

# Attitudes regarding tuberculosis among Samoans

PETER LEIATAUA AHCHING<sup>\*</sup>

MERINA SAPOLU<sup>\*\*</sup>

MILI SAMIFUA<sup>\*\*\*</sup>

SEIJI YAMADA<sup>\*\*\*\*</sup>

## Abstract

The research reported here examines knowledge, attitudes, and practices related to tuberculosis (TB) among Samoan immigrants through the use of a focus group.

Samoan health workers to discuss participants' explanatory models regarding TB convened a focus group of eight Samoans living in Hawaii.

The participants expressed a belief in the extreme contagiousness of TB. This leads to social stigma and isolation. Most agreed that biomedical treatment is necessary. Traditional herbal medicine was seen as adjunct to biomedical treatment.

Focus group participants were found to subscribe to largely biomedical explanatory models regarding TB, but belief in traditional medicine also persists. TB was believed to be more transmissible than it actually is. TB continues to be a stigmatized disease.

<sup>\*</sup>Medical student, University of Hawaii John A. Burns School of Medicine, 1960 East-West Road, Honolulu, HI 96822. <sup>\*\*</sup>Health educator. <sup>\*\*\*</sup>Health educator, Kokua Kalihi Valley Comprehensive Family Services, 1848 Gulick Ave, Honolulu, HI 96819. <sup>\*\*\*\*</sup>Associate Professor, University of Hawaii Dept. of Family Practice & Community Health, 95-390 Kuahelani Ave, Mililani, HI 96789. Contact S. Yamada. Email: seiji@hawaii.edu

## Introduction

Tuberculosis (TB) is the leading cause of death in adults worldwide, with new cases of TB estimated at 7.96 million in 1997<sup>1</sup>. The incidence of TB in the U.S. increased in the late 1980s and early 1990s, but has decreased since 1992 to an all-time low of 6.4 new cases per 100,000 populations in 1999<sup>2</sup>. The proportion of TB cases occurring in immigrants, however, has increased yearly since 1993, such that more than one third of the cases of tuberculosis (TB) in the United States occur in foreign-born persons<sup>3</sup>. Of note, the people of American Samoa are U.S. nationals<sup>4</sup> and are not counted as foreign-born by the Centers for Disease Control and Prevention (CDC).

American Samoa is a United States Territory in the South Pacific currently with a relatively low incidence of TB of 6.3 per 100,000 in 1999<sup>5</sup>. The latest figures reported by the WHO are 8 per 100,000, though this last figure is noted to be an underestimate<sup>6</sup>. For purposes of comparison, the incidence rate of TB in Samoa was 22 per 100,000 (1994)<sup>7</sup>, 15.5 in Hawaii (the U.S. state with the highest incidence), 45.4 per 100,000 in Guam, 59.7 in the Republic of Palau (Belau), and 95.4 in the Commonwealth of the Northern Mariana's Islands (1999)<sup>8</sup>.

## TB in American Samoa from the 1920s to the present

American Samoa in the 1920s had a TB incidence rate of 347 per 100,000. By the 1950s, the incidence rate had fallen to 112 per 100,000 population<sup>9</sup>. In the 1970s, the rate was at 34 cases per 100,000<sup>10</sup>. Finally, in the 1990s, American Samoa achieved a TB incidence rate under 10 per 100,000 population.

The decline of TB incidence in American Samoa has been attributed to health policies implemented by U. S. Naval Medical Department from 1921 up to the 1960s. During this period the government of American Samoa pursued a policy of educating the Samoan population about tuberculosis. The tuberculosis control program included tuberculin testing, contact examinations, BCG vaccina-

**Table 1. Samoans in the United States: Two waves of immigration**

1900	American Samoa became a U.S Territory
1910 - 1940s	Samoan Mormon missionaries settled in Laie, Oahu Hawaii. Samoans enlisted in the U.S military
1950 - today	American Samoans as U.S nationals freely migrate to Hawaii and mainland United States for better opportunities

tions, free treatment (isoniazid, streptomycin, artificial pneumothorax and collapse therapy) and follow up clinics. Non-cooperative, contagious TB patients were forced into isolation by the legal system, with few visitation rights for family and friends<sup>11,12</sup>. The TB control program in American Samoa has since undergone modernization following changes implemented in the United States.

## Patients, materials, and methods

We conducted a focus group of Samoans in Hawaii in 1994. The focus group was part of a research project conducted by the Association of Asian Pacific Community Health Organizations (AAPCHO) with grant support from the CDC.

**Subjects:** The focus group was conducted in Hawaii in the Samoan and English languages. The members of the groups were recruited from the patient populations of a community health center. Patients who had been diagnosed with TB or who were skin test positive were preferentially recruited. The focus group consisted of eight immigrants born in either Samoa or American Samoa. Most had immigrated to Hawaii ten or more years ago. The group consisted of men and six women.

**Focus Group Procedures and Analysis:** Samoan-speaking staff of the community health center conducted the group. The questions used (Appendix 1) were adapted from Kleinman's questions for eliciting patient explanatory models of illness<sup>13</sup> and the CDC's *Improving Patient Adherence to Tuberculosis Treatment*<sup>14</sup>.

The focus group session was audiotaped and transcribed. Each question was discussed in turn, and every member with an opinion was allowed to express it. The authors independently reviewed the focus group transcripts. The most commonly expressed themes were extracted and tabulated. Individual quotations, such as those reporting on particular traditional practices, were also identified.

Through a reiterative process of review and revision, the authors arrived at a consensus regarding the themes

expressed in the focus group. Some individual responses were retained, however, to represent the diversity of viewpoints.

## Results

Comments by the focus group participants revealed several themes. These themes related to causation and mechanism of TB, the social and psychological implications of TB, and the treatment of TB.

### Theories of causation and mechanism of disease

The focus group participants cited a wide variety of factors as causing TB. Some individuals cited a number of factors. These have been sorted into categories outlined in Table 2. The participants viewed TB as highly contagious. It is commonly believed that TB can be contracted from a coughing sufferer, germs in the air, flies that settle in food, sharing of TB-contaminated clothing or utensils, or stepping on spit or mucus from a TB sufferer.

**All confirmed that the general attitude toward the victim of TB is stigmatization. Other families shun the infected person and his or her family. One focus group participant expressed the opinion that TB victims and their families are thought to be doomed.**

If one's immune system is weak, TB germs can multiply in the lungs, blood, brain, skin and other organs to produce the disease. TB germs produce mucus and cause holes in the lungs, hence the cough and bloody cough. In the

focus group, the following symptoms were noted to be indicative of TB: cough, bloody cough, weight loss, poor appetite, chills and fatigue.

The body is thought to become ugly: the chin becomes long and the sufferer loses weight. It is believed that TB worsens with cigarette smoking. Without medical treatment, death soon results.

### Social implications

Members of the focus group considered the victim of TB as contagious and, therefore, requiring isolation. One focus group member noted,

"If I had TB, I would avoid contact with my spouse and family." Sufferers may refuse to kiss their spouses for fear of TB transmission.

**Table 2. Theories of Causation**

<b>Natural forces/environmental exposures</b>
Exposure to airborne TB bacteria*
Insects (flies, others) carrying TB germs
Smoking cigarettes
Unsanitary conditions, poor hygiene - spitting, flies, insect-infested toilets
Wearing TB contaminated clothing - unwashed <i>lavalavas</i>
<b>Imbalances of the body</b>
Overwork*
Poor nutrition, poor appetite, TB germ in cow's milk (TB germ contaminated food)*
Coughing *
Not fully recovering from a previous illness (weakened immune system)*.
Pregnancy ( <i>failele gau</i> )
<b>Contagion</b>
Contact with a person with TB <sup>+</sup>
Sharing eating utensils*
Talking with a TB infected person
Kissing a person with TB
Airborne spread by direct inhalation of TB germs

\*These items were noted by at least three focus group members.

All confirmed that the general attitude toward the victim of TB is stigmatization. Other families shun the infected person and his or her family. One focus group participant expressed the opinion that TB victims and their families are thought to be doomed. Such families can be taunted for generations.

Another noted:

In my family, I had brothers and sisters that were in the hospital diagnosed with TB. They were isolated from other patients. This disease, if a family in Samoa had someone who's infected with TB, there is a stigma on that family. People keep away and don't want to use anything that is our families.

**Psychological implications**

The life of the TB victim is characterized by suffering. Victims focus on their disease and impending death to the exclusion of all else, losing interest in work and other aspects of life. The stigmatization of TB leads to feelings of shame, isolation, and victimization. Because families in

American Samoa live in close proximity to each other, some sufferers choose to seek medical attention immediately to avoid stigmatization. The consequence of social stigmatization appears to include features that border on clinical depression.

A Samoan focus group member noted

" TB makes a person feels sad. It can bring a lot of depression to one who has TB. This is so because, we feel that once you have TB, your days are numbered to live. TB kills people."

**Treatment**

Focus group members' ideas about treatment also include multiple modalities, as noted in Table 3. Seeking modern medical care and taking medicines is considered to be the most effective treatment and a necessary component of any treatment program. Some members acknowledged the importance of patient compliance with TB medications. Non-compliant TB patients may continue to spread TB if they are not successfully treated.

**Table 3. Ideas about treatment**

<b>Modern medical attention*</b>
Traditional medicine
Changes in environment and exposures
Prevention of exposure to TB - isolation & treatment of TB sufferers
Good sanitation at home
Stop smoking
Good nutrition without TB germs*
Full recovery from previous illnesses*
Correcting imbalances of the body
Having a strong immune system

\*These items were noted by at least three focus group members

Focus group members noted that in American Samoa medical treatment for tuberculosis is free and easily accessible.

Traditional Samoan medicine, as noted by some of the focus group members, is not used to directly remedy tuberculosis. However, Samoan herbs are used instead to enhance the TB victim's immune system and indirectly improve his or her recuperative capabilities from TB. These individuals saw traditional treatments as adjuncts to biomedical interventions. The group did not mention specific herbs.

### Effects of treatment

One effect of treatment mentioned was that the victim is no longer infectious to others. The victim is no longer stigmatized and is able to live and enjoy life. A focus group member noted: "All the years they were in the hospital thinking they will never return home. Now it is though they never had TB." The community as a whole is made happy by the cure. Furthermore, migration to the United States becomes possible for those with successful TB treatment.

### Discussion

We found that Samoan immigrants regard TB to be an extremely contagious disease. This leads to isolation and stigmatization for persons with TB, causing them suffering and sadness. Many note the germ theory as the main cause of tuberculosis, but these same participants listed other contributing factors. (Of note, contagiousness should not be conflated with the germ theory. In Southern Europe, TB was believed to be contagious for centuries before Koch identified the TB bacillus<sup>15</sup>. Further, the germ theory is not the only "scientific" understanding of tuberculosis. Evolutionary geneticist Richard Lewontin identifies industrial capitalism as the "cause" of TB<sup>16</sup>.)

All agreed that medical attention was necessary for TB, and patient compliance is very important. Traditional herbs are not used to cure tuberculosis directly, but they are used as adjuncts to medical treatment to strengthen the TB victim's health. As noted by Macpherson and Macpherson in regards to indigenous and introduced paradigms in Western Samoa, "Relatively peaceful coexistence of two systems seems likely to ensure the continuation of Samoan medical belief and practice."<sup>17</sup>

Because American Samoa has a landmass of 72 square miles and a relatively small population of about 56,000<sup>18</sup>, it is relatively easy to monitor TB incidence in the population. While TB poses a barrier for those immigrating to the United States from many countries, American Samoans have free entry into the United States. Free TB treatment is available to those who seek such entry.

### Focus group questions

1. What do you think causes tuberculosis?
2. What causes tuberculosis to start up?
3. What does tuberculosis do to people? How does it work?
4. What makes a case of tuberculosis mild or severe? Does it last a short or long time?
5. What should be the treatment for tuberculosis? (If only biomedical models are mentioned) Are there any traditional treatments for tuberculosis? Can traditional healers help treat tuberculosis?
6. What are the most important results from treatment?
7. What are the chief problems tuberculosis causes?
8. What is the most dangerous thing about tuberculosis?
9. Does tuberculosis kill people? Are you afraid of dying from tuberculosis?
10. Can tuberculosis be cured? Is tuberculosis easy or hard to cure?
11. What do people in the community think of people with TB? Is there something about some people that makes it easier for them to get TB? Do people look down on people with TB?

### Implications for public health and medical practice

Tuberculosis is perhaps the disease that first comes to mind when we think about the relationship between larger social and economic conditions and the distribution of disease<sup>13,19</sup>. Crowded housing and workplace conditions and poor nutrition are associated with TB. While the population of American Samoa is relatively dense, the low incidence of TB at the present time points may indicate that social conditions that foster tuberculosis are not as pronounced as they are in other Pacific jurisdictions. Affordability and availability of medical care in American Samoa may be factors that have contributed to the lowering of the incidence of TB to its current rate. TB incidence was high in the preceding decades, however, so that many in the population are infected (PPD positive). Thus, as the population ages, surveillance for reactivation of TB must continue.

For the community health planner, in order to overcome perceived and real barriers to TB control programs, must be informed of the perspectives of the people served. For practitioners who care for Samoan immigrants, awareness of common cultural attitudes builds bridges of understanding between patient and practitioner, enhancing the effectiveness of the clinical encounter.

## Limitations of the study

One limitation of this study is that our focus group participants were not randomly selected to represent Samoans in the United States, so the attitudes that they expressed cannot be generalized to Samoans who are acculturated to different degrees. A second limitation is that focus group members held divergent opinions; all of their opinions could not be incorporated into our report. A third limitation is that the individuals who conducted the focus groups were involved in the interpretation of the results. While this may be an appropriate qualitative methodology in some circumstances, it also represents an opportunity for biases to be incorporated into the results.

## Conclusion

Our inquiry has emphasized a patient-centered viewpoint, with a particular emphasis on cultural and social influences on patients' beliefs and practices. A culturally competent approach is one in which providers seek to educate themselves about such influences. Practitioners must query individual patients about their personal viewpoints, but prior knowledge of such perspectives will foster successful clinical partnerships. We seek to delineate attitudes regarding TB among Samoan immigrants and thereby seek to improve the cultural competence of those providing TB services for them.

An implication of this study is that practitioners who care for the Samoan patient with TB may need to focus patient education around the degree of transmissibility of TB and the manner in which it may be reduced. In addition, community-based educational interventions among Samoan immigrants about the true degree of transmissibility of TB may lead to less stigmatization. Such efforts may foster community-wide TB control.

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