Title

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Journal

The International Journal of Tuberculosis and Lung Disease, 18(2)

ISSN

1027-3719

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Publication Date

2014-02-01

DOI

10.5588/ijtld.13.0181

Peer reviewed

INT J TUBERC LUNG DIS 18(2):168–173

http://dx.doi.org/10.5588/ijtld.13.0181

A systematic review of global cultural variations in knowledge, attitudes and health responses to tuberculosis stigma

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SUMMARY

SETTING: Tuberculosis (TB) related stigma is associated with lack of treatment adherence. Individual perceptions of stigma differ by societal context. Limited data are available on variations of TB stigma worldwide.

OBJECTIVE: To describe the influence of TB stigma on knowledge, attitudes and responses to TB and to identify similarities and differences across countries.

DESIGN: Systematic review of international descriptive studies.

RESULTS: A total of 1268 studies were identified from PubMed/Medline, Web of Science, Cochrane, PsycINFO and Cumulative Index to Nursing and Allied Health Literature database searches. Eighty-three studies from 35 countries met the inclusion criteria for English, peer-reviewed, original and non-interventional studies. Variation and similarities in the influence of TB stigma on knowledge, attitudes and responses to TB across countries were identified. Stigma antecedents included negative attitudes and misperceptions regarding the causes of TB and the association with the human immunodeficiency virus. Decisions about illness disclosure and choices between traditional healers and public or private providers were influenced by TB stigma. Sex-influenced perceptions and management of TB and public health responses contributed to TB stigma.

CONCLUSION: Our findings confirm cultural variations with respect to TB and the potential for stigma. Cultural variations should be considered in the development of interventions aimed at reducing stigma and improving treatment adherence.

KEY WORDS: sex; HIV/AIDS; TB

AN ESTIMATED 8.7 MILLION individuals worldwide are currently infected with the *Mycobacterium tuberculosis* bacillus, with 1.4 million deaths from tuberculosis (TB) occurring in 2011.[1] TB is a widespread global disease that affects family and social relationships and results in adverse health and economic consequences.[2,3] Individuals with TB and their families can experience prejudice and negative attitudes, such as shame, blame and a sense of judgment.[4–8] Enacted TB stigma refers to exclusion, rejection or devaluation by others against patients and their families based on beliefs of social unacceptability or inferiority.[9] Perceived TB stigma refers to patient and family fears of inferiority stemming from the anticipation of an adverse judgment related to a TB diagnosis.[9] TB stigma can be a barrier to early diagnosis and a deterrent to treatment adherence.[10–13] Multicountry studies comparing TB stigma suggest intra- and inter-country differences.[14–16] However, little is known as to how similarities or differences in the knowledge, attitudes and health responses of individuals or communities influence TB stigma. To reduce barriers to diagnosis and treatment pathways, TB stigma needs to be understood within the socio-cultural context. This will allow for control efforts to address stigma at the individual, community and system levels.

The aim of this review was to describe the influence of stigma on knowledge, attitudes and responses to TB and to identify similarities and differences across countries.

METHODS

For this review, the PubMed/Medline, Web of Science, Cochrane, PsycINFO and Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases were searched in January 2012. Medical subject heading (MeSH) terms included 1) 'tuberculosis' AND 'tuberculosis/psychology' and 2) 'prejudice' OR 'stereotyping' OR 'social perception' OR 'social stigma' OR 'social isolation' OR 'health knowledge, attitudes, practice.' Inclusion criteria were English language, peer-reviewed, original research using qualitative, quantitative or mixed methods, and study

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Article submitted 11 March 2013. Final version accepted 30 September 2013.

findings related to attitudes, beliefs or responses in relation to TB stigma. Exclusion criteria were intervention studies, review articles, dissertations, commentaries, letters and guidelines. The title and abstract were first reviewed by one author, then both authors screened the remaining articles based on the inclusion criteria.

The 'signal and noise' technique, a narrative interpretive method of systematic review and a technique that is intuitive and value-based, was used for study appraisal.[17,18] According to Edwards et al., the 'weight of evidence' in a topic area can be judged by assessing the 'signal' from available research publications and tempering the importance attached by the level of 'noise' (the inverse of methodological quality).'[17] The signal and noise evaluation technique is valid and reliable and can be applied to the 'qualitative overview' segment of systematic reviews.[17] As an alternative to evaluating the quality of studies, a signal score is used to assess the relevance of publications. The process does not eliminate research simply because it lacks a certain level of evidence or has methodological weaknesses. According to Higginson et al., there may be some articles in which the design is suspect (high noise level), but the findings appear important (strong signal).[19] We based the signal score (possible points 0–3) on study relevance.

After selection of relevant studies, Nvivo software, version 9 (QSR International Pty Ltd, Burlington, MA, USA) was used to extract qualitative and quantitative data relevant to the study aims. The first author independently extracted and then coded the data into themes and classified them into three categories: knowledge, attitudes and health responses. Both authors reviewed these themes and subthemes to ensure the appropriateness of data classification. We reported themes based on two criteria: 1) if the main findings were in the abstracts of the selected studies, and 2) if the main findings were supported by most of the studies. These selected studies were arranged in the order of the six World Health Organization (WHO) regions (African, Eastern Mediterranean, European, the Americas, South-East Asia, and Western Pacific) to examine regional differences in findings relevant to TB stigma.

RESULTS

As presented in the flow chart (Appendix Figure),* our search yielded 83 studies relevant to this systematic review. In Appendix Table A.1, results are presented for 35 countries, including 17 (77%) of the 22 countries identified by the WHO as having the greatest prevalence of TB in the world.[1] Of the 83 studies, 41 were quantitative, 32 qualitative and 10 mixed (Appendix Table A.2).

Knowledge of tuberculosis, causal factors and labels

Across countries and cultures, there was a broad range of causal attributes for TB (Appendix Table A.3).[2,10,14,20–45] TB is believed to be an infectious lung disease among the Vietnamese in the United States,[2] caused by germs in Viet Nam[45] and Rwanda,[39] a respiratory infection in Russia,[38] and transmitted by air in Tanzania,[42] India[29] and Malaysia.[32] In Ethiopia[20–22] and Kenya,[30] exposure to cold air is believed to cause TB. In Kenya,[30] Malawi,[31] South Africa[40,41] and Uganda,[10] smoking is believed to be the cause. Nutrition is implicated in Haiti,[14] Rwanda[39] and Peru,[36] and living conditions in Morocco.[33]

In many countries, providers avoid using TB as a label and instead use names such as '*chebuonit*' or '*kifua kikuu*' in Kenya,[30] 'weak lung' disease in the Philippines[37] and 'lay category bird' in Ethiopia.[25] In Rwanda,[39] Uganda[10] and Ethiopia,[24] TB is believed to be caused by the supernatural and is referred to as 'evil eye'.[23]

Scientifically unfounded beliefs regarding TB transmission were associated with negative attitudes towards TB in Colombia.[46] Mistaking TB for a foodborne illness resulted in bans on sharing utensils in Uganda[10] and Peru[36] and among Mexican Americans in the United States.[44] The cause of TB is believed to be associated with sexual contact in Malawi[31] and India.[28] In Kenya,[30] Uganda[10] and Viet Nam,[45] TB is believed to be a hereditary condition. In Pakistan, TB is blamed for infertility and diminished marriageability[34] among women.[35] TB is attributed to hard labor in Kenya,[30] Rwanda,[39] South Africa[47] and Viet Nam.[45] Mental health issues attributed to TB include worry, stress and trauma in Pakistan,[34] India,[27] Viet Nam[45] and Turkey,[43] and suicidal ideation in India.[48]

Association with human immunodeficiency virus/acquired immune-deficiency syndrome

The belief that TB is associated with HIV/AIDS (human immunodeficiency virus/acquired immune deficiency syndrome) is common in Ethiopia,[20,24] Kenya,[49] Malawi[16] and Haiti[14] (Appendix Table A.4).[14,16,20,24,39,49–53] Signs of TB are seen as signs of HIV/AIDS in Rwanda[39] and Zambia.[53] TB-HIV co-infected patients report feeling more stigmatized than patients without co-infection in Ethiopia[50] and Thailand.[51] African patients with TB living in the United Kingdom often refuse HIV testing for fear of stigmatization.[52]

Attitudes toward tuberculosis

TB is experienced as embarrassing and shameful in Congo,[5] Zambia,[53] the United States[15] and Malaysia[32] (Appendix Table A.5).[2–6,8,9,14,15,20,21,23,24,32,35,43,46,47,53–71]

*The Appendix is available in the online version of this article at http://www.ingentaconnect.com/content/iuatld/ijtld/2014/00000018/00000002/art00008

This 'dirty' disease is believed to affect poor people; patients with TB feel less respected by others or inferior in Ethiopia[23] and Viet Nam,[6] with women in Bangladesh feeling shame and rejected by others.[7] Discrimination was reported in South Africa,[47] Indonesia[8] and Nepal.[4] In Brazil, TB is perceived as difficult and isolating, changing a person's perception of themselves.[54] Fear of infection was reported in Ghana,[58–60] South Africa,[65] Zambia[53] and Colombia[56] and in North Carolina, United States.[70] Cough is extremely stigmatizing in Bangladesh[72] and India.[73] Greater TB stigma is experienced by Thai patients if they have more symptoms,[67] by patients in Ghana if they have more physical frailty,[60] and by patients in Nigeria[63] if they have weight loss or a history of smoking or drinking.

Different societies have different levels of acceptance for patients with TB. People with TB may be ostracized; others are fearful of physical contact with persons with TB in Ethiopia[20] and Pakistan.[64] However, family and friends in Malaysia[32] or the United Kingdom believe that TB is socially acceptable and do not feel threatened.[68] Social isolation for patients with TB has been reported in Congo,[5] Ethiopia,[20,24] South Africa,[65,66] Pakistan[35] and Croatia,[57] and among Samoans[71] and African Americans in the United States.[69] Women fear isolation in India[28] and Viet Nam,[9] and loneliness is reported by Turkish patients.[43] Loss, sadness and dissatisfaction are common among patients with TB in Brazil.[54] Marriage prospects are affected as a result of TB in Ghana,[58] Pakistan,[35] India[61] and China.[55] Ethnic identity is negatively associated with TB among Haitians in the United States.[14] Adults who were tested for TB in Ecuador reported feeling stigmatised just by undergoing testing.[3]

Treatment and health responses to tuberculosis

Multiple factors related to stigma can influence treatment-seeking behaviour, including knowledge and social attitudes toward TB, preferences for treatment, time or cost constraints and convenience or confidentiality of anti-tuberculosis treatment (Appendix Table A.6).[9,10,25–27,30,31,34,35,37–40,42,49,55,58,71,74–78] Patients with TB often consult traditional healers in Gambia,[74] South Africa,[40] Uganda,[10] Thailand,[77] Malaysia[76] and the Philippines.[78] Traditional herbal medicine is used by Samoans in the United States.[71] Patients in Kenya[49] and Rwanda,[39] who believe that TB is caused by supernatural forces, believe they can only be cured by traditional healers.

Patients with TB choose between self-treatment and private or public doctors. Patients prefer using self-medication first before formal treatment in Kenya,[30,49] Tanzania[42] and China.[55] Self-medication is affected by the concept of 'weak lung' in the Philippines, where TB is thought to be like other lung diseases and is usually treated by self-medication.[37] In Viet Nam, self-medication is preferred before turning to other providers, particularly among women.[9] When self-medication fails, patients with TB in China seek less-qualified health care providers because of availability and cost concerns.[55] Patients seek private providers first in India[27,31] and Bangladesh.[31] Public health services are sought first in Malawi.[31] Patients discontinue medication after symptoms are relieved in Pakistan.[34]

Age and sex differences in health responses

For patients with TB, age and sex have a role in health-seeking behaviors. For example, young individuals in India generally seek care from private providers, whereas older individuals generally prefer government facilities.[75] Older patients are reluctant to constitute a financial burden for their children and are more likely both to delay care and to choose care from village providers over the option of a public hospital.[55]

Men and women report feeling different levels of stigmatization and social and economic consequences (Appendix Table A.7).[7,9,16,31,35,45,72,73,75,79–85] Four factors related to sex differences in TB stigma were found: 1) financial dependence of women on men to obtain treatment in Pakistan,[35] 2) low priority of women's health in Peru,[83] 3) social isolation of women in Bangladesh[31] and Viet Nam,[9] and 4) decreased marital prospects in Malawi,[16] Pakistan,[35] and India.[16,28] In Viet Nam, women worried more than men about the social consequences of the disease,[84] and women perceived more TB stigma than men in Kosovo[82] and India.[79] However, in India, TB affects marital prospects for men rather than women.[80]

In general, men and women manage TB differently. Women in Gambia use healers more because of their stronger traditional beliefs, time restrictions and confidentiality of care.[74] Men in Thailand who experience more TB stigma report increased treatment delay, whereas women report decreased treatment delay.[81] In Viet Nam, men delayed treatment until the serious disease stage of TB and then sought public providers, while Vietnamese women self-medicated and then sought private services.[9]

Stigma related to public health responses

Attitudes and practices of health care professionals and stigma associated with treatment at TB clinics can be associated with stigmatisation in African countries. Due to the fear of infection, health care workers may avoid, blame and impose restrictive practices that promote TB stigma. For example, prohibition of full burial rites for individuals who die of TB in Ghana, the belief that working on TB units is a form of punishment[59,86] and negative attitudes toward providing grants, information or treatment for TB in South Africa contribute to TB stigmatisation.[87] Because of the stigma associated with public health services for TB in Ethiopia, patients choose to seek out private providers.[25]

Disclosing tuberculosis diagnosis and stigma

Disclosure of TB diagnosis can affect patient choices regarding the diagnosis and treatment of TB. In Nicaragua, responses to disclosure ranged from the belief that patients deserve support to the withholding of support due to the fear of infection and the belief that patients with TB are unlucky.[62] In South Africa,[88] Nicaragua,[62] India,[79,80] the Philippines[78] and Croatia,[57] patients avoid disclosure of TB disease due to the fear of stigma and negative impact on their social status or marriage prospects. However, disclosure encourages support in Malawi[89] and fear and discrimination in Tanzania.[90] Disclosure of TB status results in stigma in Nigeria,[63] and worry and suicidal thoughts in India.[48]

DISCUSSION

This review of 83 studies suggests that TB has different meanings for different ethnic and cultural groups based on social context. Cultural variation exists across the 35 countries with respect to knowledge of TB related to causes and transmission routes, as well as attitudes and health responses. Age and sex can affect how individuals perceive and manage TB disease, and public health responses, including negative attitudes from health care providers or restriction measures, can contribute to TB stigma.

This review reveals a frequent association between TB and HIV stigma in countries with high HIV prevalence (Appendix Table A.4). Visible signs or symptoms of TB are often believed to be a result of HIV/AIDS.[53] TB-HIV co-infected patients are more likely to have perceived stigma compared to patients who are not co-infected.[50] TB is most commonly associated with HIV/AIDS in countries with a high prevalence of HIV/AIDS, such as in Africa, where HIV/AIDS is the leading cause of death,[1] and in other parts of the world, such as Haiti and Thailand. In Malawi, India and Bangladesh, women appear to suffer most from TB stigma because of their vulnerable situation in marital relationships.

Given the scope of this review, we are unable to determine whether the relationship between stigma and public health responses is causal or coexistent. Stigmatisation of TB arises from public health responses to TB; for example, isolation measures can thwart patients' access to timely care when they develop TB symptoms. This relationship needs to be confirmed in future studies.

Potential limitations of the present review include the fact that we used only English-language articles for analysis. The search was limited by the use of words relevant to stigma without the use of 'meaning', or 'health and ethnology', which might have resulted in the inclusion of studies of broader understanding of the meaning of TB among different cultural groups. Further research is needed to elucidate the associations between TB stigma and health outcomes.

The implications of these findings may be far-reaching for the provision of culturally sensitive TB prevention and treatment and the promotion of early diagnosis and treatment adherence. To reduce stigma, clinicians may need to identify cultural factors that promulgate TB stigma and explore how it impacts on family and social relationships. Education regarding stigma needs to be provided to health care providers, communities and patients, and system-wide policies need to be put in place to protect patient privacy and to provide culturally sensitive care.

CONCLUSION

Our findings suggest that public health interventions designed to improve treatment rates or adherence rates should include consideration of the individual patient's cultural and social context and the role that stigmatization may have in health-seeking behaviors. The study of TB stigma needs to be conducted in a socio-cultural context, and associations with knowledge, attitudes and health responses need to be further explored. A successful stigma intervention may need to be sensitive to the cultural context of TB patients and their families and communities.

Acknowledgement

The authors express their gratitude to K Lee for reviewing this manuscript.

Conflict of interest: none declared.

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APPENDIX

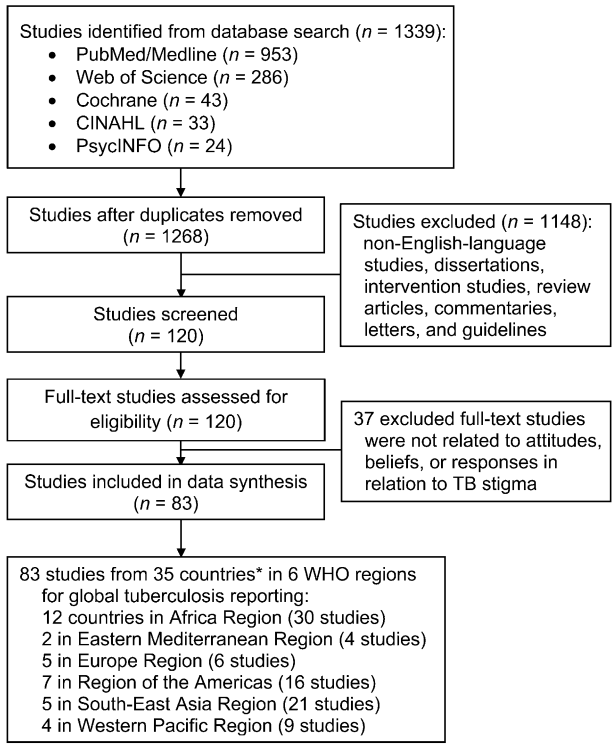

Figure Flow diagram for systematic review on tuberculosis stigma. *Some studies were conducted in more than one country. CINAHL = Cumulative Index to Nursing and Allied Health Literature; TB = tuberculosis; WHO = World Health Organization.

Table A.1 Listing of 35 countries in six WHO regions represented in the 83 studies surveyed in the present study

WHO region, country	Study number	Studies/ country *n*	High TB burden country
Africa region			
Congo	1	1	X
Ethiopia	2	8	X
Gambia	3	1	
Ghana	4	4	
Kenya	5	2	X
Malawi	6	1	
Nigeria	7	1	X
Rwanda	8	1	
South Africa	9	7	X
Tanzania	10	2	X
Uganda	11	1	X
Zambia	12	1	
Eastern Mediterranean region			
Morocco	13	1	
Pakistan	14	3	X
Europe region			
Croatia	15	1	
Kosovo	16	1	
Russia	17	1	X
Turkey	18	1	
United Kingdom	19	2	
Region of the Americas			
Brazil	20	1	X
Colombia	21	2	
Ecuador	22	1	
Haiti	23	1	
Nicaragua	24	1	
Peru	25	2	
United States	26	8	
South-East Asia region			
Bangladesh	27	4	X
India	28	11	X
Indonesia	29	1	X
Nepal	30	1	
Thailand	31	4	X
Western Pacific region			
China	32	1	X
Malaysia	33	2	
Philippines	34	1	X
Viet Nam	35	5	X

WHO = World Health Organization; TB = tuberculosis.

Table A.2 Methodologies used in the 83 studies analysed in the present study

Type of study	*n* (%)	Methods	Study participants
Quantitative	41 (49)	Survey, cross-sectional study and structured questionnaire (interview)	Patients with TB, their relatives, individuals suspected of having TB, community members, health care workers, university students, housewives, professionals, male and female parents/care givers of children and adolescents, heads of household, school heads, opinion leaders, religious leaders, care givers, educators, farmers, employers, and representatives of non-governmental organizations
Qualitative	32 (39)	Focus group discussion, in-depth interview, semi-structured questionnaire, key informant interview, and ethnographic study (structured interview)	
Mixed methods	10 (12)	Combination of interview and focus group; cultural epidemiology, semi-structured Explanatory Model Interview Catalogue	

TB = tuberculosis.

Table A.3 Knowledge of TB and causal factors by country (in alphabetical order)

Country	Selected findings
Ethiopia	Caused by cold[20] or cold air[21,22] or 'evil eye'[23] or 'evil spirit.'[24] Perceive TB as 'lay category bird,' an illness caused by the cold or blowing wind.[25] Local model sees causal factors unrelated to tubercle bacillus[26]
Haiti	Stigma is associated with poverty and malnutrition[14]
India	Caused by germs and worry.[27] Sexual experience as the cause of TB.[28] Airborne transmission mode[29]
Kenya	Smoking, alcohol, hard work, exposure to cold and sharing with patients with TB; TB is hereditary[30]
Malawi	Men emphasize smoking and drinking alcohol as causes of TB, and women report sexual causes associated with HIV/AIDS[31]
Malaysia	Caused by germs, transmitted by air[32]
Morocco	Causes related to living conditions. Popular understandings of TB etiology and transmission differ from biomedical view[33]
Pakistan	Contaminated food as source of infection and emotional trauma/stress as causative agent.[34] TB leads to infertility and reduced chances of getting married following infection.[34] Pregnancy enhances the risk for relapse and decreases women's marriage prospects[35]
Peru	Transmitted by sharing eating utensils and is prevented by nutrition[36]
Philippines	'Weak lungs' associated with TB is broad and covers a variety of symptom states inclusive of TB. Some equate 'weak lungs' with TB, many others think that weak lungs may develop into TB over time[37]
Russia	Consider TB as per other respiratory infections[38]
Rwanda	Causes of cough-related illness include biomedical (germs, internal body dysfunction and worms), environmental (seasonal changes and dust), cultural (inheritance), socio-economic (hard work, malnutrition and tobacco) and supernatural (witchcraft)[39]
South Africa	Result of breaking cultural rules that demand abstinence from sex after the death of a family member and after a woman has a spontaneous abortion.[40] 'Western' type TB caused by environmental pollution, smoking or alcohol excess.[40] Caused by smoking.[41]
Tanzania	Transmitted through air[42]
Turkey	'Unhappiness and stress' as the major cause of illness in patients with TB[43]
Uganda	TB etiologies: sharing utensils, heavy labor, smoking, bewitchment and hereditary transmission[10]
United States	Transmitted through air and widespread misperceptions about TB transmission (kissing, sharing clothing or eating utensils, or exchanging body fluids) among Mexican Americans.[44] Hard manual labor, smoking, alcohol consumption and poor nutrition as risk factors among Vietnamese[2]
Viet Nam	Caused by germs. Traditional beliefs of four TBs: 1) *lao truyen* (hereditary TB), handed down from older generations via 'family blood'; 2) *lao luc* (physical TB), caused by hard work; 3) *lao tam* (mental TB), caused by too much worrying; 4) *lao phoi* (lung TB), dangerous and caused by TB germs, transmitted through the respiratory system.[45]

TB = tuberculosis; HIV = human immunodeficiency virus; AIDS = acquired immune deficiency syndrome.

Table A.4 Association with HIV/AIDS by country (in alphabetical order)

Country	Selected findings
Ethiopia	Those who had heard about HIV/AIDS considered an association between HIV/AIDS and TB.[24] Associated with HIV/AIDS.[20] Patients with TB and co-infected with HIV more stigmatized than those without coinfection[50]
Haiti	Stigma associated with HIV coinfection[14]
Kenya	Perceived link between TB and HIV[49]
Malawi	Association with HIV/AIDS linked to TB stigma[16]
Rwanda	TB symptoms mistaken for AIDS[39]
Thailand	Coinfection with HIV is associated with greater TB stigma[51]
United Kingdom	HIV disease worsens TB stigma. Patients decline HIV testing, fearing stigmatization and poor illness outcome if positive (among Africans)[52]
Zambia	Association between TB and HIV.[53] Visible signs of TB a trigger for TB-HIV stigma.[53]

HIV = human immunodeficiency virus; AIDS = acquired immune deficiency syndrome; TB = tuberculosis.

Table A.5 Attitudes toward TB by country (in alphabetical order)

Country	Selected findings
Brazil	'Living with tuberculosis is suffering'—isolates people and changes an individual's perception of himself/herself and difficult treatment; presentation of TB is expressed as loss, sadness and dissatisfaction[54]
China	Social stigma associated with TB influences marriage prospects and impedes important social interactions within the community[55]
Colombia	Cough, contagion, illness and fear.[56] Fear and compassion are associated with evocations among patients and their relatives, contagion among lay people, and isolation among health care personnel.[56] Scientifically unfounded beliefs about TB transmission are associated with negative attitudes toward TB[46]
Congo	Likens to a person (creature) invading people. Respond by isolation, shame and contempt of individuals with TB and uncertainty of who is infected with TB[5]
Croatia	Report feeling uncomfortable near a TB patient and would avoid any contact[57]
Ecuador	Link TB to multiple adverse health, economic, psychologic and social consequences, including stigma and feeling stigmatized just by being tested for TB[3]
Ethiopia	Patients are not accepted in the community, who fear physical contact with patients.[20] Individuals suspected of having TB consider themselves inferior.[23] Women and illiterate individuals have greater prejudice toward individuals with TB than men and literate individuals.[21] Stigmatization and social isolation of patients with TB.[20] Ostracism toward patients with TB[24]
Ghana	Fear of infection.[58-60] Fear of infection, physical frailty, association with HIV/AIDS, perceived causes and spread of TB, outdated societal beliefs and practices regarding TB, public health practice and discourse, health staff's own fear of TB, self-stigmatization by those with TB, judgment, blaming, and shaming of those with TB and past experiences with TB.[60] Those with TB considered not marriageable.[58] Health care workers fear infection when interacting with those with TB; shun, avoid, and advocate the segregation of patients with TB at home and in hospitals[59]
India	Isolating TB patients from family, avoiding food sharing, quitting job, prohibiting marriage, shunning from social functions[61]
Indonesia	Patients with TB face joblessness and negative attitudes from neighbors and relatives[8]
Malaysia	Patients with TB are socially acceptable, but contracting TB is embarrassing[32]
Nepal	Existences of patients' self-discrimination and discrimination from general public[4]
Nicaragua	Contradictory feelings and attitudes: feelings of affection and supportive attitudes toward those with TB as opposed to fear of being infected; consider those with TB to be unlucky as opposed to mistrust of those with TB and considering them to be negligent[62]
Nigeria	Stigma determined by age, low socio-economic status, education below secondary level, history of weight loss, previous smoking and history of alcohol consumption[63]
Pakistan	Community rejects those with TB.[64] Stigmatization and social isolation of those with TB and their families[35]
South Africa	Fear of infection; not keen to associate with individuals with TB.[65] Isolation for TB sufferers and consideration of the harm TB sufferers do to others.[66] Stigma attached to patients with TB by others, which differentiate TB patients from 'normal' people[47]
Thailand	TB disease severity and knowledge, individual's religion—associated with stigmatizing behaviors/attitudes and/or social support. TB patients with more severe symptoms experience greater stigma.[67]
Turkey	Three difficulties in their lives owing to TB: financial problems, loneliness and hospitalization.[43]
United Kingdom	Do not feel threatened by TB and believe TB is not infectious to their family or friends. Consider TB to be acceptable to family and friends.[68]
United States	Having TB adversely impacts work, family, community activities, and relationships among Vietnamese in New York.[2] African American patients felt family and friends avoided or shunned them, causing them to isolate themselves and become secretive about their illness.[69] Fear and aversion toward persons with TB among North Carolinians.[70] Belief of extreme contagiousness of TB leads to social stigma and isolation among Samoans.[71] TB more socially acceptable to Whites and Latinos compared to Blacks. Social stigma with TB—TB is dirty and an embarrassment.[15] TB stigma among Haitians in South Florida involves Haitian identity as a negatively stereotyped minority community within the larger society[14]
Viet Nam	Dirty disease affects poor people; TB patients feel less respected by others.[6] Women's fear of social isolation[9]
Zambia	Judgment, blame, shame, and fear of contagion.[53]

TB = tuberculosis; HIV = human immunodeficiency virus; AIDS = acquired immune deficiency syndrome.

Table A.6 Health responses toward TB by country (in alphabetical order)

Country	Selected findings
Bangladesh	Private doctors preferred[31]
China	Only seek health care after they fail to treat themselves;[55] older people less likely than younger to seek care or more likely seek care from less-qualified, village-level health care providers[55]
Ethiopia	Both private and public clinics manage patients according to the 'lay category bird.'[25] Therapeutic preference depends on using ethnobotanical remedies and their expected emetic effects[26]
Gambia	Consult traditional healers and pharmacies first; women use these healers more because of stronger traditional beliefs, time constraints and increased confidentiality[74]
Ghana	Sociophysical distance and participatory restrictions on those suffering from the disease[58]
India	Private doctors preferred.[31] First source allopathic treatment, and shift to municipal and non-government organization health services when private treatment becomes unaffordable.[27] Whereas younger patients access care from private providers, older patients prefer government facilities[75]
Kenya	TB patients treat themselves and consult with the traditional health sector.[30] Visit diviners, others alternate between self-treatment, hospital treatment, and herbalists.[49] Sociostructural and superstructural forces in beliefs and perceptions on treatment and disease-causing factors affect treatment-seeking[49]
Malawi	Public health services preferred[31]
Malaysia	Seek modern medicine for cure; other forms of treatment (traditional medicine) sought if modern medicine fails to cure the disease[76]
Pakistan	Owing to fear, patients deny the diagnosis and reject treatment.[35] Discontinue medications following relief of symptoms[34]
Philippines	Faith in biomedicine is strong. Concept of 'weak lungs' affects self-treatment practices and over-the-counter TB medications[37]
Russia	Illness identity is associated with delay.[38] Internalized shame is associated with increased medication adherence, whereas financial insecurity is associated with decreased adherence[38]
Rwanda	Home care, health facility, and the traditional healer are three health-seeking endpoints.[39] Use of herbal treatment for chronic cough.[39] Believe TB is due to witchcraft and can only be treated traditionally[39]
South Africa	If a result of breaking culture rules, TB can only be treated by traditional healers, which delays presentation to hospitals[40]
Tanzania	Self-medication preferred, health care facility consultation least-preferred option[42]
Thailand	TB patients with high stigma more likely to have taken antibiotics before anti-tuberculosis treatment and to have first visited a traditional healer or private provider[77]
Uganda	Care combined from traditional healers and biomedical system[10]
United States	For Samoans in Hawaii, biomedical treatment is necessary; traditional herbal medicine is seen as an adjunct to biomedical treatment.[71] Biomedical treatment is necessary, many believe in the effectiveness of traditional and popular treatments among Filipinos in California and Hawaii[78]
Viet Nam	Men neglect symptoms until the disease reaches a serious stage and then go directly to public health services.[9] Women seek out private services and practice self-medication before seeking care at public services.[9]

TB = tuberculosis.

Table A.7 Gender differences in health responses by country (in alphabetical order)

Country	Selected findings
Bangladesh	Exaggerated concerns about the risk of spread, despite treatment, contribute to social isolation of women.[31] Women are faced with adverse consequences more often than men; coughing up sputum in public by women is culturally frowned upon, resulting in enormous suffering.[72] Men are less likely to disclose their condition, stay away from work or report that their spouse refused sex because of TB; women report feeling ashamed or embarrassed, think less of themselves and feel that others refuse to visit them or avoid them[7]
India	Women experience more stigma than men.[79] Marital problems are anticipated more for women;[75] anticipation of support or attention is more definite for men.[75,80] Males are more likely to anticipate marital problems.[80] Men worry about the impact of TB on income and job; women are concerned about reduced chances of marriage.[16] Perceived stigma is significantly higher among men; change of behavior of community, and ashamed to cough in front of others[73]
Kosovo	Women are more stigmatized than men[81]
Malawi	Women more concerned about the impact on marital prospects[16]
Pakistan	Both male and female patients face social and economic problems; female patients affected more, in marriage.[35] Women depend economically on their husbands and in-laws and need their cooperation to obtain treatment[35]
Peru	Women's health inherently lower priority than men's health.[82] Women experienced adverse psychosocial and economic consequences of TB diagnosis more than men[82]
Thailand	Men with greater TB stigma have a small increase in delay times, whereas women have a small decrease in delay times[83]
Viet Nam	Men perceived to get TB more often than women because they are exposed more to risk factors during both work and leisure time.[45] Women contribute to delay in care, owing to fear of social isolation from family or community, and men contribute to fear of individual costs of diagnosis and treatment.[9] Men worry about economic-related problems, whereas women worry about social consequences of the disease.[84] Insufficient knowledge and individual cost of treatment are reported as main obstacles to compliance among men (poor patient adherence), whereas sensitivity to interaction with health staff and stigma in society are main obstacles among women.[85]

TB = tuberculosis.

RÉSUMÉ

CONTEXTE : La stigmatisation de la tuberculose (TB) va de pair avec une déficience de l'adhésion thérapeutique. Les perceptions individuelles de la stigmatisation sont différentes en fonction du contexte sociétal. On ne possède que des données limitées sur les variations de la stigmatisation de la TB au niveau mondial.

OBJECTIF : Décrire l'influence de la stigmatisation de la TB sur la connaissance des attitudes et des réponses à l'égard de la TB et identifier les similitudes et les différences d'un pays à l'autre.

SCHÉMA : Revue systématique des études descriptives internationales.

RÉSULTATS : On a identifié 1268 études lors d'une recherche des bases de données PubMed/Medline, Web of Science, Cochrane, PsycINFO et Cumulative Index to Nursing and Allied Health Literature. Quatre-vingt trois études provenant de 35 pays ont répondu aux critères d'inclusion pour des études en langue anglaise, revues par des pairs, originales et non-interventionnelles. On a pu identifier d'un pays à l'autre des variations et des similitudes de l'influence de la stigmatisation de la TB sur la connaissance, les attitudes et les réponses à la TB. Les antécédents de stigmatisation comportent des attitudes négatives et des erreurs de perception concernant les causes de la TB et son association avec le virus de l'immunodéficience humaine. Les décisions concernant la divulgation de la maladie et les choix entre les guérisseurs traditionnels et les pourvoyeurs de soins publics et privés sont influencées par la stigmatisation de la TB. Des perceptions influencées par le sexe et la prise en charge de la TB ainsi que les réponses des services de santé publics ont contribué à la stigmatisation de la TB.

CONCLUSION : Nos observations confirment les variations culturelles concernant la TB et son potentiel de stigmatisation. Les variations culturelles devraient être prises en compte dans l'élaboration d'interventions visant à réduire la stigmatisation et à améliorer l'adhésion thérapeutique.

RESUMEN

MARCO DE REFERENCIA: Los estigmas vinculados con la tuberculosis (TB) se evocan como causa de la falta de cumplimiento terapéutico. La percepción de los estigmas varía en los diversos contextos sociales. Existen pocos datos sobre la diversidad de los estigmas asociados con la TB en el mundo.

OBJETIVO: Describir la influencia de estos estigmas sobre los conocimientos, las actitudes y las respuestas frente a la TB y reconocer las semejanzas y las diferencias entre los países al respecto.

MÉTODOS: Fue esta una reseña sistemática de los estudios descriptivos internacionales.

RESULTADOS: La búsqueda en las siguientes bases de datos reveló 1268 estudios: PubMed y Medline, Web of Science, la Biblioteca Cochrane, PsycINFO y Cumulative Index to Nursing and Allied Health Literature. De ellos 83 provenientes de 35 países cumplían con los criterios de inclusión definidos: artículos escritos en inglés, publicados en revistas con comité de lectura, originales y sobre estudios que fuesen de intervención. Se reconocieron variaciones y semejanzas entre los diferentes países en cuanto a la influencia de los estigmas de la TB sobre los conocimientos, las actitudes y las respuestas a la enfermedad. En general, los estigmas consistieron en actitudes negativas y percepciones erradas sobre las causas de la enfermedad y su relación con el virus de la inmunodeficiencia humana. Asimismo, los estigmas influyeron en las decisiones relacionadas con la revelación de la enfermedad y la elección de los curanderos tradicionales o los profesionales de salud del sector público o privado. El sexo influyó en la percepción y el tratamiento de la TB. Las respuestas de salud pública contribuyeron a la persistencia de los estigmas vinculados con la enfermedad.

CONCLUSIÓN: Estos resultados confirman la variación cultural frente a la TB y la posibilidad vigente de aparición de estigmas. Es importante tener en cuenta la diversidad cultural cuando se elaboran las intervenciones encaminadas a disminuir los estigmas y mejorar el cumplimiento terapéutico.