 0.05*
Marital status						
Married	16	53.3	14	46.7	0.75	> 0.05
Non-married	15	65.2	8	34.8		
Education						
Illiterate	7	58.3	5	41.7	0.00	> 0.05
Literate	24	58.5	17	41.5		
Occupation						
Dependent	23	62.2	14	37.8	0.68	> 0.05
Independent	8	50.0	8	50.0		
Family members						
≤ 5	19	54.3	16	45.7	0.75	> 0.05
> 5	12	66.7	6	33.3		
Family income						
Non-Appropriate	11	57.9	8	42.1	0.04	> 0.05
Appropriate	20	58.8	14	41.2		
N° of house room						
≤ 2	7	33.3	14	66.7	9.06	< 0.05*
> 2	24	75.0	8	25.0		
Current smokers						
Yes	8	40.0	12	60.0	4.52	< 0.05*
No	23	69.7	10	30.3		

As regards clinical profile of the study population, 81.1% had pulmonary TB and 75.5% had positive sputum smear. The majority of patients (67.9 %) take treatment regularly as presented in Table 2. Toxic symptoms were the most prevalent among TB patients (58.5 %) followed by fever (39.6 %) and cough with sputum (35.8 %) (Figure 1).

The stigma prevalence among TB patients was found to be 41.5% (Table 3). Stigma is more prevalent among younger age groups (43.5%), males 43.9% and among married patients (46.7%). There was an immense stigma observed among urban residence (57.7%), current smokers (60.0 %) and those who had two or less rooms in their house (66.7%) and this was found to be a statistically significant difference (P<0.05)(Table 4).

Table 5: Distribution of stigma score of TB patients according to community perspectives

Items	No (%)	Uncertain (%)	Possibly (%)	Yes (%)
Some people may not want to eat or drink with you	58.4	1.9	5.7	34.0
Some people feel uncomfortable about being near you	52.8	1.9	7.5	37.8
Some people don't want your child playing with their children	56.6	1.9	5.7	35.8
Some people keep their distance from you	54.7	3.8	9.4	32.1
Some people think that you are disgusting	60.3	3.8	3.8	32.1
Some people do not want to talk with you	58.4	1.9	5.7	34.0
Some people are afraid of you	56.6	1.9	5.7	35.8
Some people try not to touch you	52.8	5.7	5.7	35.8
Some people may not want to eat or drink with you	54.7	1.9	9.4	34.0
Some people prefer not to have those with TB living in their community	58.5	1.9	3.8	35.8
Doctors fear to approach you	84.9	0	0	15.1
Nurses deal with you very conservatively	84.9	0	0	17.0

Stigma faced in community by TB patients: About one third of TB patients reported that some people prefer not to have those with TB living in their community and 35.8% reported that some people don't want their children to play with a TB patient's child (Table 5).

Table 6: Distribution of stigma score of TB patients according to patient perspectives

Items	No (%)	Uncertain (%)	Possibly (%)	Yes (%)
You feel hurt by how others react to knowing you have TB	43.5	5.7	9.4	41.5
Do you lose friends when you share with them that you have TB?	58.5	3.8	1.9	35.8
Do you feel lonely?	50.9	3.8	5.7	39.6
Do you keep distance from others to avoid spreading TB germs?	35.8	1.9	56.6	5.7
Are you afraid to tell persons outside your family that you have TB?	47.2	1.9	9.4	41.5
Are you afraid of going to TB clinics because other people may see you there?	67.9	1.9	1.9	28.3
Do you choose carefully who you tell about having TB?	50.9	0.0	0.0	49.1
Do you feel guilty because your family has the burden of caring for you?	47.2	1.9	3.8	47.1
Do you feel guilty for getting TB because of your careless behaviors as smoking?	60.4	1.9	7.5	30.2
Are you afraid to tell your family that you have TB?	75.5	0.0	3.8	20.7

Perceived Stigma among TB patients: Out of a total of 53 patients 41.5% reported feeling hurt by how others react to knowing that they have TB and 35.8% lose friends when they share with them that they have TB. Being afraid of going to TB clinics because other people may see them was reported by 28.3% of TB patients. While about half of the patients, 47.1%, felt guilty because their family has the burden of caring for them (Table 6).

Discussion

Globally, 14.6 million people have active TB disease. Each year 8.9 million people develop active TB(24). Patients often isolate themselves to avoid infecting others and to avoid uncomfortable situations such as being shunned or becoming the subject of gossip (25). Hence, the aim of this study was to improve the quality of life of TB patients by identifying the magnitude and the burden of TB stigma on patients. Results of the current study indicated that the majority of the study sample were men (77.4 %); the same results were supported by Aryal(26).

Approximately half of the cases were married (56.6 %) and the majority were literate and this is in agreement with Abioye et al. (27). However this was not supported in a study in Bangladesh where the majority of patients had not received any formal education and this is due to the difference in culture and socioeconomic characteristics(28). Our study shows also that the majority had appropriate family income (64.2%) which matches the urban community where the study took place.

Results showed that 41.5% of the TB patients had experienced stigma; similar results were found in Nepal (63.3%)(26). The same prevalence was found in a study conducted in southern Thailand by Rie AV, which shows that stigma is present in patients' perspective towards TB (29).

Several studies suggest that health-care providers and at-risk community members perceive TB stigma to have a more substantial impact on women's health-care-seeking behavior than on men's(30). However this disagrees with the study results in which stigma was slightly more prevalent among men. This is because most women in our community do not work and do not come in direct contact with community members such as men. In another study work-related aspects of stigma were frequently re-ported, and they were more likely to be an issue for men (28). In urban areas, there may be more fears of being discriminated in the work environment, or of losing jobs. This explains the study results that show that immense stigma observed among urban residence.

Abioye et al, 2011 found that patients presenting with previous smoking history were more likely to experience stigma in a study in Lagos, Nigeria (27) and this also can be found in this study, where there is a statistically significant relation between stigma and smoking.

Abioye et al.(2011), studied stigma among patients with pulmonary tuberculosis in Lagos, Nigeria. They found that limited education and patients who are in the working age groups (20 to 50 years) had TB stigma. However according to the current study results, no statistically significant association could be revealed between these two sociodemographic determinants.

TB stigma has been raised as a potential barrier to home- and work-based direct observational therapy (DOT) (31). Perceived TB stigma was also associated with noncompliance among Pakistani patients on DOT (32). However, this study shows an insignificant relation between TB stigma and regularity of TB treatment and this may have contributed to the effect of TB-related stigma and social discrimination on the patients that forces them to be compliant to drugs so that they can avoid the stigmatization.

Although several survey instruments are in development for measuring perceived and internalized TB stigma, most research uses qualitative techniques for assessing TB stigma. The use of different measurement tools may explain why TB stigma is a predictor of diagnostic delay and treatment nonadherence in some studies and not in others(33). In this study Toxic symptoms were the most prevalent among TB patients (58.5 %) followed by fever (39.6 %) and cough with sputum (35.8 %), but the relation between TB symptoms and stigma were not statistically significant as most stigmatized TB patients usually do not disclose their symptoms as this increases the state of discrimination in their life; they want to hide their symptoms from others.

Some of the patients also revealed that they go to the DOTS center which is farther from their home so that nobody knows that they are taking TB drugs (26).

In this study 35.8% lose friends when they share with them that they have TB. This is in agreement with another study conducted in southern India that showed that many men felt inhibited from revealing the diagnosis to friends (43%) and even to their spouse (16%) (34). The study results shows that 41.5% reported feeling hurt by how others react to knowing that they have TB and 35.8% lose friends when they share with them that they have TB. This was revealed in another study in India where most of the patients said that they have impaired self-esteem, felt shamed or embarrassed, and have felt less respect from others in the society (34). Another study conducted revealed that TB patients perceive their neighbors and friends attitudes towards them as rather negative (35)which was in agreement with this study.

Conclusion

TB stigma has been raised as a potential barrier to home- and work-based direct observational therapy (DOT) (31). Health education programs should be conducted to reduce TB stigma and improve patients' compliance.

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