James W. Carey, PhD MPH
Margaret J. Oxtoby, MD
Lien Pham Nguyen
Van Huynh
Mark Morgan
Marva Jeffery, MPH

At the time of the study, Dr. Carey and Mr. Morgan were with the Division of Tuberculosis Elimination, Centers for Disease Control and Prevention (CDC), Atlanta, GA. Dr. Carey was a Research Anthropologist, and Mr. Morgan was a student intern. Dr. Carey is now a Behavioral Scientist with the Division of HIV/AIDS Prevention, CDC, Atlanta, and Mr. Morgan is a Peace Corps volunteer in Lesotho. Dr. Oxtoby and Ms. Jeffery are with the Bureau of Tuberculosis Control, New York State Department of Health, Albany. Dr. Oxtoby is the Director of the Bureau, and Ms. Jeffery is a Public Health Representative. Ms. Nguyen is an Outreach Worker with the Mohawk Valley Resource Center for Refugees, Utica, NY. Mr. Huynh is a Counselor with the Refugee Assistance Program, Johnson City, NY.

Address correspondence to Dr. Carey, Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, 1600 Clifton Road NE, Mailstop E-37, Atlanta, GA 30333; tel. 404-639-8300; fax 404-639-8874; e-mail <jfc9@oddhiv1.em.cdc.gov>.

# Tuberculosis Beliefs Among Recent Vietnamese Refugees in New York State

#### SYNOPSIS

**Objective.** To identify newly arrived Vietnamese refugees' beliefs about tuberculosis (TB) and TB education needs.

**Methods.** In 1994, the New York State Health Department and the Centers for Disease Control and Prevention conducted a survey of 51 newly arrived adult Vietnamese refugees in two New York counties. After being trained in interview methods, two bilingual researchers asked 32 open-ended questions on the causes of TB, TB treatment, and the disease's impact on work and social relationships.

**Results.** Respondents correctly viewed TB as an infectious lung disease with symptoms such as cough, weakness, and weight loss. Hard manual labor, smoking, alcohol consumption, and poor nutrition were believed to be risk factors. Many respondents incorrectly believed that asymptomatic latent infection is not possible and that infection inevitably leads to disease. Nearly all respondents anticipated that having tuberculosis would adversely impact their work, family, and community activities and relationships.

**Conclusions.** Targeted patient education is needed to address misconceptions about TB among Vietnamese refugees and to help ensure adherence to presribed treatment regimens.

n 1994, there were 24,361 cases of active tuberculosis (TB) in the United States. It is estimated that a total of 10 to 15 million residents are infected with *Mycobacterium tuberculosis* bacilli. Approximately 10% of those with normal immunity who are infected and do not complete preventive therapy may develop active disease.

Although TB affects many segments of society, it is of special concern for people from countries where it is highly prevalent.<sup>3–7</sup> In 1994, clinical TB cases among people born outside the United States and its territories accounted for 31.9% of the total reported U.S. cases.<sup>8</sup> From 1986 through 1993, the ageadjusted TB incidence rate among the foreign-born was 30.6 new cases per 100,000 person-years, a rate nearly four times higher than that for people born in the United States.<sup>5</sup>

People from Vietnam, Mexico, the Philippines, China, Haiti, India, and Korea account for roughly two-thirds of the TB cases among foreign-born people in the United States. In 1994, of the 7627 people with TB who were for-

eign-born residents of the United States, 869 (11.4%) were from Vietnam. Since 1975, more than 1.2 million Vietnamese have come to this country. The TB cumulative incidence rate in Vietnam was approximately 150 cases per 100,000 per year in 1994, compared to 9.4 cases per 100,000 in the United States. 8,9

Prior to entering the United States, Vietnamese immigrants and refugees with active disease are medically screened and given treatment. Those who have a chest radiograph compatible with active TB but a negative sputum smear and those with inactive TB are allowed to enter the country without treatment since they are not considered contagious; they are referred to health departments for further evaluation.

Although a person with a negative radiograph may have a latent infection, most refugees do not undergo tuberculin skin testing for infection prior to entering this country. People with untreated latent infection may subsequently develop active disease; chemoprophylaxis (preventive therapy) reduces the risk that TB infection will progress to disease. Once incoming refugees arrive at their destination points in the United States, state and local health departments generally attempt to ensure that they are tested for TB infection and that preventive therapy is prescribed when appropriate.

According to unpublished data from the Division of Quarantine at the Centers for Disease Control and Prevention (CDC), tuberculin skin test screening results for newly arrived Vietnamese refugees commonly show that slightly more than 50% of new arrivals have an induration ≥10mm. This suggests that as many as half of newly arrived Vietnamese may have a latent *M. tuberculosis* infection or a history of BCG vaccination. Although it is not generally recommended in the United States, BCG vaccination is used for TB control in many countries, especially in infants. <sup>10</sup> A history of BCG vaccination can lead to a false positive result on the tuberculin skin test; there is no reliable way to distinguish reactions caused by BCG vaccination from those caused by infection. People with latent infection have no symptoms of the illness and cannot spread TB to other people.

Although effective drugs exist for latent TB infection and for clinical disease, it is difficult to ensure complete treatment. Cultural factors—such as misperceptions about appropriate treatment methods—in combination with other barriers may adversely affect adherence and lead to improper uses of TB medications. 3,7,11-14 Poor adherence may contribute to the emergence of drug-resistant bacilli. Some patients may not fully understand their condition, comprehend its significance, or be aware of appropriate treatments. 15-17 Differences between patients' and providers' understandings of illnesses can interfere with adherence to treatment. 18-21 Misconceptions about TB, communication barriers, or fears of becoming socially stigmatized may lead to medical problems for some patients: they may be reluctant to seek treatment, might not take TB medications as prescribed, and may have difficulty under-

standing explanations offered by health care personnel. Previous research has shown that misconceptions and barriers to adherence are widespread in many different groups in the United States and other countries. 11-14,22

To promote therapeutic adherence and to improve patient services, the New York State Department of Health and CDC conducted a survey among newly arrived Vietnamese refugees. Our goal was to identify TB beliefs that might adversely affect adherence to treatment. This paper describes the study findings and discusses how they can be used to improve TB education and adherence among Vietnamese refugees.

## Methods

Eligible study participants were Vietnamese adult refugees ages 18 and older who arrived in Broome or Oneida counties in New York State between January 1 and November 30, 1994. Participants were identified by the local health departments and refugee agencies. Both counties have histories of receiving large numbers of Vietnamese refugees, and the health departments and refugee agencies had expressed interest in further strengthening their TB services. We focused on new arrivals because longer-term Vietnamese residents may alter their TB beliefs following contact with the American health care system; in addition, once established in the United States, refugees often discontinue contact with health departments.

An advantage of limiting the sample was that the findings would be pertinent to the TB service needs in these specific two New York counties. One disadvantage was that because the number of refugees arriving in the counties varies each month, prior to the study we could not accurately predict the number of potential study participants. Since the number of Vietnamese who arrived during the study period was small, the sample was also small. This limited the degree of statistical precision achieved in the analysis.

According to New York State Department of Health Records for the fiscal year July 1, 1994, through June 30, 1995, a total of 453 Vietnamese refugees 18 years of age or older resettled in New York State. Using chi-square tests, we determined that the age and sex distribution of our study sample did not significantly differ from the larger group of 453 refugees. Thus, at least in terms of these factors, our sample was representative of adult Vietnamese refugees throughout the state.

An interview guide was developed in consultation with county health departments, resettlement agencies, and the state health department's Bureau of Tuberculosis Control. The interview protocol included structured questions eliciting respondents' sociodemographic characteristics and 32 open-ended questions covering beliefs about the symptoms and causes of TB, susceptibility to the disease, prognosis, skin testing procedures, prevention, treatment, and the perceived social consequences of having TB.

Before the study, two bilingual interviewers who were

themselves Vietnamese refugees participated in a three-day interview skills workshop that included interactive discussions, lectures, and in-class exercises on several topics: the content and rationale of the interview guide, techniques for asking open-ended questions, strategies to motivate respondents to give useful and valid answers, active listening skills, procedures for writing standardized and reliable responses to the interview questions, and methods for managing diffi-cult interview situations.<sup>23,24</sup> The workshop also included updates on TB and its epidemiology and on refugee programs in the state. A written manual reinforced the training. Following the workshop, the interviewers completed practice interviews with 12 non-study Vietnamese adults to identify additional training needs. Finally, once data collection began, the two senior authors reviewed all interview write-ups to clarify ambiguities prior to analysis.

Each interview was conducted in Vietnamese and typically lasted one to two hours after informed consent was given. More than 90% were administered in respondents' homes rather than in medical clinics to help avoid responses being biased by reluctance to speak openly in front of health providers. The interviews not completed in respondents' homes were conducted in privacy at local refugee agencies or health departments. The interviewers wrote notes during the interview and later typed English response summaries into computer files.

Responses to structured questions were analyzed using Epi Info.<sup>25</sup> A special effort was made to develop a replicable analysis protocol for responses to the open-ended questions. 23,24,26,27,29 Themes were identified in the responses to each question. A theme was defined as a stated belief or idea, and codes were assigned to each unique theme. For example, the code "causesmk" was given to the belief that TB is caused by smoking tobacco. Altogether, 171 distinct themes were identified and defined in a code book. Using Tally software, two researchers assigned codes to the text passages containing the corresponding themes. 28 The number of themes present in response to a question varied between respondents, depending on the content, length, and complexity of their statements. Final intercoder reliability in theme identification was 88.1%.<sup>29</sup>

### Results

Of 64 eligible people invited to participate in the study, 51 (79.7%) agreed to be interviewed. Twenty-six of these were from Broome County and 25 were from Oneida County. According to medical records provided by the U.S. Immigration and Naturalization Service to the county health departments, none had a known history of clinical TB (based on x-rays taken prior to leaving Vietnam). No statistically significant differences were observed between the two counties in respondent characteristics, including gender, age, education, and former residence or occupation in Vietnam (Table 1). Because the limited sample size precluded a useful stratified analysis, only aggregate results for

Table 1. Sociodemographic characteristics of Vietnamese refugees participating in tuberculosis beliefs study, New York State, 1994 (N=51)

Characteristic	Respondents	
	Number	Percent
Gender		
Male	32	62.7
Female	19	37.3
Education		
No school	1	2.0
Some or all primary school	10	19.6
Some or all junior high school	13	25.5
Some or all high school	25	49.0
Some university	2	4.0
Former residence in Vietnam		
City	18	35.3
Town	18	35.3
Rural	11	21.6
Not asked	4	7.8
Former occupation in Vietnam		
Farmer	8	15.7
Small business	7	13.7
Student	5	9.8
Tailor/seamstress	5	9.8
Homemaker	4	7.8
Other <sup>a</sup>	22	<b>43.1</b>

NOTE: Mean age 35.4 years; standard deviation 15.0 years; range 18-67

the combined sample will be presented here.

Respondents generally described TB as a contagious disease that affects the lungs and identified 26 symptoms that they thought were associated with TB (Table 2). Most respondents (84.3%) stated that coughing is a TB symptom. Less frequent responses included weakness, thin appearance, weight loss, appetite loss, sleeplessness, coughing up phlegm, and pale skin. All of the symptoms identified in the table are roughly consistent with the symptoms of pulmonary TB.<sup>10</sup>

Asked about causation, respondents identified 29 factors (Table 3). Most mentioned combinations of behavioral causes (smoking, alcohol consumption), environmental causes (exposure to others with TB, exposure to germs, living in unhygienic conditions, breathing dirty air), and other factors such as hard manual labor, poor nutrition, and lack of sleep. Some respondents also identified heredity or weak immune systems as contributory factors.

Nearly two-thirds of the sample (32 respondents, or 62.7%) said that it was possible to have TB microorganisms inside one's body without experiencing symptoms. Explanations for this phenomenon typically involved having a

<sup>&</sup>lt;sup>a</sup>Other occupations included manual labor, skilled trades, factory work, nursing, and bookkeeping, among others. In addition, one respondent was a traditional healer.

Table 2. Vietnamese refugees' beliefs about TB symptoms, New York State, 1994 (N=51)

	Number of		
Symptom	Respondents	Percentage	95% CI
Cough	43	84.3	71.4, 92.8
Weakness	18	35.3	22.4, 49.9
Thin appearance	17	33.3	20.8, 47.9
Weight loss	13	25.5	14.3, 39.6
Appetite loss	10	19.6	9.8, 33.1
Sleeplessness	10	19.6	9.8, 33.1
Cough with phlegm	7	13.7	5.7, 26.3
Pale skin	5	9.8	3.3, 21.4

NOTE: Each of 18 other responses was given by one to four respondents.

CI = confidence interval

strong immune system that stopped harm to the body. However, four (7.8%) of the respondents were unsure and 15 (29.4%) specifically said that they did not believe asymptomatic TB infection was possible. Although only a small proportion of untreated people with latent infection develop active disease, 15 (29.4%) of the respondents incorrectly thought that development of disease was inevitable following infection. Such a belief could lead to a view that chemoprophylaxis is useless. Fortunately, 33 of the 51 respondents (64.7%) understood that disease is not inevitable following infection. Of these 33 people, 21 (63.6%) explained that development of the disease depended on the strength of the immune system, and 18 (54.5%) stated that disease could be

Table 3. Vietnamese refugees' beliefs about causes of TB, New York State, 1994 (N=51)

	Number of		
Causes	Respondents	Percentage	95% CI
Hard manual labor	26	51.0	36.6, 65.2
Smoking	25	49.0	34.8, 63.4
Drinking alcohol	21	41.2	27.6, 55.8
Poor nutrition	20	39.2	25.8, 53.9
Exposure to others			
with TB	16	31.4	19.1, <del>4</del> 5.9
Exposure to germs	14	27.5	15.9, <del>4</del> 1.7
Heredity	9	17.6	8.4, 30.9
Weak immune			
system	9	17.6	8.4, 30.9
Living in unhygienic			
conditions	7	13.7	5.7, 26.3
Lack of sleep	6	11.8	4.4, 23.3
Breathing dirty air	5	9.8	3.3, 21.4

NOTE: Each of 18 other causes was cited by one to four respondents. CI = confidence interval

prevented by taking medicines.

Other questions pertained to TB prevention and treatment. Table 4 lists the methods that respondents thought could be used to prevent TB. The most common idea was to avoid other people who had the disease. Reference to traditional medicines or herbal preparations was largely absent. Slightly more than half of the respondents (52.9%) correctly stated that prophylactic drugs are available. A few people specifically mentioned the drug isoniazid by name. The majority appeared very receptive to biomedical health care, and several specifically stated that traditional medicines do not work for TB. Less common beliefs about preventing TB were to avoid smoking, get plenty of rest, not work too hard, follow a physician's advice, eat nutritious foods, avoid alcohol, get exercise, and maintain good general hygiene. Nine respondents (17.6%) stated that TB could be prevented by not sharing contaminated objects, reflecting the medically incorrect idea that TB is transmitted through direct contact with physical objects previously handled by a person with TB. References to vaccination, including BCG vaccination, were made by only eight people, even though BCG vaccine is commonly used in Vietnam. An important misconception held by some was that taking TB-preventive drugs stopped a person from becoming infected.

Table 4. Vietnamese refugees' beliefs about ways of preventing TB, New York State, 1994 (N=51)

	Number of		
Method	Respondents	Percentage	95% CI
Avoid people who			
have TB	28	54.9	40.3, 68.9
Use modern			
medicines	27	52.9	38.4, 67.1
Do not smoke	18	35.3	22.4, 49.9
Get plenty of rest			
and do not			
overwork	16	31.4	19.1, 45.9
Follow physician's			
advice	15	29.4	17.4, 43.8
Eat nutritious			
foods	15	29.4	17.4, 43.8
Do not drink			
alcohol	13	25.5	14.3, 39.6
Do not share			
TB-contaminated			
objects	9	17.6	8.4, 30.9
Get exercise	9	17.6	8.4, 30.9
Maintain good			
hygiene	9	17.6	8.4, 30.9
Get BCG			
vaccination	8	15.7	7.0, 28.6

NOTE: Each of seven other methods was mentioned by one to three respondents.

CI = confidence interval

In regard to treatment of clinical disease, respondents preferred modern biomedical procedures over traditional herbal remedies. The most frequently mentioned treatment was modern medicines (56.9%); other common suggestions were for people with TB to follow a physician's advice (52.9%) and to eat nutritious foods (52.9%). Only 11.8% of the sample mentioned herbal remedies or traditional medicine. Less frequently suggested treatments were to get plenty of rest and not work too hard (27.5%), to avoid smoking (21.6%), to get exercise (21.6%), to avoid alcohol (15.7%), to live in healthy environments (15.7%), and to maintain good overall hygiene (13.7%). As with prevention, respondents' beliefs about treatments for active TB generally corresponded with their perceptions of the causes or risk factors for acquiring TB. In response to two other questions, the majority stated that TB treatment should not vary by a patient's gender (60.8%) or ethnic group (72.5%).

There was a strong consensus about who should be con-

sulted for treatment-50 out of 51 (98.0%) preferred physicians. The one person who did not mention physicians suggested getting medical attention from hospitals or clinics. A traditional healer who by chance was in the sample was the only respondent to suggest consulting a traditional healer, and even he thought that physicians were more appropriate for treating TB. In addition to physicians, almost one-third of the sample mentioned nurses. None suggested consulting any type of non-health care personnel such as a religious leader.

To learn about social barriers to seeking TB care or to adherence to treatment, participants were asked if having TB might affect a person's ability to work, perform family responsibilities, or maintain relationships with friends and community members. Nearly all respondents (94.1%) believed that having TB would negatively affect one's ability to work. Common concerns included getting fired, feeling too tired to do one's job adequately, avoidance by coworkers because of fear of becoming infected, and high levels of anxiety interfering with job performance.

Adverse family-related effects of having TB were anticipated by 90.2% of the sample. Respondents explained that TB patients would avoid interacting with their families because of fear of spreading the disease. Other reasons included fatigue preventing participation in family activities, economic hardship due to job loss, and high levels of worry impacting the quality of family relationships.

We also asked respondents how people in their communities would act toward a person with TB. Most (76.5%) said that community members would fear and avoid someone known to have TB. Only one person thought that community members would not be afraid. The remaining 21.6% said they were uncertain how community members would react.

## Discussion

Our study of Vietnamese refugees indicates that they, not unlike other groups, hold heterogeneous beliefs about TB and concerns about the potential adverse social consequences of the disease. Our overall impression is that they have more familiarity with TB than might be expected of the average native-born U.S. citizen; further inter-ethnic research is needed to test this hypothesis. Research on conditions such as hypertension or diabetes has shown that

patients from diverse populations often have complex mixes of medically accurate and inaccurate beliefs. <sup>18,19</sup> Even though our sample was small, considerable variation was observed.

Although we believe that our sample is representative of Vietnamese adults in Broome and Oneida counties, it is unclear if the findings are generalizable to Vietnamese refugees elsewhere. It is possible, for example, that TB beliefs vary by year of immigration. The earliest refugees, reaching the United States from 1975 to 1977, tended to be an upper-class elite group

an upper-class elite group consisting of U.S. employees and member of the South Vietnamese government or military. Those arriving from the late 1970s onward tended to be less well educated. Although all of the people in our sample arrived in the United States directly from Vietnam, many of the other Vietnamese people living in this country spent considerable time in resettlement camps in other Asian countires prior to their entry into the United States. These differences in history and background could conceivably be associated with differing levels of general education and familiarity with medical treatment for TB.

Another limitation is that we could not satisfactorily control for the extent of a respondent's exposure to TB education prior to the immigration process. According to TB clinic records of the two county health departments, nearly all of the respondents (88.2%) had received some TB education during their health assessment immediately following

A traditional healer who by chance was in the sample was the only respondent to suggest consulting a traditional healer, and even he thought that physicians would be more helpful in treating TB.

arrival in the United States. Although this could be expected to have influenced their responses in favor of a conventional medical view of TB, the extent of misconceptions reported by many respondents after having received basic TB education is a cause for concern. Our results are consistent with those from focus groups conducted with Vietnamese refugees in a separate recent study.<sup>31</sup>

Our findings suggest that TB patients among Vietnamese refugees may vary in the extent of their knowledge about the disease. Educational efforts should address patient-specific needs; people with different kinds of misconceptions or concerns require different health messages. Providers should allow sufficient time to learn each patient's level of pre-existing knowledge, specific beliefs or misconceptions, and possible concerns about the social consequences of the disease or treatment. Appropriate use of interpreters can be helpful in this regard.<sup>30</sup>

The fact that respondents expressed a preference for

physicians as a source of medical treatment suggests that some Vietnamese refugees may be less receptive to information given by non-physicians. If it is not possible for a physician to offer TB education, he or she should clearly endorse the accuracy and importance of the information provided by other clinic staff.

Misunderstandings about asymptomatic TB infection were common in our sample. More than one-third did not realize that a person can be infected without feeling sick. People for whom preventive therapy is indicated should understand that they are already infected and that taking the medications can stop future development of TB disease. Explicit educational effort should address these potential misconceptions.

Vietnamese refugees may have preconceptions about what types of people are susceptible to TB (for example, people who do hard manual labor or do not get enough rest, people who smoke or drink alcohol, or people who have poor nutrition or live in unhygienic conditions). Those who do not fit the perceived TB risk profile may not believe themselves to be susceptible to TB; they may see little reason to adhere to prescribed preventive regimens. Misconceptions about the routes of TB transmission, such as through objects thought to be contaminated by people with TB, should be corrected. Although they are likely to be open to biomedical therapy, Vietnamese refugees may also see value in getting plenty of rest, eating a nutritious diet, not smoking or drinking alcohol, maintaining good hygiene, and getting exercise and fresh air. Providers can confirm the general benefits of these methods while emphasizing the necessity of taking anti-TB drugs to ensure a cure.

Respondents saw TB as having highly adverse social

consequences. Attending TB clinics, talking with health care providers, and taking anti-TB drugs constitute public acknowledgment by a patient that he or she is infected. Vietnamese refugees may be extremely concerned about the negative social consequences of being viewed as having TB (for example, job loss and adverse reactions from family, friends, or community members). Concern about the social consequences of being known to have TB is very common in other ethnic groups as well. 13,14 From the patient's perspective, these problems may be more important than taking medications or keeping appointments. TB services, especially those given outside the clinic setting such as directly observed therapy, should be delivered in a way that maximizes protection of patient confidentiality. With the patient's permission, providers can meet with family members to help alleviate misconceptions and concerns. Community education may be useful in lowering the adverse social consequences of having infection or clinical disease.

Providers should allow sufficient time to understand each patient's specific beliefs and concerns.

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