Tuberculosis and Stigmatization: Pathways and Interventions

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SYNOPSIS

The institutional and community norms that lead to the stigmatization of tuberculosis (TB) are thought to hinder TB control. We performed a systematic review of the literature on TB stigma to identify the causes and evaluate the impact of stigma on TB diagnosis and treatment. Several themes emerged: fear of infection is the most common cause of TB stigma; TB stigma has serious socioeconomic consequences, particularly for women; qualitative approaches to measuring TB stigma are more commonly utilized than quantitative surveys; TB stigma is perceived to increase TB diagnostic delay and treatment noncompliance, although attempts to quantify its impact have produced mixed results; and interventions exist that may reduce TB stigma.

Future research should continue to characterize TB stigma in different populations; use validated survey instruments to quantify the impact of TB stigma on TB diagnostic delay, treatment compliance, and morbidity and mortality; and develop additional TB stigma-reduction strategies.

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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.[1] Stigma, which is shaped and promulgated by institutional and community norms and interpersonal attitudes, is a social determinant of health.[2] Stigma is a process that begins when a particular trait or characteristic of an individual or group is identified as being undesirable or disvalued.[3] 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.[4] These attitudes produce a set of behaviors that include hiding the stigmatized trait, withdrawing from interpersonal relationships, or increasing risky behavior.[5,6] 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.[7,8] 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.[3,9]

Stigmatization is a complex process involving institutions, communities, and inter- and intrapersonal 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.[2,10] 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.[11,12] Substantially less study has been conducted on the mechanisms through which stigma impacts the health of individuals at risk for or infected with tuberculosis (TB).

In this article, we review the available literature on TB stigma. Our goal was to identify the causes of TB stigma and to assess the impact of stigma on TB diagnosis and treatment. We identified three themes in the existing literature on TB stigma: (*1*) studies that characterize and measure TB stigma, (*2*) studies that explore the effect of TB stigma on TB diagnosis and treatment, and (*3*) studies that describe interventions to reduce TB stigma and the impact of these interventions on TB diagnosis and treatment. We also considered the gaps in existing research on stigma and the TB pandemic, and assessed potential interventions to reduce the health impact of TB stigma.

METHODS

Search strategy

Using the terms "tuberculosis AND stigma," "tuberculosis AND stigmatization," "tuberculosis AND stigmatized," "tuberculosis AND stigmatizing," "TB AND stigma," "TB AND stigmatization," "TB AND stigmatized," and "TB AND stigmatizing," we searched PubMed for articles addressing TB stigma. We reviewed the reference sections of identified articles to locate additional publications not found in our initial search.

We reviewed each article, noting its date of publication, geographic location, study type, use of qualitative and/or quantitative methods, and key results and conclusions. We then assigned it to one of three mutually exclusive content categories, based on the authors' primary focus. The first category involved articles characterizing and measuring TB stigma, including articles identifying the causes and socioeconomic consequences of TB stigma. This category also included articles reporting on the development or evaluation of TB assessment tools and articles using qualitative or quantitative techniques to measure TB stigma in various populations. The second category included articles focusing on the theoretical and empirical connections between TB stigma and TB diagnosis and treatment. The third category included articles on interventions to reduce TB stigma and the impact of such reductions on TB diagnostic delay and treatment compliance. We excluded articles that did not fit into these categories or were not in English.

RESULTS

The literature review yielded 168 articles (Figure 1), 159 from the PubMed search and nine from the reference sections of identified articles. Of the 168 articles, 69 were excluded from this review. The most common reasons for exclusion included focus on the effects of HIV stigma on TB diagnosis and treatment (five articles), one or more of the authors was affiliated with TB-related institutions although the article was not on TB (13 articles), and the article was not in English (six articles). Of the 99 articles included, the majority (52 articles) characterized or measured TB stigma. A smaller number (38 articles) examined the impact of TB stigma on TB diagnosis and treatment. Relatively few (nine articles) described interventions to reduce TB stigma. Included studies were published between 1976 and 2009. Geographically, most studies involved Asia/Pacific Islands (33%) or Africa/Middle East (28%) compared with multiregional (17%), North America (9%), Latin/South America (8%), or Europe/Russia (4%).

Characterizing and measuring TB stigma

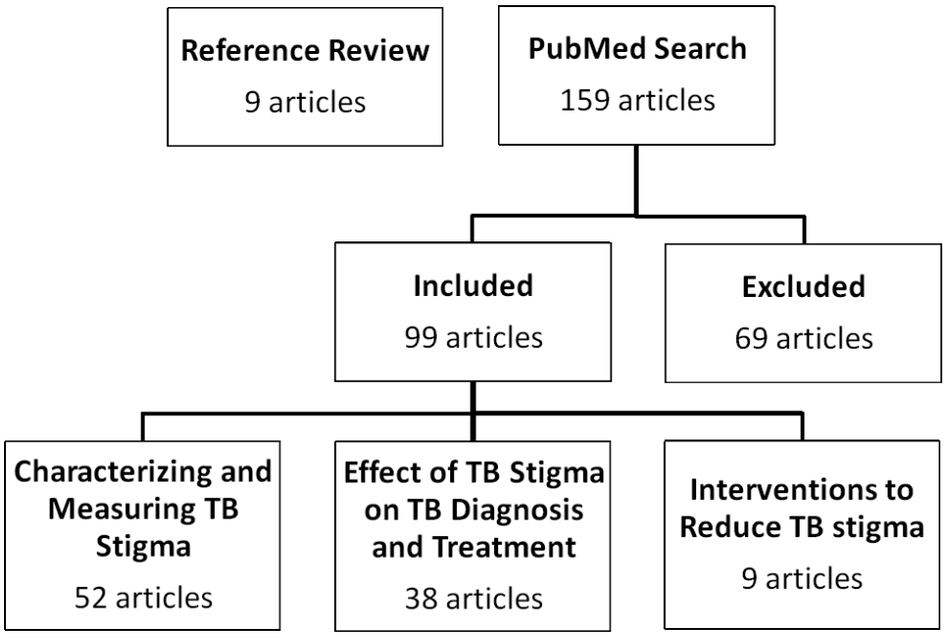
Characterizing TB stigma. Understanding the origins of TB stigma is integral to reducing its impact on health. Using surveys, focus groups, and unstructured and focused interviews, a number of studies have explored the causes of TB stigma. Although there is geographic and cultural variation in the explanations for why TB is stigmatized, most authors identify the perceived contagiousness of TB as a leading cause of stigmatization.[13–22] Lack of knowledge regarding routes of TB transmission may also contribute to TB stigma.[23–26] Even among people with relatively good knowledge of TB transmission and transmissibility, however, the perceived risk of transmission can lead to stigmatization and isolation of individuals with TB.[27]

In areas of high HIV prevalence, where HIV and TB co-infection is common, the link between the two diseases has contributed to the stigmatization of TB.[28–34] TB is perceived as a marker for HIV positivity; therefore, HIV-associated stigma is transferred to TB-infected individuals.[35] Other causes of TB stigma include the perceived associations of TB with malnutrition,[36] poverty,[37] being foreign-born,[38] and low social class.[14] As with HIV, TB is stigmatized in this context because it is linked to other disvalued characteristics, which themselves are also social determinants of health. Finally, TB stigma may occur because an affected individual's community believes he or she must have done something to deserve to be infected.[19,27] This judgment may reflect the belief that TB is divine punishment for a moral or personal failing, which then licenses stigmatization.[14]

TB-infected individuals perceive themselves to be at risk for a number of stigma-related social and economic consequences. Because the most common result of TB stigma is isolation from other members of the community, TB infection can substantially impact economic opportunities. For example, the stigmatization of TB in Ghana has led to the prohibition of TB-infected individuals from selling goods in public markets and attending community events.[17] When an individual dies of TB, fear of TB stigma can lead families to hide the cause of death from other members of the community, even when such information might be useful in targeted TB screening.[39] Similarly, fear of TB stigma can lead infected individuals to hide their TB status from their families.[16,22] TB stigma also results in a sense of shame or guilt, leading to self-isolation as TB-infected individuals internalize their community's negative judgments about the disease.[37,40]

The socioeconomic consequences of TB stigma differ in men and women. In general, men are more concerned with the impact of TB stigma on their economic prospects, which include job loss and reduced income.[41–43] While TB stigma also affects their financial

Figure 1. Flow diagram of literature search on TB and stigmatization (*n*=168)



TB = tuberculosis

status, women tend to be more concerned that TB stigma will adversely impact their marriage prospects or that their families will shun them.[43–46] In some areas, however, men are more worried than women about the effect of TB stigma on their marriage opportunities.[46] Married women with children may fear that their husbands will reject them if they are diagnosed with TB and that they will be unable to care for their families.[43,47]

Measuring TB stigma. In addition to characterizing the causes of TB stigma, several authors have attempted to capture the prevalence of perceived, internalized, and actually experienced TB stigma and to compare the extent of TB stigma in different geographic regions. Many studies use qualitative instruments (e.g., in-depth interviews and focus groups) to gauge the degree to which TB is seen as stigmatized in a community. Considerable geographic variability exists in the perceived prevalence of TB stigma, with 27% to 80% of at-risk individuals reporting that TB is stigmatized in their communities.[48–50] TB stigma is felt more strongly in certain subpopulations, including women, refugees, individuals from rural areas, and people with lower education levels.[51–54] Discordance between perceived and actual experiences of stigmatization among at-risk and TB-infected individuals has also been documented. For example, in one study of at-risk, TB-negative Mexican Americans, half the participants believed that someone with TB would experience social isolation. In a demographically similar comparison population of individuals with documented TB infection, none had actually experienced social isolation.[38]

To assist in better understanding the prevalence of TB stigma, several authors have developed standardized TB stigma assessment tools. For example, Macq et al. introduced and validated a quantitative TB stigma questionnaire based on surveys designed to measure mental health stigma.[55] Their instrument captures both perceived and internalized TB stigma. Van Rie et al. developed a comprehensive TB stigma assessment scale covering domains such as fear of disease transmission, attitudes toward TB, association of TB with shame and judgment, and disclosure of disease status. Their scale has good internal consistency and reasonable test-retest reliability.[56] Although measuring any type of stigma is a challenge, a number of instruments have been developed to quantify the stigmatization of other conditions; these may also be adapted to measure perceived and internalized TB stigma.[57]

The effects of TB stigma on TB diagnosis and treatment

It is a widely held view that TB stigma contributes to delays in TB diagnosis and negatively impacts treatment compliance. A number of qualitative studies report that community members without TB, individuals with TB, and health-care providers who treat TB perceive TB stigma to be a barrier to prompt diagnosis of the disease.[58–62] At-risk individuals report that fear of TB stigma and the social and economic impact of stigma affects their willingness to undergo TB screening and to seek medical care after the onset of symptoms associated with TB.[63–65] Individuals with TB-like symptoms may first attempt to see private physicians so as to avoid TB stigma. Because private clinics typically have longer waits for appointments, this may translate to diagnostic delay and increased financial costs for patients.[66]

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.[67–70] Balasubramanian et al., however, found that although women in south India felt TB stigma more strongly than men, they were more likely to access health services.[71] Only one study recommended considering the impact of TB stigma on children when designing a TB screening program.[72]

Individuals with TB and their health-care providers also identify TB stigma as a cause of noncompletion of treatment.[73–77] Even after the start of therapy, concern about being identified as having TB and suffering the consequences of TB stigma may lead individuals to drop out of treatment programs. TB stigma has also been raised as a potential barrier to home- and work-based direct observational therapy (DOT), given that the presence of TB nurses might mark a person as infected.[78,79] Collectively, these studies suggest that at-risk communities and infected individuals perceive that TB stigma causes diagnostic delay and can lead to treatment noncompliance.

Attempts to quantify the contribution of TB stigma to diagnostic delay and treatment adherence, however, have produced mixed results. Kiwuwa and colleagues surveyed newly diagnosed TB patients in Uganda to assess factors related to the duration of time between the onset of symptoms and their first health-care visit. Predictors of delays of more than two weeks included daily alcohol use and subsistence farming, but not perceived TB stigma.[80] Similarly, TB stigma was not a predictor of significant delay between the onset of symptoms and seeking health care in Zambia or Syria.[81,82] In a study in Cameroon, Cambanis et al. found that perceived TB stigma was a significant predictor

of delays of more than four weeks, but the association disappeared with multivariate adjustment.[83] The impact of TB stigma on treatment compliance is also unclear. Woith and Larson found that, among Russians with active pulmonary TB, TB stigma was actually a predictor of treatment adherence.[84] In contrast, TB stigma was the most common motivation cited by HIV-infected Tanzanian patients who did not complete isoniazid preventive therapy.[85] Perceived TB stigma was also associated with noncompliance among Pakistani patients on DOT.[86]

Interventions to reduce TB stigma

Relatively few interventions have been introduced to reduce TB stigma, and few investigators have measured whether reductions in TB stigma decrease diagnostic delay or improve treatment compliance. No studies have assessed whether decreased TB stigma affects TB morbidity or mortality. Several authors have suggested that TB education/support programs, aimed at healthcare providers, individuals with TB, and at-risk community members, may reduce TB stigma, although little data exist on the effectiveness of these strategies.[87–89] Rajeswari and colleagues found that perceived TB stigma did not change in a surveyed population of TB-infected individuals in south India after completion of a DOT program with an educational component.[90]

As is true with other stigmatized conditions including HIV and mental illness, the most promising approach to reducing TB stigma may be to empower individuals with TB to resist stigmatizing external judgments, while working to change community norms about the disease.[2,91,92] For example, several studies have assessed the impact of TB clubs, particularly in Africa, on perceived TB stigma and treatment compliance.[93,94] These clubs, which typically consist of three to 10 individuals with TB, are organized by TB health workers and meet weekly to offer social support, arrange transportation to clinics, encourage treatment adherence, and monitor for treatment side effects.[93] They also encourage TB screening among other at-risk community members.[95]

Using a focus group-based approach, Demissie et al. have shown that individuals enrolled in TB clubs perceive themselves to be less affected by TB stigma than those receiving standard, clinic-run treatment.[94] A likely explanation is that TB clubs reduce social isolation and offer an environment in which TB status is highly visible and accepted. Demissie et al. also found that the presence of TB clubs in the broader community appears to reduce negative attitudes and practices concerning TB. In their study, individuals enrolled in Ethiopian TB clubs were more likely to complete TB treatment than TB-infected patients with similar sociodemographic characteristics in areas without TB clubs.

Macq and colleagues conducted a similar study on the effect of TB clubs on TB stigma in rural Nicaragua.[96] Compared with TB patients in municipalities without TB clubs, patients enrolled in TB clubs had a small but significant reduction in internalized TB stigma, as measured on a 10-question stigma assessment scale. There was, however, no difference in treatment completion rates between the two populations. Finally, Liefooghe and colleagues found that TB-positive Pakistani patients randomized to receive counseling to strengthen their perceived self-efficacy, which is often adversely impacted by TB stigma, had a 13% reduction in treatment defaulting compared with patients who did not receive counseling. The intervention was even more beneficial for women, especially housewives, among whom the reduction in treatment defaulting was 25%.[97]

DISCUSSION

Stigmatization is a social determinant of health. Stigma occurs because of community and institutional norms about undesirable or disvalued behaviors or characteristics. When diseases are stigmatized, the fear of the social and economic consequences following diagnosis can make individuals reluctant to seek and complete medical care. The structure of a community's beliefs and norms about a disease and the resulting stigma can, therefore, substantially impact health. In this article, we systematically reviewed the literature on TB stigma, including studies that characterized and measured TB stigma; assessed its impact on TB diagnosis and treatment; and explored interventions to reduce TB stigma.

The most common cause of TB stigma is the perceived risk of transmission from TB-infected individuals to susceptible community members. Depending on geographic region, however, TB is also stigmatized because of its associations with HIV, poverty, low social class, malnutrition, or disreputable behavior. TB stigma has a more significant impact on women and poor or less-educated community members, which is especially concerning given that these groups are often at higher risk for health disparities. TB stigma may, therefore, worsen preexisting gender- and class-based health disparities.

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. In general, however, health-care providers and at-risk community members perceive that TB stigma leads to TB diagnostic delay and treatment noncompletion. Some interventions, particularly TB clubs, have been shown to decrease TB stigma and improve TB treatment adherence. However, there are no studies that address whether reductions in TB stigma correspond with improved TB morbidity or mortality. TB clubs may help TB-positive individuals resist stigmatization, and they may also change community norms about TB by increasing the visibility of the disease.

Limitations

While several clear themes emerged from our literature review, it is important to note its limitations. First, although stigma is conceptually different from related experiences, such as discrimination, bias, and prejudice, not all authors make these distinctions in the same way. Given our narrowly tailored search strategy, it is possible that we may have missed articles relevant to TB stigma because they were categorized as involving TB discrimination, bias, or prejudice. Second, because we focused on the biomedical literature on TB stigma as found via PubMed and through review of the reference sections of identified articles, we may have missed articles on TB stigma from sociological or psychological resources not indexed in PubMed.

CONCLUSIONS

Based on our review of the available literature on TB stigma, we identified several areas where additional research is needed. Figure 2 summarizes these recommendations, which are explained more fully in the following sections.

Recommendations for characterizing TB stigma

The origins and consequences of TB stigma have been well characterized in multiple geographic regions. Because the socioeconomic impact of TB stigma varies among different groups (e.g., men and women), it is important to continue to investigate the effects of TB stigma in other subpopulations including adolescents and individuals with latent TB. This information can be used to design and target interventions that specifically address the impact of TB stigma on a given group. For example, knowing that women are typically more concerned about the effect of TB stigma on their marriages can direct health-care providers to offer specific counseling and educational resources about partner notification. Because improved TB education has been proposed as a method of reducing TB stigma, it is important to determine whether knowledge of TB transmissibility and transmission routes actually correlates with TB stigma.

Recommendations for measuring TB stigma

The recent introduction and validation of two stigma assessment questionnaires is helpful in efforts to measure and track changes in TB stigma over time.[55,56] These instruments should be tested and validated among men and women, in multiple geographic locations, and in varied ethnic and cultural groups. Widespread adoption of one or more of them, supplemented with qualitative data, will allow better comparisons among studies. A common stigma assessment tool will

Figure 2. Summary of recommendations for additional research on TB stigma

Target area	*Recommendation*
Characterizing TB stigma	• Investigate TB stigma in other subpopulations including adolescents and migrants • Investigate whether education about TB transmission routes correlates with the persistence of TB stigma
Measuring TB stigma	• Validate a TB stigma assessment tool in men and women, in multiple geographic locations, and in varied ethnic and cultural groups
TB stigma and TB diagnosis/ treatment	• Continue to investigate whether TB stigma is associated with delay between the onset of TB-like symptoms and presentation to a health-care provider • Determine whether TB stigma is associated with a delay in TB treatment completion rates and increased TB morbidity/mortality
Reducing TB stigma	• Continue to investigate the impact of TB clubs on TB stigma • Assess whether reducing TB stigma leads to shorter time to TB diagnosis, treatment compliance, and improved TB morbidity and morality • Develop and investigate other interventions, including introducing default screening policies in high TB prevalence areas, to reduce TB stigma

TB = tuberculosis

also assist in targeting interventions toward particular aspects of TB stigma (e.g., self-isolation or hiding one's TB status) as identified using these instruments.

Recommendations for studying the effects of TB stigma on TB diagnosis and treatment

An important challenge for future research on TB stigma is to better assess the impact of TB stigma on TB diagnostic delay and treatment compliance. While TB stigma is perceived to have a negative impact on prompt TB diagnosis and treatment completion rates, studies that formally assessed the effect of TB stigma have had mixed findings. The availability of quantitative survey instruments should allow researchers to determine whether TB stigma is associated with delay between the onset of TB-like symptoms and presentation to a health-care provider and whether a higher degree of TB stigma is associated with longer delay. Similar research should examine the impact of TB stigma on TB treatment completion rates.

Recommendations for interventions to reduce TB stigma

Although community and institutional norms ultimately mediate stigmatization, wide-scale interventions to change these norms can be difficult. A more promising approach appears to be helping TB-infected individuals resist TB stigma, particularly through TB clubs. Additional studies in regions where TB stigma is common should be conducted to validate the impact of TB clubs on TB stigma and to assess whether a reduction in TB stigma leads to improved time to TB diagnosis, treatment compliance, and, ultimately, reduced TB morbidity and mortality. This research should employ one of the standardized TB stigma measurement tools to track changes in TB stigma over time and to correlate changes in individual- and community-level TB stigma with diagnostic delay and treatment completion. Assessing TB stigma among individuals at risk for TB before and after the introduction of TB clubs can also help determine whether the increased visibility of TB-infected individuals changes broader norms about the disease. Finally, it is essential to continue to develop other interventions—for example, counseling TB-infected patients or introducing default screening policies in high TB prevalence areas—to reduce TB stigma.

It is also important to supplement this bottom-up approach to reducing TB stigma with an assessment of interventions designed to directly address stigmatizing community norms about TB. While greater education about the cause and routes of transmission of TB has been proposed as a method for reducing TB stigma, more research is required to assess whether simply providing more information about TB can change these norms. Studies from the HIV literature suggest that widespread educational efforts have had minimal effect on HIV knowledge and only a small effect on stigmatization of that disease.[98,99] It would, however, be useful to assess whether interventions known to reduce HIV/AIDS stigma have any effect on TB diagnosis and treatment.

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