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Title: Community knowledge about tuberculosis and perception about tuberculosis associated stigma in Pakistan

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Tuberculosis (TB) associated stigma is well-documented phenomenon that may contribute to sub-optimal TB care in Pakistan. The objective of study was to assess TB related knowledge and perceived stigma among community members. This was cross-sectional survey using convenience sample of 183 individuals recruited between October and December 2017. A validated stigma measurement tool developed by Van Rie et al. was adapted. Data was analyzed using SPSS version 20.0. 183 individuals (73% males; n=134) participated in survey. Eighty-seven percent were aware that TB is curable disease (n=159) and 91% thought that it could be transmitted by coughing (n=167). However, respondents also thought that TB was spread through contaminated food (73%; n=134), sharing meals (55%; n=100), sharing utensils (53%; n=96) and by having sexual intercourse with a TB patient (51%; n=93). Fifty-seven percent (n=104) associated TB with high levels of stigma. Persons who had less than six years of education (crude OR = 1.2; 95% CI: 0.89, 1.72) and lacked knowledge that TB is curable (crude OR = 3.42; 95% CI: 1.20, 9.70) were more likely to associate TB with stigma. In addition, females (crude OR = 1.33; 95% CI: 0.87, 2.04) and those who were unemployed (crude OR = 1.06; 95% CI: 0.65, 1.74) were also more likely to associate TB with stigma. We found an association between lack of knowledge about TB and perceived stigma. This highlights need for improved education and awareness about TB.

Keywords: Social stigma, Tuberculosis, Knowledge, Stigma measurement, Pakistan.

Introduction

Described as the world's leading infectious disease killer, tuberculosis (TB) continues to affect an estimated 10.4 million people worldwide every year.[1] Pakistan is one of the 30 high burden TB countries globally that, combined, account for 56% of the global TB burden [1]. Lack of disease-specific knowledge may contribute to the high TB burden in Pakistan [2]. Prior knowledge about disease is known to determine a person's response to the disease [3]. Prevailing misconceptions about TB leads to social discrimination [4], social aversion [5] and stigmatization. Additionally, TB knowledge and stigmatization are linked with health care seeking behavior and subsequent health care provision [6].

Stigmatization is a complex phenomenon that affects institutional, community and individual-level attitudes. Its identification, characterization and measurement over time makes it challenging in regards to measuring the development of de-stigmatization-focused interventions [7,8].

The concept of stigma was first introduced by Goffman in 1963 and was described as a trait that lowers an individual from a usual person to a tainted one [9]. Stigma generates a sense of disvalue [10] and stigmatized individuals may internalize feelings of guilt, shame and disgust [9]. A set of behaviors may then be produced that put a stigmatized individual at risk, such as avoidance behavior, withdrawal from interpersonal relationships, self-isolation and delayed health seeking behavior [11,12]. In addition, the stigmatization and the behaviors that rise from it may result in psychological stress, depression, fear, and further deterioration of health [13-15]. Stigma is also a social determinant of health that is promulgated by community norms and it is likely to influence inter- and intrapersonal attitudes [8].

Globally, a number of studies have examined TB associated stigma and its consequences have been documented in a number of setting [16]. Stigma negatively impacts on public health efforts to diagnose TB early and treat it [10]. For instance, stigma is a factor which contributes to delayed diagnosis [17] and treatment non-adherence [18].

TB associated stigma is thought to be a major problem in Pakistan, perpetuated by myths and misconceptions about the disease. In the context of Pakistan, there are some qualitative data available on TB associated stigma [6,19], however none of the quantitative studies have used validated stigma measurement scales to quantify it.

Therefore, we aimed to assess community knowledge about TB and perceptions of TB associated stigma by interviewing a sample of people attending private health care clinics in Pakistan. The objectives of this study were twofold: i.e., (1) to assess TB related knowledge, and (2) to assess perceived stigma associated with TB. The findings of this study will inform the development of educational and awareness raising activities to reduce TB related stigma.

Material and Methods:

Study Setting

There are 75 districts who are participating in the Public Private Mix (PPM) model of the national TB control program in Pakistan. In the PPM Model there are approximately 2,000 private healthcare providers who are involved in the implementation of PPM interventions and who are providing free TB treatment services. They are trained on Directly Observed Therapy (DOT) implementation and on the provision of standardized TB prevention and are services. A team of trained public health professionals visit them regularly and check their compliance to treatment protocols.

Study Design

This was a cross sectional survey using a convenience sample.

Sampling Approach

A sample of 27 clinics was selected using convenience sampling from the twenty-four districts participating in the PPM model. Survey participants, more than 18 years of age, regardless of sex and education were then randomly selected from outpatient department of these health care facilities as they visited the facility for consultation related to a general ailment.

Data Collection

The data collection tool was used the stigma measurement scale [20] developed by Van Rie et al., with minor modifications for the linguistic and socio-cultural context of Pakistan. The tool consists of two sub-scales: (1) a sub-scale for measuring the community's perception about TB, and (2) a sub-scale for measuring the community's knowledge about TB. Demographic information were also collected.

17 questions constitute the perception sub-scale, where each question consists of four responses (i.e., strongly agree, agree, disagree and strongly disagree). 'Strongly agree' and 'agree' represent the presence of perceived stigma and 'strongly disagree' and 'disagree' represent the absence of perceived stigma. The knowledge sub-scale includes a range of questions concerning facts about TB causation and acquisition with closed responses of 'Yes', 'No' or 'Don't Know'. Demographic information were also collected.

Face-to-face interviews were administered by trained interviewers at the PPM-enrolled primary healthcare clinic between October and December 2017. Interviews were conducted within clinic attendees within the premises of the health care clinic, ensuring privacy and confidentiality. These interviews were carried out during routine monitoring visits of the public health professionals.

Data Analysis

Data were collected in ODK Collect and were exported to SPSS for analysis (IBM Corp. Released 2011 SPSS Statistics for Windows, Version 20.0 Amonk, NY: IBM Corps.).
The presence of stigma (i.e., a response of strongly agree or agree) was assigned a score of 1, whereas the absence of stigma (i.e., a response of strongly disagree or disagree) was assigned 0. A total stigma score was calculated by summing the scores of all questions. A mean stigma score (i.e., 44) was calculated by using the total stigma score (n=8142) as the numerator and the study population as denominator (n=183). Stigma scores range from 1 to 4, where the number corresponds to the degree of stigmatization, i.e., the higher the number, the higher is the level of stigma. Respondents who had an individual total stigma score higher than the mean score were categorized as persons with high levels of stigma towards TB, whereas,

111 respondents with an individual total stigma score less than the mean score were categorized
112 as persons with low levels of stigma towards TB. Others variables such as location,
113 educational level, employment status, knowledge about TB (i.e., TB is curable and TB spreads
114 through coughing) were dichotomized for the analysis. We used descriptive analyses
115 calculating numbers, proportions and odds ratios, with 95% confidence intervals.
116
117 ***Ethical Approval***

118 Ethical approval was provided by the Ethical Review Board of Health Oriented Preventive
119 Education (HOPE), which is recognized by the United States Department of Health and
120 Human Services Office for Human Research Protection (OHRP). Oral informed consent was
121 obtained from each participant.
122
123 **Results:**

124 A total of 183 individuals (n=134, 73% males; n=49, 27% females) participated in the study
125 with a mean age of 37 years (±12) (Table 1). Seventy-three percent (n=134) were aged 25-
126 54 years and 69% (n=127) resided in urban areas (Table 1). Fifty-one percent of the
127 respondents (51%; n=93) were recruited from the province of Punjab (Table 1). The
128 majority were Muslim (91%; n=167) and 32% (n=58) had 13-16 years of education (Table
129 1). Twenty-eight percent (n=52) of respondents were illiterate. In terms of occupation, 26%
130 of respondents (n=48) were not employed (i.e., unemployed, housewife, student), 30%
131 (n=55) were labourers, 19% (n=35) were involved in a business and the remaining 25%
132 (n=45) were either government employees or in the private sector. (See Table 1).

133 **Table 1:** Socio-demographic characteristics of study participants

Characteristics	Variables	Number (percentage)
Sex	Male	134 (73)
	Female	49 (27)
Age (years)	Early working age (15-24)	31 (17)
	Prime working age (25-35)	66 (36)
	Prime working age (36-54)	68 (37)
	Mature working age (55-64)	13 (7)
	Elderly (≥ 65)	5 (3)

Mean Age (SD)		37 (±12)
Years of Education	Illiterate	52 (28)
	Till primary (1-5)	32 (18)
	6-8	27 (15)
	9-12	14 (8)
	13-16	58 (32)
Occupation	Unemployed	4 (2)
	Housewife	28 (15)
	Student	16 (9)
	Laborer	55 (30)
	Small scale business owner	17 (9)
	Business (or landlord)	18 (10)
	Government employee	3 (2)
	Private sector employee	42 (23)
Religion	Muslim	167 (91)
	Christian	1 (0.5)
	Hindu	15 (8.5)
Location	Urban	127 (69)
	Rural	56 (31)
Province	Punjab	93 (51)
	Sindh	57 (31)
	Khyber Pakhtunkhwa	12 (7)
	Balochistan	21 (11)
Total		183

Community Perceptions about Tuberculosis

Seventy-four percent of respondents(n=136) stated that people would feel uncomfortable if they were close to a person with TB and 38% (n=78) of respondents commented that people would think that a person with TB is disgusting (Table 2). Sixty-two percent of respondents (n=113) expressed their fear of someone with TB, however, approximately half of the respondents (52%; n=95) said that some people try not to touch others with TB (Table 2). Twenty-seven percent of respondents (27%; n=49) said that people would not prefer a person with TB living in the same community (Table 2).

143

144 **Social Isolation**

145 The respondents stated that people with TB may not like to eat and drink with relatives
146 (78%; n=143) and friends (76%; n=139) and 74%; (n=136) said that people keep their
147 distance from a person with TB (Table 2). However, relatively fewer respondents (34%;
148 n=63) said that some people do not want to talk to a person with TB (Table 2). Approximately
149 half of the respondents (52%; n=95) commented that some people do not try to touch others
150 with TB and 41% (n=75) said that some people think that a family with TB patient should
151 not allowed to participate in any social gathering (Table 2). Forty-four percent of the
152 respondents (n=81) said that community members will behave differently towards persons
153 with TB for the rest of their lives, even if they have been treated. (Table 2).

154

155 **Gender Perspectives Regarding Tuberculosis**

156 Seventy-two percent of respondents (n=131) thought that a person with TB faces social
157 challenges such as diminished marriage prospects, continuation of employment, continuing
158 education and attending social gatherings. Specifically, 78% of the respondents thought that
159 a male with TB may face problems in finding a wife, however, a higher proportion (86%;
160 n=157) of respondents stated that a female with TB faced diminished marriage prospects.
161 More than half of the respondents (57%; n=105) thought that females with TB are dependent
162 upon the support of their husbands and their husbands' parents to receive treatment.
163 Approximately one fifth of respondents (21%; n=38) said that some people think that a
164 female with TB should be sent back from her husbands' family home to her parent's home
165 (Table 2).

166 **Table 2:** Level of Perceived Stigma Associated with Tuberculosis

Items of perceived stigma sub-scale	Status of stigma for each item	
	Present (%)	Absent (%)
Some people may not like to eat and drink with relatives who have TB.	143 (78)	40 (22)
Some people feel uncomfortable about being near those with TB.	136 (74%)	47 (26)
If a person has TB, some community members will behave differently towards that person for the rest of his/her life, even if s/he is treated and cured	81 (44)	102 (56)

Some people do not want those with TB playing with their children	118 (64)	65 (36)
Some people keep their distance from people with TB	136 (74)	47 (26%)
Some people think that those with TB are disgusting	70 (38)	113 (62)
Some people do not want to talk to others with TB	63 (34)	120 (66)
Some people are afraid of those with TB	113 (62)	70 (38)
Some people try not to touch others with TB	95 (52)	88 (48)
Some people may not like to eat and drink with friends who have TB	139 (76)	44 (24)
Some people prefer not to have those with TB living in their community	49 (27)	134 (73)
Some people think that those with TB, both male and female face same social problems (marriage, job, continuing education, attending social gatherings etc)	131 (72)	52 (28)
Some people think that those males with TB face more problems in marriage	142 (78)	41 (22)
Some people think that those females with TB face more problems in marriage	157 (86)	26 (14)
Some people think that those females with TB depend economically on their husbands and in-laws and need their cooperation to obtain treatment	105 (57)	78 (43)
Some people think that a family with TB patient should not allowed to participate in any social function	75 (41)	108 (59)
Some people think that female TB patient should be sent off to her parent's house	38 (21)	145 (79)

Knowledge about Tuberculosis

Almost 90% of community members were aware that TB is curable disease (87%; n=159) and that it spreads by coughing (91%; n=167). However, community members also stated that it was transmitted through contaminated food (73%; n=134), sharing meals (55%; n=100), unclean water and food (62%; n=114), sharing eating utensils (53%; n=96), touching (33%; n=61) and by having sex with a person with TB (51%; n=93). Half of the respondents (50%; n=91) said that emotional stress is a cause of TB and 30% of the respondents (n=54) thought that TB leads to infertility (Table 3).

Table 3: Knowledge about Tuberculosis among Community Members

Knowledge Variable	Number (%)

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TB is curable	159 (87)
TB patient also has HIV/AIDS	45 (25)
TB leads to infertility	54 (30)
Emotional stress is a cause of TB	91 (50)
Perceived mode of TB transmission	
Contaminated food	134 (73)
Cough	167 (91)
Sharing meal with a person with TB	100 (55)
Unclean water and food	114 (62)
Sharing utensils with a person with TB	96 (53)
Touching a person with TB	61 (33)
Sex with a person with TB	93 (51)

Factors Associated with Stigma

More than half of the respondents (57%; n=104) associated TB with high levels of stigma (Table 4). Individuals with education less than 6th grade were more likely to associate stigma with TB than those with higher levels of education (crude OR = 1.2; 95% CI: 0.89, 1.72) (Table 4). Respondents who lacked knowledge that TB is curable were also more likely to associate TB with stigma (crude OR = 3.42; 95% CI: 1.20, 9.70). Similarly, those who lacked knowledge that TB is spread by coughing were also more likely to associate stigma with TB (crude OR = 1.27; 95% CI: 0.49, 3.34) (Table 4).

Table 4: Factors associated with perceived stigma about tuberculosis

Variable		Stigma Level		Crude Odds Ratio (95% CI)
		High n (%)	Low n (%)	
Sex	Male	72 (53.7)	62 (46.3)	0.82 (0.63, 1.06)
	Female	32 (65.3)	17 (34.7)	1.33 (0.87, 2.04)
Urban or Rural Location	Urban	72 (56.7)	55 (43.3)	0.99 (0.82, 1.21)
	Rural	32 (57.1)	24 (42.9)	1.01 (0.65, 1.57)
Education Level	Till grade 5	52 (61.9)	32 (38.1)	1.2 (0.89, 1.72)
	Above grade 5	52 (52.5)	47 (47.5)	0.84 (0.64, 1.10)
Employment Status	Employed	76 (56.3)	59 (43.7)	0.98 (0.82, 1.17)
	Unemployed	28 (58.3)	20 (41.7)	1.06 (0.65, 1.74)
TB is curable	Yes	86 (53.4)	75 (46.6)	0.87 (0.79, 0.96)
	No	18 (81.8)	4 (18.2)	3.42 (1.20, 9.70)

TB spreads through cough	Yes	94 (56.3)	73 (37.5)	0.98 (0.89, 1.07)
	No	10 (62.5)	6 (37.5)	1.27 (0.49, 3.34)

Discussion

Stigma associated with health conditions, such as HIV/AIDS, leprosy, TB, mental illness and epilepsy, is a global and social phenomenon that affects individuals suffering from disease, and their families. As a result, the effectiveness of public health programs in preventing, diagnosing and treating these conditions may also be affected [21]. Accordingly, organizational and community norms that result in the stigmatization of TB, are believed to damage efforts to prevent, diagnose and treat TB [18]. In our study, TB was perceived as a stigmatized health condition by community members from outpatient clinics. However, the level of stigma varied by sex, educational level, employment status and the degree of disease-specific knowledge.

In our study, the majority of the community were aware that TB spreads through coughing (91%) and that it is curable (87%). These are similar findings to those of other studies, for example in Brazil, 91% of individuals believed that TB spreads through coughing [22]. However, in Somalia this figure was lower at 59% [23]. However, while many understood the correct mode of TB transmission, there was also a sizeable proportion of respondents who had incorrect knowledge about TB transmission. For example, half of the respondents considered stress as cause of TB, a similar finding that was also reported in Karachi, Pakistan (57%) [24] and in Vanuatu (17%) [25]. Similarly, in our study 53% considered sharing utensils as a potential mode of TB transmission, a common finding in other studies; 57% in Pakistan [24] and 36% in Somalia [23].

Existing literature highlights the significance of community based awareness strategies to eliminate misconceptions and wrong beliefs about TB [26,27]. However, studies are scarce, and few focus on interventions among community members. In a recent systematic review, which focused on evidence based interventions to reduce TB related stigma, only two of seven interventions were aimed at reducing TB related stigma in the community [28]. In one of these studies, conducted in Nigeria, 10 community volunteers were trained to provide TB education to the community and to detect and refer persons with presumptive TB to a nearby clinic [29]. Based on surveys conducted pre and post the intervention, mean knowledge

scores increased significantly and mean attitude scores (including stigmatizing attitudes) decreased significantly after the intervention, indicating a positive effect of community education [30]. In the other study on a community based stigma reduction intervention, knowledge and attitude surveys were conducted in different areas of Bangladesh, some of which had received community based educational interventions about TB and leprosy [30]. In the areas that had received the educational intervention there were better levels of knowledge about TB symptoms (90% thought that cough was a symptom in the areas that received the educational intervention vs. 44% in the non-intervention areas) [30]. Moreover, in the intervention areas 76% of respondents said that they would not buy goods from a shopkeeper with TB, whereas in the intervention areas this figure was reversed [30]. In addition, there are a number of other studies which focus on interventions to reduce stigma, aimed at TB patients.

Demissie et al. (2003) reported that '*TB Clubs*' were helpful in eliminating stigmatizing attitudes and enhancing patient's compliance to treatment through the exchange of patient support and information [31]. During the gatherings of *TB Club* members and general communities, dissemination of education material was influential in changing people's attitudes towards TB. In addition to these TB specific interventions, broader rights based approaches may also reduce TB. Smith (2002) has emphasized a broader rights-based approach to TB care that aims to shift from disease-specific knowledge to enforcement of rights, such as access to care and prevention services, confidentiality of patient's information, that will reduce stigma, discrimination and inequalities in health [32].

Our study focused on the examination of perceived stigma, which should be given serious consideration because it reflects the prevalence of stigmatized beliefs and attitude of the community [33]. We found that unemployment, being female, living in a rural location and incorrect knowledge about TB causation and transmission were associated with TB related stigmatization, although only the belief that TB was not curable was statistically significant. Another study conducted in Chine among TB patients also noted a statistically significant association between less TB knowledge and TB related stigma [34].

The cultural context and social practices construct a socio-cultural sphere of human activity that is highly relevant for TB including community norms about TB and perceptions of stigmatization [35]. Effective control of TB is associated with social determinants and social

247 systems that require an inter-disciplinary response, beyond the purely biomedical model of
248 disease causation, incorporating important social knowledge and concepts such as stigma
249 [35,36]. TB related stigma is acknowledged to shape poor health seeking behavior and to
250 negatively impact on health outcomes [37]. Therefore, social scientists emphasize the need
251 for examination of unequal power distribution in social and economic contexts that positions
252 individuals in this world differently increasing their vulnerability [38]. In addition,
253 characteristics of the healthcare system and the conditions in which people born, live, work
254 and grow (known as social determinants) influence the health status of individual and
255 community at large [39,40]. Consequently, intersectionality has emerged as a conceptual
256 framework to unfold these complexities with an aim to reduce difference or inequalities [41].
257 Intersectional approaches examine the hierarchies of race, class, gender and other social
258 identities to unlock the complexities that lie in a social phenomenon and its effect on
259 individual's health or health outcome [41].

260 **Conclusion**

261 Pakistan is a high incidence TB country, and TB is a stigmatized disease, with many
262 misconceptions about how it is caused. TB associated stigma remains, despite decades of TB
263 control efforts at the national level to correct misconceptions about the disease. Stigma was
264 significantly associated with lack of knowledge about TB. However, it is acknowledged that
265 these are often difficult to design, implement and evaluate and there is limited evidence on
266 their effectiveness. Additional research on the effectiveness of educational interventions to
267 reduce TB related stigma are needed. Our study also highlights that stigma and its
268 intersection with society, should be further examined if the issue is to be comprehensively
269 addressed.

270 **Data Availability:**

271 The survey data used to support the findings of this study are available from the
272 corresponding author upon request.

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275 **Authors Contribution:**

SMA conceived research idea and developed its methodology and NA, FN, AR contributed in its refinement. SMA, MI, AR supervised the data collection and checked data for quality. SMA, NA, SMA and KV planned and conducted data analysis. SMA drafted paper and KV contributed significantly to the discussion section. NA, FN, AN and KV reviewed draft several times and suggested changes. KV proofread the final version. All researcher read the final version of the draft before submission.

Conflict of Interest:

The authors declare no conflict of interest

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