Social impact of tuberculosis in southern Thailand: views from patients, care providers and the community

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SUMMARY

BACKGROUND: There is growing recognition that attention to social and behavioral factors in tuberculosis (TB) control needs to complement biomedical emphasis on better drugs, vaccines and new diagnostic tools.

METHODS: Using qualitative methods, we conducted 10 focus groups and seven individual interviews to explore how TB is perceived or experienced in southern Thailand. Participants included male and female patients with TB, patients with AIDS, TB care providers, family members of patients with TB, religious leaders (Buddhist and Muslim), and unaffected community members.

RESULTS: Responses informed two conceptual frameworks on stigma and social support. The first model dichotomized the meaning of TB into ‘good’ and ‘bad’ factors related to social support and stigma, respectively. The second model identified three themes—disease severity, religion, and knowledge of TB—linked to either stigma, social support, or both.

CONCLUSION: Social support as a facilitator and stigma as a barrier are diametrically opposed concepts that need to inform TB care and treatment. Interventions to reduce stigma and promote social support at the patient, household, community, and health care system levels should be part of future efforts in the control of TB in Thailand.

KEY WORDS: TB; stigma; social support; HIV; Thailand

THE WORLD HEALTH ORGANIZATION (WHO) estimates that nearly 3 million cases and 700,000 deaths occur annually from Mycobacterium tuberculosis in South-east Asia.1 Thailand is one of five countries in the region that account for 95% of the caseload and deaths, and is one of 22 countries that contribute 80% of global incident tuberculosis (TB) cases.1 The fight against TB in Thailand has been hampered by multidrug-resistant tuberculosis (MDR-TB)—defined as resistance to at least isoniazid (INH) and rifampicin (RMP)—at a rate of 2.9% primary MDR-TB, and the impact of the HIV epidemic (7% HIV positivity rate among patients with TB). Unlike the acquired immune-deficiency syndrome (AIDS), TB can be cured when standard treatment regimens are provided. TB, like AIDS, is a social disease, and prevails where poverty and lack of access to care are prevalent.

Studies have explored social issues affecting the lives of patients with TB. Stigma is a complex social construct that can be perceived and/or experienced, and has been documented in many cultures, including Thailand.2–15 Felt and experienced stigma has been linked to negative patient experiences in different social settings.2,4,16 Social support is essentially the opposite of stigma, with trust and openness forming the basis of interaction between patients and their environment. For patients with TB, their experience and relationship with their social network may thus have an impact on their care-seeking behavior and adherence to treatment.10,12,15,17 As part of a larger project to develop scales measuring TB and AIDS stigma among patients with TB in southern Thailand, we conducted a qualitative study to explore patients’, care providers’, and community members’ perceptions and experiences to better understand the socio-cultural dynamic regarding TB in southern Thailand.

METHODS

Study participants
Quota sampling, a non-random sampling strategy,18 was used to select 82 adult (aged ≥18 years) participants for 10 focus groups (FGs) (5–10 persons per FG). To capture a breadth of views, we conducted four FGs with TB patients treated in public sector clinics, two FGs with household members of patients with...
TB, two FGs with unaffected community members, one FG with patients with AIDS, and one FG with health care workers (HCWs) from the public sector. We further sub-stratified the FGs by sex (male and female), religion (Buddhist and Muslim), or both, as women may be reluctant to voice their opinions in front of men, and because of the ongoing strife between the Buddhist majority and the Muslim minority in southern Thailand. In addition to the FGs, we conducted individual, face-to-face interviews with two physicians and one patient from the private sector to gain their perspectives, as well as with four religious leaders (two Buddhist and two Muslim) because of their prominence in the social hierarchy of southern Thai culture.

To ensure participation from a broad social context, FG members were from different socio-economic backgrounds and resided in 10 districts of the provinces of Songkhla, Yala, and Pattani in southern Thailand. Except for the FG with AIDS patients (recruited from one hospital in the Ranot district in Songkhla Province) and HCWs (recruited from TB centers in four districts in the provinces of Pattani and Yala), most FG participants were strangers to one another. Individual interview participants were of higher socio-economic status, but were recruited from the same three provinces.

All participants provided written informed consent and received a modest financial incentive. The Institutional Review Boards of The University of North Carolina at Chapel Hill (UNC-CH) and Prince of Songkla University approved the study.

Data collection and analysis

To encourage discussion about what it is like for a person to live with TB or take care of a patient with TB, two open-ended questions were asked at the start, and one open-ended question at the end of each FG or individual interview: ‘When thinking about TB, what is the first thing that comes to your mind?’ ‘How are persons with TB treated differently than persons with other diseases?’ and ‘What is the best and worst experience you have had?’ (patients with TB) or ‘What is your best and worst experience with someone with TB?’ (other participants).

FGs and individual interviews were conducted in Thai or local Malayu. Each FG session had a moderator/interviewer to facilitate the discussion and two research assistants to take notes and audiotape the sessions. During the individual interviews, only the interviewer was present and sessions were audiotaped. Audiotapes were transcribed verbatim, a codebook was developed, and a thematic content analysis was performed by two Thai investigators to identify main themes and their sub-themes. A summary was translated into English and discussed with the US team of authors at a meeting in Thailand, resulting in a final set of themes.

RESULTS

Themes generated from responses to the first two open-ended questions were used to develop conceptual frameworks (Figures 1 and 2) exploring two social outcomes: stigma and social support. Although stigma was not directly stated by participants, the Thai research team identified terms that come close to the meaning of stigma: tra-bahb, and tee-tra, which translate into English as ‘branded with sin’ and ‘stamped’, respectively. Other linguistic cues for stigma included perceiving a person with TB as ‘dirty,’ being ‘disgusted’ or ‘annoyed’ by someone with TB, or feeling ‘isolated’ and ‘separated’ as a TB patient.

TB perspectives or experiences

For the question ‘When thinking about TB, what is the first thing that comes to mind?’, the main theme

![Figure 1](image1.png)  
**Figure 1** TB perspectives and experiences affecting stigma or social support. TB = tuberculosis.

![Figure 2](image2.png)  
**Figure 2** Factors associated with the social outcome of TB. Thematic associations from interviews are represented by solid lines; dashed lines represent possible associations. TB = tuberculosis; HIV = human immunodeficiency virus; AIDS = acquired immune-deficiency syndrome.
was being a ‘bad’ or ‘good’ patient. Sub-themes reflected different characteristics of being a ‘bad’ or ‘good’ patient, and how this related to the social consequences of being or feeling stigmatized, or receiving social support (Figure 1).

Symptoms and behaviors exhibited by a patient with TB, including coughing, smoking and looking like a patient with AIDS, were associated with being a ‘bad’ TB patient. Patients with TB were blamed for being ‘bad’ patients by some physicians. A private sector physician denied that patients with TB face stigmatization, but at the same time blamed patients for their non-adherence:

Most patients do not face stigmatization from the society . . . The problem is that patients do not regularly take medication. . . . If they do not regularly take medicines, I will not allow them to visit the clinic again.

—Private doctor

Patients were categorized as those who conceal and those who reveal their TB, with the former being less accepted and tolerated, and therefore more stigmatized:

There are two groups of patients. The first group is those who reveal their disease to society . . . This is better than the other group who try to conceal their illness. At least people in the first group allow those around them to know beforehand and can interact with them carefully. The other group is very risky because of their concealment.

—Buddhist religious leader

In some circumstances, stigmatization arose from individuals’ misperceptions of the etiology of TB. A Buddhist religious leader said ‘TB is caused by allergies related to weather, dust, and dirt.’ Others expressed that ‘people who smoke or live unhealthy lifestyles are the ones who get TB; or ‘pretty or attractive people should not get TB, whereas those who have dark complexities do get TB’.

Factors associated with the social outcome of TB

Responses to the question on how TB is different from other diseases identified three main themes—TB symptoms, religion, and TB knowledge—associated with stigmatizing behaviors/attitudes and/or social support (Figure 2).

The first main theme concerned severity of symptoms or disease; TB patients with more severe symptoms experienced greater stigma:

If TB status is not very severe—patients only have a bit of a cough without the blood and sputum—I have not observed any associated stigma. However, if they have lot of sputum and spit very often, people will stigmatize them.

—Muslim religious leader

Because people may conflate TB with AIDS due to overlapping clinical presentation, the link between TB and AIDS can lead to stigma:

I think of AIDS because they are skinny . . . I suspect whether those patients also have the AIDS infection. I want them to go to the TB center.

—Buddhist household member

On the other hand, TB may be distinguished from AIDS as being less severe, and therefore moral judgment is more likely to be reserved for patients with AIDS:

Using the phrase ‘mark of sin’ might not be an accurate description since TB is not caused by promiscuous behavior. It is not the same as AIDS.

—Private doctor

Religion, the second main theme, also influenced attitudes about patients with TB. Buddhists expressed more stigmatizing attitudes towards patients with TB compared to Muslims, who tended to be more supportive:

Patients with TB are often stigmatized by people around them . . . However, this is not applicable to the Muslim people I have seen. Sometimes, relatives of Muslim patients are still in contact with patients. Even children sometimes also contact patients.

—Private doctor

The third main theme, knowledge of TB, could lead to both social support and stigma. Increased knowledge about TB can contribute to a more positive outlook:

When I visited a doctor, I was educated in relation to the prevention of disease transmission, medication administration, and physiological change due to TB. I educated my relatives and people in my community that TB is not as severe as we first thought.

—Patient with TB, male, Muslim

Being less knowledgeable, however, may make a person more afraid to be around a patient with TB, thereby acting more stigmatizing:

Those who do know about TB, don’t want to have a close relationship with patients with TB. They also avoid sharing things with TB-infected patients.

—Unaffected community member

Having knowledge can create a fine balance between what can be considered stigmatizing as opposed to appropriately protecting oneself from disease exposure:

It is commonly known that we have to be careful not to contract TB when we are around patients with TB. I do not stigmatize patients with TB but I’m afraid of contracting this disease.

—Buddhist household member

Other dimensions included disclosure of TB diagnosis to immediate family members but keeping TB a secret from the community; and having to wear a mask in the clinic, with not wearing a mask symbolizing compassion. In the following quote, the various dimensions of social support and stigma merge, promoting improved adherence to medications:
My family and I are originally from Hat-Yai, so we know a lot of people in this city. If I wear a mask, they might realize I have TB even though I want to keep it secret . . . One day I met a staff member who works with patients with TB . . . This group of staff members didn't wear a mask when talking with me. This encouraged me to come in for medication. After that, I didn't care how other people treated me since my mom and family members treated me very well, I looked past the stigma from society.

—Female patient with TB, Buddhist

For the open-ended questions asking for best and worst experiences, respondents identified many negative consequences of having TB, including drug side effects, separation from the family, isolation, and effects of the disease on daily life. They also, however, expressed positive consequences of having TB, such as receiving good treatment and care, receiving social support, being more knowledgeable about TB, learning from other patients with TB with respect to treatment adherence, gaining strength to lead a healthier life, and having more faith in God.

DISCUSSION

The findings from this study provide insight into what leads to stigma, social support, or the intersection of these two types of social outcome from the perspectives of patients with TB, patients with AIDS, care providers (medical and household), religious leaders, and unaffected community members.

Stigma, the notion of being ‘stamped’ or ‘branded with sin’, caused patients with TB to be more secretive about their disease and prevented them from advocating for their health care, whereas social support aided patients in their adherence to treatment. Similar findings of stigma and social support have been documented in other cultures.10,12,13,15–17 Victim blaming is a dimension of stigma that takes different forms in multiple segments of society. Our findings support previous literature,20 and demonstrate that victim blaming by physicians can happen when they believe that barriers to treatment adherence are solely under patients’ control.

An unexpected finding was of religious differences associated with stigma and social support. We felt it was important to highlight this observation to contrast it with the stereotypical and pejorative discourse globally about Muslims and Islamic religion. It would be erroneous, however, to interpret from our findings that all Buddhists stigmatize and all Muslims support patients with TB in southern Thailand, which is why our conceptual framework in Figure 2 accounted for possible cross-associations between religion and the two social outcomes of stigma and social support.

Some limitations of this study should be noted. First, this study was part of a larger project to assess the content validity of items measuring TB and AIDS stigma, and the open-ended questions were only intended to encourage discussion about stigma rather than to statistically compare responses between the different sub-groups and individuals interviewed. Focus group and individual interview participants were purposefully selected as male, female, Buddhist, Muslim, patients with AIDS or TB, or HCWs, and no information on the other socio-economic or cultural characteristics of these participants was collected. The findings therefore have limited generalizability of the cultural and social processes underlying TB and AIDS stigma (or social support) in southern Thailand.

In conclusion, this study describes the relationship between perceptions of, and experiences in dealing with TB, and the diametrically opposed concepts of social support and stigma in southern Thailand. Supportive attitudes from household members and a nurturing and trusting health care setting are critical to issues of adherence and success of TB control. Implementation of interventions to reduce stigma, to highlight positive experiences of patients with TB, and to promote social support at multiple levels—patient, household, community, and the health care system—will be necessary to complement biomedical efforts in the control of TB in Thailand.

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References

CONTEXTE : On admet de plus en plus que l’attention portée aux facteurs sociaux et comportementaux dans la lutte antituberculeuse doit compléter l’insistance biomédicale concernant de meilleurs médicaments, des vaccins et de nouveaux outils de diagnostic.

MÉTHODES : En recourant à des méthodes qualitatives, nous avons mené 10 groupes focaux et sept interviews individuelles pour explorer la façon dont la tuberculose (TB) est perçue ou supportée au Sud de la Thaïlande. Les participants ont inclus des patients tuberculeux de sexe masculin et féminin, des patients atteints du syndrome de l’immunodéficience acquise (SIDA), des pourvoyeurs de soins pour la TB, les membres des familles de patients atteints de TB, des leaders religieux (Bouddhistes et Musulmans) ainsi que des membres de la collectivité non atteints par la maladie.

RÉSULTATS : Les réponses ont permis de former deux réseaux conceptuels sur la stigmatisation et le soutien social. Le premier modèle divisait de façon dichotomique la signification de la TB en facteurs ‘bon’ et ‘mauvais’ en relation respectivement avec le soutien social ou la stigmatisation. Le second modèle a identifié trois thèmes (gravité de la maladie, religion et connaissance de la TB) reliés soit à la stigmatisation, soit au soutien social, soit aux deux.

CONCLUSION : Le soutien social comme facilitateur et la stigmatisation comme barrière sont des concepts diamétralement opposés qui doivent intervenir dans les soins TB et le traitement. Les interventions visant à réduire la stigmatisation et à promouvoir le soutien social au niveau du patient, de la famille, de la collectivité et du système de soins de santé devraient faire partie des efforts futurs pour la lutte antituberculeuse en Thaïlande.

MARCO DE REFERENCIA : Cada vez se otorga mayor importancia a la atención de los factores sociales y de comportamiento en la lucha contra la tuberculosis (TB), como complemento al énfasis biomédico en mejores medicamentos, vacunas y nuevos métodos diagnósticos.

MÉTODOS : Se organizaron 10 grupos de discusión y siete entrevistas individuales utilizando métodos cualitativos, con el fin examinar la percepción y la experiencia de la TB en el sur de Tailandia. Participaron pacientes de ambos sexos con TB, pacientes con SIDA, proveedores de atención en TB, familiares de pacientes con TB, líderes religiosos (budistas y musulmanes) y otros miembros sanos de la comunidad.

RESULTADOS : Las respuestas se utilizaron para elaborar dos marcos conceptuales sobre las variables estigmatización y apoyo social. En el primer modelo se dicotomizó el significado de TB en factores ‘buenos’ relacionados con el apoyo social y ‘malos’ relacionados con la estigmatización. En el segundo modelo se definieron tres temas (gravidad de la enfermedad, religión y conocimiento sobre la TB) vinculados ya fuese con el estigma, con el apoyo social o con ambos.

CONCLUSIÓN : Dos conceptos diametralmente opuestos deben tenerse en cuenta en el manejo y el tratamiento de la TB: el apoyo social como facilitador y la estigmatización como obstáculo. Las futuras iniciativas en la lucha contra la TB en Tailandia deberán contar con intervenciones que busquen reducir la estigmatización y fomentar el apoyo social a escala del paciente, del hogar, de la comunidad y del sistema de atención de salud.