Clinical Ramifications of TB Stigma in Baguio City, Philippines

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ABSTRACT

Objective. Stigmatization due to a disease is a complex process, particularly in the case of tuberculosis (TB) in Baguio City, Philippines. This article reveals findings important to healthcare professionals in the outpatient setting. Complex aspects of stigma vary among people and healthcare professionals in different roles and settings, facilitating behavior that controls TB in some cases and spreads it in others.

Methods. With ethnographic and historical methods, Ladia analyzed a wide range of understandings of 36 healthcare providers and 14 persons affected by TB (PATB). These understandings shape clinical behavior with significant implications for patient outcomes and community health. TB treatment and control historically established concepts and behavioral patterns that have a significant bearing on public understanding today. Comparisons with national survey data supported the analysis.

Results and Conclusions. Sources of varied understandings of TB include the history of sanitaria, poverty, and incomplete dissemination of current scientific information. While some behavior related to stigma could benefit the health of PATB and their household members, the struggle against stigma leads to counterproductive behavior in a number of cases, sometimes spreading disease and sometimes resulting in unnecessary labor and expense. Healthcare providers can provide accurate, accessible, detailed information to address patients' problems.

Key Words: infectious disease, stigma, tuberculosis, Philippines

Introduction

The TB prevention and control program in the Philippines started in the 1900s, and transformations continue today, depending on funding, government policy, international programs, and scientific advances. Through the years, the inflow of financial resources and technical assistance from international sources has propelled efforts in combating the purported disease of poverty in specific directions. The longstanding stigma of the disease, however, counters public health endeavors in some ways.[1] Julia Keller writes of TB having an early, romantic image in the era[2] before it was scientifically understood as spread by germs.

The relationship of TB to germs increased tendencies toward stigmatization, which is still a powerful force in the Philippines and many parts of the world.[3] The classic conceptualization of stigma comes from the work of Goffman , "that attribute that is significantly discrediting."[4] His work and that of Parker and Aggleton, building on Foucault[5], proved useful in our analysis.[6] In this article, we present findings particularly useful for healthcare professionals in dealing with people affected by TB.

Some cultures downplay the stigma of TB by using less negative terms for the disease.[7,8] Nichter's study in the Philippines found that "weak-lungs" is used both by physicians and the lay population for a broad range of illnesses that include TB. As an ambiguous term, it is used to "call attention to a state of ill health linked to tuberculosis while deflecting attention from the stigma of this disease".[9] Such terms may lessen stigma; however, they confound the understanding of TB. Furthermore, while the disease may be cured, such terms may facilitate the persistence of a "spoiled identity," to use Goffman's phrase.[4]

Herek et al. argued: "When a disease is stigmatized, public health policy can help protect those who are ill from popular prejudice, or it can promote discrimination against them".[10] In this article, we show that in Baguio City, the sense of discrimination varies in relation to TB; thus, stigma results in some unexpected behavior that counters control of the disease.

Methods

Baguio City was a suitable study site for analyzing TB stigma because of its long history with infectious disease management including nearly a century of TB programs.[11,12,13] The first author of this article (MAJL) implemented a primarily qualitative study of the history and current status of TB control and prevention programs in the Philippines. The research methods included a review of the literature on TB control and prevention programs from late 1800s through the twentieth century, which reveals longstanding influences on stigma, the isolation of patients, and regimens of TB treatment and control.

The study includes interviews with a purposive sample of "TB patients," both from public and private health facilities in Baguio City. They included new sputum-positive patients who were at least 25 years of age, nine males and

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five females. They were recruited from a list of "TB patients" and "TB cases." To avoid contracting TB, the trained interviewers and MAJL took several recommended precautionary measures including interviewing only those who had taken TB medication for at least two months and therefore had a low probability of being contagious. MAJL asked persons affected by TB (PATB) to narrate their life course experience of illness by starting with a general question of how they began to recognize their disease. MAJL elicited their perceptions of how they acquired, treated, and endured TB, and in these discussions, MAJL explored factors that framed and informed their understandings and responses to the illness.

Among health providers, MAJL interviewed a purposive sample of 36 private and public health practitioners, representing a cross-section of the different types of health professionals (11 physicians, 12 nurses, seven midwives and six *barangay* health workers) using a semi-structured questionnaire.

A more detailed methodology was described in previous publication.[6]

Results

TB Control History

The review of the history of TB control and prevention (by MAJL), shows that as scientific understanding of TB progressed, the guidelines for the isolation of PATB changed over time, leaving a residue among the public of some of the earlier restrictions that are no longer in use as well as misunderstandings of the earlier and current methods for reducing exposure to the disease.[14,15] "There was nothing with which to cure TB" before World War II.[16] Baguio City was established as hill station to house American soldiers with TB[11,12,13] and for a century has been a site to test new TB treatments.

Official advice today continues to call for isolation of TB patients, but only until they are no longer infectious.[17] The sanitoria are closed, and the remaining sites for isolation are hospitals, other in-patient care facilities, and the home. The first two are beyond the budget of poor people, and their homes tend to be crowded, making isolation of a patient extremely difficult.

Profile of PATB

The 14 PATB have a median age of 57 years, mostly with no or low education, although some had attended vocational school and some had taken college courses (Table 1). They and their households have low incomes; they are unemployed or work at low-wage or temporary jobs. Those with jobs earn wages amounting to PhP 300 (approximately US$ 6) per day or they work for agencies paying them monthly salaries ranging from PhP 2,000 (approximately US$ 40) to PhP 6,000 (approximately US$ 120). The 2015 poverty threshold for a family of five of at least PhP 9,064 per month (approximately US$ 182) signifies that nearly all PATB live in poverty.[6,18]

Table 1. Socioeconomic Profile of 14 PATB

Age	range	28-80 years
	median	57 years
Educational attainment	generally none	
No schooling	or low	6 PATB
Some elementary		3 PATB
Elementary graduate		---
Some high school		1 PATB
High school graduate		---
Vocational courses		2 PATB
Some college		2 PATB
Occupation	none	5 PATB
	blue-collar job	9 PATB
Individual wages or monthly income		
Driver, vendor, gardener, carpenter		US$ 6 per day
Aide, laborer		US$ 40-120 per month

Contemporary TB stigma

The 1997 National Prevalence Survey conducted in the Philippines provides data that amplify the statements of many of the PATB in this research. The survey revealed that 50 percent of patients with TB-like symptoms do not seek medical help. This is partly due to stigma, according to Dr. Rodrigo Romulo, then president of the TB Clinic Foundation, who noted, "TB is often viewed as a shameful and unclean disease".[19]

Some PATB in Baguio City label their health condition not as TB but with less stigmatizing terms: *"ubo lang,"* a simple cough, or *"nakaro nga uyek,"* an intense cough:

"Hindi naman TB ito, ubo lang!" [This is not TB, it is simply a cough!] – Merlita, 65 years old

Ta napigsa ti uyek ko, isunga kunada nga TB. [My coughing is intense so people think it is TB.] – Rosendo, taxi driver

Other PATB, due to stigma, simply deny to most people that they are infected. Jaime, a laborer, said: "No one else knew. I never told my friends and office workers. I am aware of the stigma associated with TB so I never told them." Twenty-eight-year-old Juan likewise said: "*Walang nakakaalam, ikaw pa lang ang pinagsabihan ko*" ["Nobody knows; you are the only person whom I told."]

To discourage patients' sense of stigmatization, Mrs. Magdalena Hernandez, the nurse in charge of medications for "TB patients" in the TB DOTS clinic said that she told those in Baguio City not to be ashamed because their disease is curable. "It is better to be sick with TB ten times than to suffer from cancer," she would tell them during counseling sessions. In the eyes of patients, however, she had little standing for giving advice to patients because of her professional status. Eight of 14 PATB recommended that TB should be treated by a physician, not a nurse.

The stigma of TB brings some PATB to move about geographically more than usual to seek health services, and others to attempt to isolate themselves from contact with

many people.[6] Also, PATB often moved between public and private clinics and hospitals for economic reasons. Some study participants moved because of a change in economic status while others were private patients who accessed free medicines available at the public facilities. Thus, the private and public medical systems are interwoven and for analytic purposes, inseparable.

Isolation and TB: Varied Concepts among PATB

At present, many believe that TB requires complete social isolation of the patient, similarly to the days of the sanitoria.[6] TB transmission normally occurs when a contagious patient coughs, spreading numerous Mycobacterium tuberculosis organisms (tubercle bacilli, which are rod-shaped bacteria) in secretions from the lungs or larynx through the air to persons in the same enclosed space. The U.S. Centers for Disease Control and Prevention (CDC), however, states that TB transmission can be prevented by "limiting an infectious person's contact with other people… [and being] placed on treatment and kept isolated until they are no longer infectious."[17] "There is virtually no danger" of TB spreading through items touched by a patient, including "dishes, linens," and "most food products."[17] (Milk products from infected cattle can transmit the disease, however.)[20]

Some PATB in Baguio City do their best to isolate themselves completely from the general public and make major efforts to avoid household members as well with the aim of preventing the spread of TB. The following statements exemplify this finding:[6]

Haanak rinumrumuar… Haanak unay rumrummuar; baka adda maalisan. [I did not go out… I do not go out a lot; somebody might be infected.] – Nelson, gardener

Haanak rumrummuar ditoy balay. Adda ac lang ditoy kwarto. Haanak makisasao. [I do not go out of the house. I am always in my room. I do not talk to anyone.] - Merlita, 65 years old

The perception that sharing utensils is a mode of TB transmission is partly reinforced by healthcare providers according to some PATB; for example:[6]

Kuna ni Doctora Magdalena idi, ilasin diay panganan na, diay usaren na, haan nga agkaiwara. [According to Doctor Magdalena, separate his eating utensils, his things; do not leave them lying around.] - Salvador, 57 years old

On the other hand, several PATB perceive no stigma and they demonstrate this perception by pointing out that their utensils are not segregated. For example, Rosa, a 58-year old housekeeper said, in Tagalog, "*Hindi naman hiwalay yung pinggan ko sa kanila!"* (My plate is not segregated from theirs! [referring to her employer's family])

Surveys conducted in the Philippines reveal that many household members still segregate the eating paraphernalia of relatives with TB. Over 72 percent of people believe that sharing utensils facilitates transmission of TB.[21,22,23] In a study of 172 Filipinos, 51 percent of respondents who separated kitchen utensils of PATB from those of other household members said that they had learned to do so from health center personnel.[7, 19]

Rosa is a participant in this research whose views were common among PATB. She narrates how she acquired TB and how she interacts with her immediate family and neighbors:[6]

"Namatay ang nanay ko dahil sa sakit na TB. Maaaring namana ko ito sa kanya… Siguro, namana rin niya sa aking lolo at lola. Sana nga hindi namana ng mga anak ko dahil mahal ang gamot.

*Yung mga anak ko, normal naman ang trato nila sa akin. Yung panganay ko, yung anak niyang bunso ay nagka-*primary complex. *Niloko niya akong nahawa ko raw yung anak niya. Pero pinapaalaga naman niya sa akin. Itong iba ko pang apo ay may* primary complex *pero sabi ng mga anak ko na normal lang daw na magka-*primary complex *yung mga anak nila. Sabi nila, normal daw. Ako pa nga ang nag-aalaga sa mga anak nila.*

Noong una akong maospital, sinabi sa aking humiwalay, eh sinong mag-aalaga doon sa mga maliliit kong anak? Hindi naman humihiwalay yung mga anak ko sa akin. Kahit sa pagtulog, tumatabi naman yung mga anak at apo ko. Hindi naman hiwalay yung pinggan ko sa kanila.

Yung isa pang sinabi sa akin, bawal tumabi sa maraming pasyente at magkakahawaan. Yan ang sinunod ko.

Sabi ng doctor na nakakahawa ang sakit na TB kaya hindi ako masyadong nakikiusap sa ibang tao. Kapag pinapansin nila ako, ngumingiti lang ako.

Wala namang sinasabi ang mga kapitbahay namin. Normal ang pakikitungo nila sa akin. Kahit noong nagtitinda ako ng barbecue *eh bumibili naman sila sa akin… Hindi naman ilag ang mga kapitbahay ko, lagi nila akong kinukumusta."*

["My mom died of TB. Maybe I inherited it from her… Maybe she herself inherited it from my grandfather and grandmother. Hopefully, my children did not inherit it (from me) because medication is expensive.

My children treat me as normal. The youngest child of my eldest had primary complex [a type of TB]. He joked that I infected their child. But then he still asks me to take care of his child. My other grandchildren have primary complex as well but according to my children, it is normal for their children to have primary complex. They say that it is normal. I even take care of their children.

The first time I had been in the hospital, I was advised to isolate myself, but who would take care of my small children? Neither did my children stay away from me. Even at night, my children and my grandchildren still sleep beside me. My plate for eating is not separated from theirs either.

I was also advised to stay away from many patients as contagion may arise. That I heeded.

The doctor said that TB is contagious so I refrained from talking to other people. When they acknowledge me, I simply smile.

My neighbors are not talking about it. They interact with me in a normal way. They used to buy barbecue when I was still selling it… My neighbors are not aloof either; they always ask how I am doing."]

Rosa's family, old and young generations alike, had been afflicted with TB or primary complex, an asymptomatic type of TB infection except for a cough and swollen lymph nodes affecting mostly children. Suffering from TB or primary complex is a normal way of life to Rosa and her children. While she was advised to isolate herself to avoid transmission of TB, she still feels responsible for the care of her small children. She sleeps beside them and her grandchildren. She does not isolate herself from her family members, but she heeds the advice when it comes to non-kin, including other patients, and for the same reason, she avoids talking to her neighbors. She perceives an absence of stigmatization because her family and neighbors do not avoid her and express concern for her.[6]

Many PATB seek private care to avoid stigma, but they lack the funds to complete treatment. Private practitioners, however, do not acknowledge TB stigma as a problem for their patients.[6] Healthcare providers often expect that if stigma is troubling, PATB will raise the issue during the clinic visit; however, it should be noted that "experience with stigma is not something that people tend to discuss readily in a society that upholds smooth social interaction".[24] It is not surprising that doctors do not hear about stigma from their patients.

When PATB treated in private practice run out of money, they go to public facilities such as the TB DOTS clinics. Having taken medication, though, they will no longer be smear positive, and thus will no longer qualify enrollment to receive free medication. In other cases, PATB remain private patients and access free medicines available at the public facilities. This situation poses a problem in both individual and public health.

Discussion and Conclusion

Research on the experience of PATB, their healthcare providers, their households, and the general population of Baguio City reveals some key insights. This analysis finds a social and cultural process in which people create different realities about TB and then live in very different ways, while prevention and control of the disease remains a challenge. Healthcare providers can improve the prevention and control of TB by addressing some aspects of this complex situation.

Because of misunderstandings about isolation and TB, healthcare providers need to provide clearer and more detailed instructions to PATB and their families. If relying on a nurse for this purpose, the doctor needs to make it clear that the nurse is trained and authoritative on TB control. Instructions need to include the thorough washing of eating utensils without a requirement of their segregation.

Denial of their health condition impedes PATB from seeking help and treatment in a timely way. Healthcare providers can provide guidance ensuring that PATB understand that they have the disease and the requirements for treatment. Guidelines must be provided for different stages of treatment, for sleeping arrangements and other close contact situations, and for exposure in public, on the job, and at home.

Private healthcare providers need to counsel patients on the cost of treatment for the entire trajectory of treatment and coach those who cannot afford it to go immediately to public clinics. In case of a decline in income that makes private treatment no longer affordable, access needs to be extended by public clinics. In addition, public clinics need to increase their accessibility in recognition of stigma and reconfigure their clinic design and service provision to allow PATB to avoid stigma. Uneven distribution of contemporary scientific knowledge about TB and the varying weight of stigma on different PATB have resulted in complex and contradictory patterns of conduct and health-seeking behavior that too often ensure the continuing transmission of the disease. Healthcare providers cannot solve all these problems, but they can make a major contribution to improving TB control among those in treatment for the disease.

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