Social Stigmatization in Tuberculous Patient: A Hospital Based Survey in Lahore, Pakistan.

Naureen Omar, Aslam Bajwa, Iram Manzoor

Department of Community Health Sciences, Fatima Memorial College of Medicine and Dentistry, Lahore, Pakistan.

Abstract

Background
Inadequate knowledge regarding Tuberculosis leads to stigmatization due to perceived risk of transmission of disease. It is pertinent to comprehend the origin of Tuberculosis stigma so as to reduce its impact on health as geographic and cultural variation may play an important role. Aim was to assess perception of stigma among patients and discriminations faced by them within the family and society.

Methods
A cross sectional study was conducted on 300 Tuberculosis patients of Gulab Devi Chest Hospital, Lahore, Pakistan after IRB clearance. Interviews were conducted after taking consent, using a validated questionnaire adopted from a previously published study. Perceptions of the participants were addressed regarding stigma related to Tuberculosis especially regarding their fears associated with disclosing their disease within and outside their families, experiencing of loneliness, losing of friends and feeling hurt on the reaction of their families, friends and outsiders. Chi square was chosen as the test of significance with a *p*-value of <0.05 considered significant.

Results
Mean age was 42.5±17 with male predominance (median 42, IQR 13.5), 239 (79.7%) having an income less than 25,000. Participants and spouses were mostly illiterate 154 (51.3%) and 161 (53.6%) respectively, 239 (79%) being self-employed. They 213 (71%) were not afraid to disclose their disease to their families and others, while 175 (58.3%) were not worried of being a burden on their family. On the contrary 158 (52.7%) felt hurt at the reaction of others on disclosing their disease (p=0.000, CI=12.57 – 35.52). Many had lost friends 216 (72%) and were experiencing loneliness (p=0.000, CI=29.95 – 52.24). Fear of visiting tuberculosis clinics was observed in 200 (67%). Participants had no fear of being perceived as AIDS patients 235 (78.3%) (p=0.000, CI=8.58 – 32.26).They had no fear of developing AIDS 243(81%) Tuberculosis 190 (63.3%) due to smoking, drinking or other risky behaviors (p=0.03, CI= 0.50 – 30.22)

Conclusions
This study concludes that substantial stigmatization and discrimination was being faced at community as compared to family level attributed to strong family bonds in countries like Pakistan.

Keywords
Tuberculosis, Stigmatization, Pakistan

Corresponding Author: Naureen Omar
Assistant Professor, Department of Community Health Sciences, Fatima Memorial College of Medicine and Dentistry, Lahore.
Email: naureen_omar@yahoo.com

Introduction
An important social determinant of health constitutes stigma which is proclaimed by communities, personal attitudes and institutions.[1] When a certain characteristic of individuals or groups is disvaluedit is stated as stigma.[2] The targeted individual develops a sense of being looked down upon by the society which leads to internal feelings of disapproval, self -accusation and shame.[3] These feelings attribute to increased risk taking behavior, concealing of the cause leading to stigma as well as disturbance within personal relationships.[4] Stigmatization is an attitude or belief aimed to attain exclusion while discrimination is the behavior due to these beliefs.[5] Individuals tend to suffer from both as they imply them to be undesirable and disvalued by the community and family.[2]

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.[1] One exception being human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) research.[6] Substantially less studies have been conducted on how stigma impacts the health of individuals at risk for or infected with Tuberculosis (TB).

It is pertinent to comprehend the origin of Tuberculosis stigma so as to reduce its impact on health. Geographic and cultural variation may play an important role, but most authors identify the perceived contagiousness of Tuberculosis as a leading cause of stigmatization.[5] Lack of knowledge regarding routes of transmission may also contribute to stigma.[7] People with relatively good knowledge of transmission, transmissibility and perceived risk can lead to stigmatization and isolation of individuals diagnosed with Tuberculosis.[8]

HIV and Tuberculosis coexist and in areas of high prevalence, stigma against Tuberculosis is on the higher side.[9] Mostly HIV

positivity is linked to Tuberculosis thus promoting HIV associated Tuberculosis stigma.[10] This stigma can be attributed to many other factors like low social class, poverty, malnourishment and foreign born.[12,13] Many communities hold the individual's activities responsible for their punishment in the form of the disease and believe that they deserved to be infected due their moral and personal behaviors.[8,13]

The stigma is so pronounced that the infected person believes that he/she can have major social and economic setbacks especially in the form of isolation from the society at large. An example being Ghana where Tuberculosis infected individuals are prohibited from selling goods in public markets and attending community events.[14]

Stigma may be held responsible for the development of fears which lead to specified behaviors within the community. Cause of death might not be shared or recorded which can be considered as an important tool for Tuberculosis screening.[15] They tend to conceal their disease from their families, friends and society.[5] They develop fears leading to self-accusation,guilt and withdrawal from families attributing to isolation.[16]

In general, men bear more socioeconomic impact than females, including job loss and reduced income.[17] The disease effects both genders. Males and females are concerned regarding the stigma they may face. Women as they believe it would affect their marriages and they would be isolated by their families and lose their homes.[18] On the contrary literature states that men feel threatened regarding their marriage prospects. Married females with families fear rejection from their husbands on being diagnosed with Tuberculosis.[19] We aim to assess the perception of stigma and discriminations faced by Tuberculosis patients in the society at large and in their relatives among the patients of Tuberculosis at Gulab Devi Chest Hospital, Lahore, Pakistan.

Materials and Methods

Cross sectional study was conducted in Gulab Devi Chest Hospital, a major tertiary care setup in Lahore, Pakistan. The hospital has six medical and chest units. In this hospital based survey, a total of 300 admitted pulmonary tuberculosis patients giving consent were enrolled and interviewed by the principal investigator. Patients suffering from extra-pulmonary tuberculosis and other ailments were excluded from the study.

A pretested validated questionnaire was used to interview the patients.[20] Interviews were conducted in the local language for better comprehension of the subjects. Study was completed within three months.

Ethical Considerations

IRB approval and permission from Gulab Devi Chest hospital was sought before the conduction of the study. Consents were taken from the participants and data was collected by the principal investigator assuring anonymity and confidentiality to ensure that ethical guidelines were followed during the study.

Data Analysis

SPSS software version 20 was utilized to analyze the data. Mean and median of age of participants was calculated, while frequencies and percentages of occupation, income, fears associated with disclosure of disease to family, friends and relatives, experience of loneliness, losing of friends, fear of developing AIDS or TB being perceived as AIDS, fear of developing TB or AIDS due to smoking,drinking and fear of visiting TB clinics were calculated, Chi square was test of significance used and p-value < 0.05 was considered significant. Table and bar graphs were the appropriate tools to present data.

Results

In the 300 pulmonary tuberculosis patients enrolled, mean age was 42.5±1, (median 42, IQR 13.5), diversity in ages can be explained due to hospital based data. Males were predominant 217 (72%), as compared to females 83 (28%). Majority belonged to lower socioeconomic status, 239 (79.7%) having an income < 25,000 compared to 61 (20.3%) with an income >25,000. About half of the participants and spouses were illiterate 154 (51.3%) and 161 (53.6%) respectively. Majority were self-employed 238 (79%) compared to government employed 28 (9%), unemployed 26 (9%) students 8 (3%).

Substantial stigmatization was being experienced by the participants within the society. In case of social factors, majority were not afraid to disclose disease to their families and others, 213 (71%) and 175 (58.3%) were not worried of being a burden on their family. On the contrary 158 (52.7%) felt hurt at the reaction of others on disclosing their disease. Many of them had lost their friends 216(72%) and more than half of them 152 (50.7%) were experiencing loneliness. Fear of visiting tuberculosis clinics was observed in 200 (67%) of the participants (Figure 1). They had no fear of being perceived as AIDS patients 235 (78.3%), no fear of developing AIDS 243 (81%) or Tuberculosis 190 (63.3%) due to smoking, drinking or other risky behaviors (Figure 2).

Significant relationships were observed between loneliness and losing friends after disclosure of Tuberculosis (p=0.000, CI=29.95-52.25). Participants were experiencing the feeling of being hurt after disclosure of Tuberculosis to people outside the family (p=0.000, CI=12.57-35.52), but had no fear of Tuberculosis being perceived as AIDS(p=0.000, CI=8.58-32.36). Most of them had no fear of developing AIDS and experiencing loneliness which exhibited a significant relationship (p=0.01, CI=9.05-37.18).

Discussion

Globally, Pakistan is included in countries having a high burden of Tuberculosis.[21] It is pertinent to assess stigmatizing attitudes towards tuberculous patients especially in countries like Pakistan

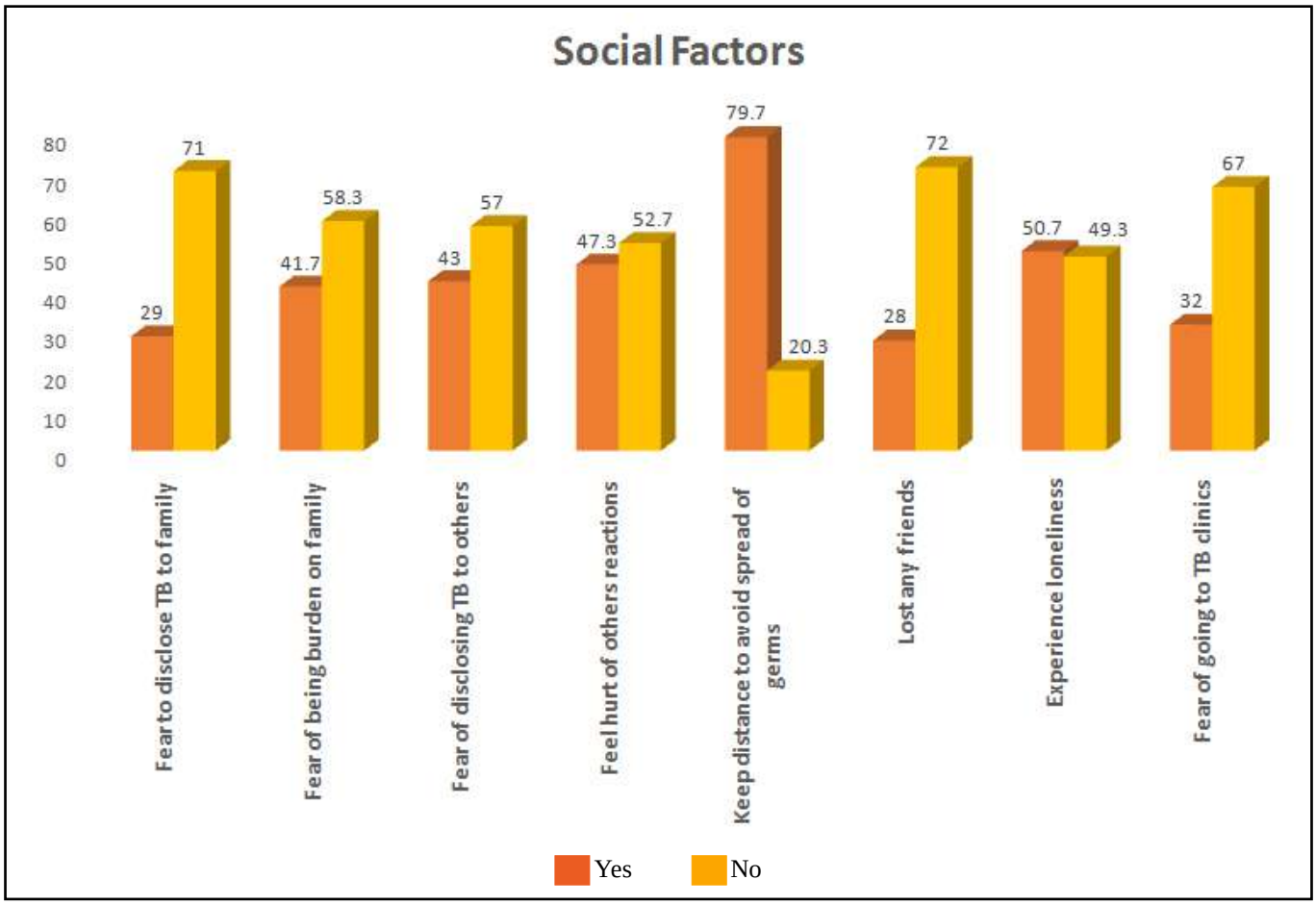

Fig 1. Social Factors associated with Stigma due to Tuberculosis

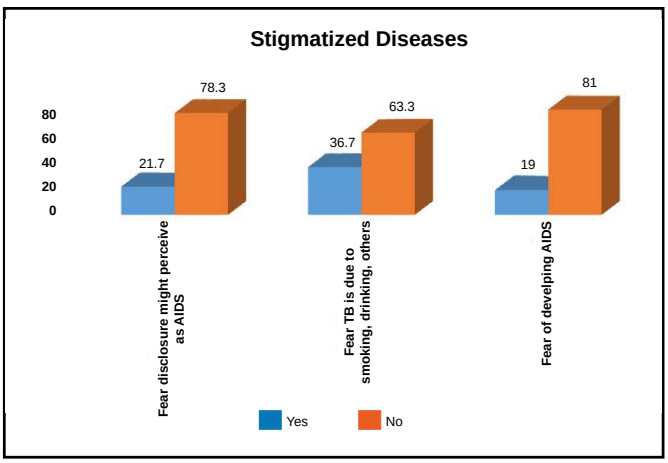

Fig 2. Stigmatized Diseases

where scarcity of studies is pronounced, in addition it also determines the health care seeking behavior of the patients. The current study evidenced male pre dominance (72%) supported by a study (70%) conducted in Thailand.[22] Middle aged groups (25 – 46 years) were the major sufferers as discussed in the literature, mean age being 34 years. Poor educational status was a consistent finding, our study featuring majority of the participants and their spouses as illiterate (51–54%), concurrent with findings of Kipp.[23] Similarly another study states that literacy status was not associated with stigmatization against Tuberculosis.[24]

Minimal stigmatization against Tuberculosis within the family was observed in the current study, participants had no fear to disclose disease to their families (71%), contrary to the findings in literature, (23%) were not afraid of disclosing disease to their families.[24] In another study, participants stated that families never left them alone, thus they had no fears disclosing their disease to them.[25]

In another study it was evident that (51.3%) had a fear of disclosing disease to their families, 47.3%) felt hurt of others reactions to their disease, (41.7%) and were fearful of being a burden on their families which was attributed to their low socioeconomic status and productive age group.[26]

Loneliness the most painful aspect of stigmatization was

Response	n (%)	n (%)	Confidence Interval	p value
	Participants lost friends after disclosure of TB	**Participants experiencing loneliness**		
Yes	84 (38.8)	68 (80.9)	29.95-52.24	<0.001
No	132 (61.1)	16 (19.0)		
	Participants fear of disclosure of TB to people outside family	**Participants felt hurt of reaction of people on disclosure of TB**		
Yes	63 (36.8)	79 (61.2)	12.57-35.52	<0.001
No	108 (63.1)	50 (38.7)		
	Participants fear of disclosure of TB outside the family	**Participants fear of disclosing TB as might be perceived as AIDS**		
Yes	32 (17.6)	33 (37.9)	8.58-32.26	<0.001
No	181 (84.9)	54 (62.0)		
	Participants fear of developing AIDS	**Participants experience loneliness**		
Yes	112 (46.0)	40 (70.1)	9.05-37.18	0.01
No	131 (53.9)	17 (29.8)		
	Participants fear that TB developed due to smoking, drinking or others	**Participants fear of developing AIDS**		
Yes	28 (49.1)	82 (33.7)	0.50-30.22	0.03
No	29 (50.8)	161 (66.2)		

experienced by (50.7%) of the participants, although only (28%) had lost their friends after developing the disease (x^2 42.811, *p*-value 0.000). Literature provides supporting evidence as various studies report that participants shared the experience of loneliness and isolation from families, communities and friends.[25,26] In a study conducted in India (98%) patients were facing discriminating attitude.[22] On the contrary some studies factualize that patients have the support and encouragement of their friends, thus it helps reduce loneliness and isolation as was observed in the current study.[22,23,27] A pertinent observation was that patients were keeping a distance or avoiding coughing in front of people as to prevent spread of germs (79.7%), supported by another study in which (69.9%)patients were practicing the same.[28]

AIDS and Tuberculosis go hand in hand as far as stigmatization is concerned. In the current study participants had minimal fears concerned with AIDS which may be attributed to illiteracy and low prevalence of HIV according to WHO in 2014, 68,000 people were reported to have HIV/AIDS in Pakistan.[29] In the current study the participants had minimal fear of TB being perceived as AIDS (x^2 19.098, *p*-value 0.000) or fear of developing AIDS, (19%). A significant association was observed between fear of developing AIDS and experiencing loneliness (x^2 10.715, *p*-value 0.01). Contrarily other studies reported stigma related to HIV (82%) and immoral behaviors as well as beliefs of patients that they had more chances of developing AIDS.[28, 30]

Smoking, drinking and many other activities can be attributed to Tuberculosis leading to misconceptions as quoted in a study, (34%) of the participants attributed their disease to smoking.[31]

In a study conducted in North Africa, (42%), smokers discontinued smoking and (41%) alcoholics discontinued drinking as they believed these activities were responsible for their disease.[32] But the current study negates these findings as (63.3%) did not attribute their disease to these factors and a significant relationship was exhibited between fear of developing TB due to smoking , drinking and fear of developing AIDS (x^2 4.702, *p*-value 0.03).

Stigmatization leads to decrease in seeking healthcare and compliance of the patient. Studies have shown that due to fear of being stigmatized patients do not access health care facilities (46.2%),[23] contrary to the observations of the current study, (32%) were fearful of accessing Tuberculosis clinics. These results may be attributed to this study being hospital based.

Conclusion

Stigmatization is an issue faced by many tuberculosis patients, the current study concludes that substantial stigmatization was being faced in the form of people having fears and experiences of loneliness and being left by friends depicted by a significant p-value. This is contributing to less health care seeking behavior and compliance of the patients which ultimately effects the overall control and spread of Tuberculosis, which is of high concern as Pakistan is high burden country for TB and we need to address and minimize this problem as much as possible. In countries like Pakistan strong family bonds and network are responsible for less stigmatization at family level.

Recommendations

1. Patients and attendants visiting specialized Tuberculosis centers should be educated regarding stigmatization of patients and its implications on their treatment and mental status.
2. Families should be involved in accepting the disease by extensive counseling, as they play a major role being the support system for the sufferer and thus can increase compliance and reduce stigma not only at family level but at community level too.
3. Further researches should be conducted in other institutions and the community involving a larger sample, as we need to highlight this topic on various forums.

Acknowledgements

The authors are thankful to the administration of Gulab Devi Chest Hospital, Lahore and the Department of Community Health Sciences, Fatima Memorial College of Medicine and Dentistry for their cooperation which made this study possible to be conducted.

References

1. Heijnders M, VanDerMeij S. The fight against stigma: an overview of stigma-reduction strategies and interventions. *Psychol Health Med* 2006; 11:353–63
2. Link B, Phelan J. Conceptualizing stigma. *Annu Rev Sociol* 2001; 27:363–85
3. Goffman E. Garden City (NY): Anchor Books; 1963. Stigma: notes on the management of spoiled identity.
4. Smith R, Rossetto K, Peterson BL. A meta-analysis of disclosure of one's HIV-positive status, stigma and social support. *AIDS Care* 2008; 20: 1266–75
5. Courtwright AM. Justice, stigma, and the new epidemiology of health disparities. *Bioethics* 2009; 23: 90-6
6. Mahajan AP, Sayles JN, Patel VA, Remien RH, Sawires SR, Ortiz DJ, *et al*. Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. *AIDS* 2008; 22(Suppl 2):S67–79
7. West EL, Gadkowski LB, Ostbye T, Piedrahita C, Stout JE. Tuberculosis knowledge, attitudes, and beliefs among North Carolinians at increased risk of infection. *N C Med J* 2008; 69:14–20
8. Mak WW, Mo PK, Cheung RY, Woo J, Cheung FM, Lee D. Comparative stigma of HIV/AIDS, SARS, and tuberculosis in Hong Kong. *SocSci Med* 2006; 63:1912–22
9. Somma D, Thomas BE, Karim F, Kemp J, Arias N, Auer C, *et al*. Gender and socio-cultural determinants of TB-related stigma in Bangladesh, India, Malawi and Colombia. *Int J Tuberc Lung Dis* 2008; 12:856–66
10. Ngamvithayapong J, Winkvist A, Diwan V. High AIDS awareness may cause tuberculosis patient delay: results from an HIV epidemic area, Thailand. *AIDS* 200; 14: 1413–9
11. Westaway MS, Wolmarans L. Cognitive and affective reactions of black urban South Africans towards tuberculosis. *Tuber Lung Dis* 1994; 75: 447–53
12. Joseph HA, Waldman K, Rawls C, Wilce M, Shrestha-Kuwahara R. TB perspectives among a sample of Mexicans in the United States: results from an ethnographic study. *J Immigr Minor Health* 2008; 10:177–85
13. Baral SC, Karki DK, Newell JN. Causes of stigma and discrimination associated with tuberculosis in Nepal: a qualitative study. *BMC Public Health* 2007; 7:211
14. Dodor EA, Neal K, Kelly S. An exploration of the causes of tuberculosis stigma in an urban district in Ghana. *Int J Tuberc Lung Dis* 2008;12:1048–54
15. Huy TQ, Johansson A, Long NH. Reasons for not reporting deaths: a qualitative study in rural Vietnam. *World Health Popul* 2007; 9:14–23
16. Kelly P. Isolation and stigma: the experience of patients with active tuberculosis. *J Community Health Nurs* 1999; 16:233–41
17. Atre SR, Kudale AM, Morankar SN, Rangan SG, Weiss MG. Cultural concepts of tuberculosis and gender among the general population without tuberculosis in rural Maharashtra, India. *Trop Med Int Health* 2004; 9:1228–38
18. Ganapathy S, Thomas BE, Jawahar MS, Selvi KJ, Sivasubramaniam, Weiss M. Perceptions of gender and tuberculosis in a south Indian urban community. *Indian J Tuberc* 2008; 55:9–14
19. Zhang T, Liu X, Bromley H, Tang S. Perceptions of tuberculosis and health seeking behaviour in rural Inner Mongolia, China. *Health Policy* 2007; 81:155–65
20: Van Rie A, Sengupta S, Pungrassami P, Balthip Q, Choonuan S, Kasetjaroen Y, Strauss RP, Chongsuvivatwong V. Measuring stigma associated with tuberculosis and HIV/AIDS in southern Thailand: exploratory and confirmatory factor analyses of two new scales. *Tropical Medicine & International Health* 2008 Jan 1; 13(1):21-30
21: Gilani SI, Khurram M. Perception of tuberculosis in Pakistan: findings of a nation-wide survey. Age (Years). 2012 Feb 1; 30(965):35
22: Jittimanee SX, Nateniyom S, Kittikraisak W, Burapat C, Akksilp S, Chumpathat N, Sirinak C, Sattayawuthipong W, Varma JK. Social stigma and knowledge of tuberculosis and HIV among patients with both diseases in Thailand. *PLoS One* 2009 Jul 23 4(7)
23: Kipp AM, Pungrassami P, Nilmanat K, Sengupta S, Poole C, Strauss RP, Chongsuvivatwong V, Van Rie A. Socio-demographic and AIDS-related factors associated with tuberculosis stigma in southern Thailand: a quantitative, cross-sectional study of stigma among patients with TB and healthy community members. *BMC Public Health* 2011 Aug 30; 11(1):1
24: Abebe G, Deribew A, Apers L, Woldemichael K, Shiffa J, Tesfaye M,

Abdissa A, Deribie F, Jira C, Bezabih M, Aseffa A. Knowledge, health seeking behavior and perceived stigma towards tuberculosis among tuberculosis suspects in a rural community in southwest Ethiopia. *PLoS One* 2010 Oct 11; 5(10)
25: Macq J, Solis A, Martinez G, Martiny P. Tackling tuberculosis patients' internalized social stigma through patient centred care: An intervention study in rural Nicaragua. *BMC Public Health* 2008 May 8; 8(1):1
26: A, Turner AN. Tuberculosis and stigmatization: pathways and interventions. *Public Health Reports* 2010 Jul 1:34-42
27. Moya EM, Biswas A, Baray SC, Martínez O, Lomeli B. Assessment of stigma associated with tuberculosis in Mexico. *Public health action* 2014 Dec 21; 4(4):226
28: Sagili KD, Satyanarayana S, Chadha SS. Is Knowledge Regarding Tuberculosis Associated with Stigmatising and Discriminating Attitudes of General Population towards Tuberculosis Patients? Findings from a Community Based Survey in 30 Districts of India. *PloS one* 2016 Feb 1; 11(2)
29: http://apps.who.int/gho/data/view.main.22100?lang=en
30: Tadesse S. Stigma against Tuberculosis Patients in Addis Ababa, Ethiopia. *PloS one* 2016 Apr 7; 11(4)
31: Pungrassami P, Kipp AM, Stewart PW, Chongsuvivatwong V, Strauss RP, Van Rie A. Tuberculosis and AIDS stigma among patients who delay seeking care for TB symptoms. The international journal of tuberculosis and lung disease: *the official journal of the International Union against Tuberculosis and Lung Disease* 2010 Feb; 14(2):181
32: Abioye IA, Omotayo MO, Alakija W. Socio-demographic determinants of stigma among patients with pulmonary tuberculosis in Lagos, Nigeria. *African health sciences* 2011; 11(3):100