Tuberculosis Knowledge, Attitudes, and Beliefs Among North Carolinians at Increased Risk of Infection

Elizabeth L. West, PA-C; Lara Beth Gadkowski, MD, MS; Truls Østbye, MD, MPH, PhD; Carla Piedrahita; Jason E. Stout, MD, MHS

Abstract

Objective: The purpose of this study was to capture and describe knowledge, attitudes, and beliefs about tuberculosis (TB) among persons at high risk for TB infection.

Methods: We conducted 11 focus groups in 3 different populations at high risk for TB infection: Spanish-speaking immigrants, homeless shelter residents, and persons attending a drug/alcohol rehabilitation center. A standardized list of open-ended questions was used to guide discussion. Using grounded theory, transcripts of the focus group sessions were reviewed by 4 independent reviewers to identify emergent themes.

Findings: Participants (N=52) generally understood that TB is an infectious disease that frequently affects the lungs and can be fatal if untreated. They also knew that a skin test can be used to diagnose TB. However, participants frequently had incorrect beliefs regarding the cause, transmission, and treatment of TB. Many participants thought that TB is transmitted in the same fashion as other infectious diseases such as human immunodeficiency virus or acquired immune deficiency syndrome (HIV/AIDS). A general sentiment of fear and aversion toward persons ill with TB was expressed.

Limitations: Focus groups were a convenience sample and subjects were not necessarily representative of the underlying populations.

Conclusions: Tuberculosis knowledge among high-risk populations is suboptimal, and false beliefs regarding transmission and treatment were common in this study. Knowledge regarding transmission of other infectious diseases such as HIV/AIDS was frequently translated into incorrect knowledge regarding TB. Stigma continues to be a barrier to TB diagnosis and treatment.

Key words: Health knowledge, attitudes, practice; focus groups; tuberculosis; homeless persons; emigration and immigration; alcoholism; substance-related disorders
response, the infected individual remains asymptomatic but frequently harbors viable TB bacteria. This individual is then said to have latent tuberculosis infection (LTBI). Persons with LTBI may remain well (and not contagious), but approximately 10% become ill with active TB during their lifetime and may then infect others.\textsuperscript{2} The detection and treatment of LTBI is thus essential to TB eradication efforts. Latent TB infection is currently diagnosed by tuberculin (purified protein derivative) skin testing, although blood tests to diagnose LTBI are becoming available.\textsuperscript{4} Persons with LTBI, defined as having a positive tuberculin skin test without clinical or radiographic signs of disease, can be treated with isoniazid to reduce the risk of progression to active TB. Treatment of LTBI with 6 to 9 months of daily isoniazid reduces the likelihood of progression to active disease by up to 90%.\textsuperscript{3} Unfortunately, a relatively low proportion of persons with LTBI complete a full course of therapy. In a general public health clinic population, only about 60% of patients prescribed isoniazid completed a full course, and in homeless populations completion rates have been as low as 15-20%.\textsuperscript{5,6}

Understanding TB knowledge and beliefs among high-risk groups may significantly enhance efforts to diagnose and treat both active TB and LTBI in those groups. Several studies have examined TB knowledge and beliefs in selected populations,\textsuperscript{8-15} but data are lacking for some high risk groups in the United States. We conducted 11 focus groups comprised of persons from groups at high risk for TB as part of a larger effort to understand and improve adherence to LTBI therapy.

\section*{Methods}

\subsection*{Study Design}

Eleven focus groups were assembled in order to gather data about TB knowledge, attitudes, and beliefs. Focus groups have been used extensively in primary care settings to explore patients’ and practitioners’ perceptions and opinions of illness, services, and programs.\textsuperscript{16} Participation in the focus groups was voluntary and anonymous. Food was offered at some of the sessions, but participants did not receive any monetary compensation for participation. Both the Duke University Medical Center Institutional Review Board and Wake County Human Services approved the study protocol.

\begin{table}[h]
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\begin{tabular}{|l|p{15cm}|}
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\textbf{Emergent Themes and Illustrative Focus Group Quotations} & \\
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\textbf{Tuberculosis is communicable and serious} & “…it is communicable and can be deadly” \\
& “It will kill eventually.” \\
& “It’s life-threatening if not treated.” \\
& “highly infectious” \\
& “easily spread” \\
\hline

\textbf{Tuberculosis can affect anyone} & “I think society in general can get it [TB].” \\
& “I would say that if you are exposed to anyone in the general public you are at risk, it doesn’t discriminate.” \\
\hline

\textbf{Tuberculosis is more likely to affect people who are not like me} & “People from other countries [are more likely to get TB]” \\
& “Street people [are more likely to get TB]” \\
\hline

\textbf{Tuberculosis stigma} & “People would feel ashamed about TB at a hairdresser, or store.” \\
\hline

\textbf{Health care costs are significant barriers to receiving good health care including tuberculosis care} & “I’m supposed to be on all kinds of medications but I can’t afford the prescriptions ’cause I don’t have insurance.” \\
& “I feel like the more money or more insurance you have the better doctor care you get.” \\
\hline

\textbf{Perception of responsibility for health affects the likelihood of taking treatment for tuberculosis} & “Of course you are going to have people who aren’t going to take it [treatment for LTBI] no matter how bad it is, ’cause they are just that way. But people who care about themselves and their health and their family are going to do it. You can’t make people care, but they either care or they don’t but the ones who do I think if they have the right information, if they were educated, they would.” \\
\hline

\textbf{Incentives (financial or emotional) will increase adherence to latent tuberculosis infection treatment} & “Society loves money, pay them [persons who need TB/LTBI treatment].” \\
& “Give them encouragement for taking the pills.” \\
& “Spend time with the person so they don’t feel so alone.” \\
\hline

\textbf{Persons who do not have regular, healthy practices will not take tuberculosis / latent tuberculosis infection treatment} & “I think the biggest problem is, is that right now a lot of people who would have to take it [the TB treatment], their lifestyle doesn’t really coincide with doing things at a normal time, like taking the medicine every day is like taking a bath every day, well a lot of people on the street don’t take a bath every day it would be hard to get them to do something on a regular basis all the time.” \\
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\caption{Emergent Themes and Illustrative Focus Group Quotations}
\end{table}
21 Caucasians, 15 African-Americans, and 16 Hispanics. Five sessions included only males, 2 included only females, and 4 included both males and females (30 male and 22 female participants total). Participants at the homeless shelters and the rehabilitation facility did not provide demographic information. Among the Hispanic participants, 5 persons were under 30 years of age (range 25-52 years), and 6 had been in the United States under 5 years (range 6 months-16 years). Ten were from Mexico, 2 from Colombia, and 1 each from the Dominican Republic, Peru, and Honduras, while the country of origin for 1 subject was unknown. A standardized list of questions was used to guide the discussions. (See Box 1.) All sessions were audio-recorded and transcribed. The Spanish transcripts were translated by one bilingual person, and a second bilingual person reviewed the original transcripts and the translation for accuracy.

Using grounded theory, the 4 reviewers (LM, LG, JS, and TO) read the English versions of the transcripts independently, initially looking for key words and emerging themes. After half the focus groups had been completed and transcribed, the researchers compared and combined their independent analyses. This procedure permitted exploration, expansion, and testing of the themes in subsequent focus groups. An extensive list of key words and themes was maintained and revised throughout the process resulting in a final analysis template which allowed the researchers to organize and code the data. All the transcripts were coded using the analysis template, making it easier to organize and manage the qualitative data. At this stage of the analysis, all the researchers met several times to examine similarities and differences across and within the identified themes. Several iterations of the findings were circulated among the research team for clarification and consensus before they were considered final.

Results

What Did the Participants Know About Tuberculosis?

Signs, symptoms, and contagiousness. Participants understood that tuberculosis is a disease associated with significant morbidity and mortality. There was also generalized knowledge among the participants in each group about the signs and symptoms of active TB: persistent cough, coughing or spitting up blood, fever, and night sweats were all mentioned. Although most participants did not report having known anyone with TB, they thought a person with TB would look very ill: “I picture them being lethargic, pale, bad cough, dark circles under their eyes” and “Coughing, shortness of breath, run down easy, someone who could only do like four hours of work instead of eight a day, drained and tired.” Those who had observed someone with active TB depicted similar images: “She looked like a walking cadaver.” Most group participants knew that TB was infectious. Participants most commonly responded that TB was spread by the cough of an infected person: “It’s mostly airborne. I mean people cough. Like you could be in a cab with somebody and they cough and you can get it that way.”

Skin Testing. Participants knew there was a skin test that could be used to diagnose TB. Participants also knew the test was available at a physician’s office, clinic, hospital, or health department. Many of the participants had previously undergone tuberculin skin testing. All participants indicated they would be willing to be tested for TB if they thought they were at risk of having TB.

What Did The Participants Not Know About Tuberculosis?

Cause and Transmission. The most obvious knowledge deficits were in the areas of causation and transmission of TB. At least one person in each group responded that TB was caused by either a bacteria or, even more commonly and erroneously, by a virus. Other suggested causes of TB were smoking, “malnutrition,” “sleeping in cold breezy places and wet floors,” and “uncleanliness.” At least one person in each group knew TB could be transmitted when an infected person coughs. Several participants indicated TB could be transmitted by using the same glass or utensils as the infected person, by holding hands with an infected person, from dirty needles, by blood, and even “like AIDS.”
Attitudes and Beliefs About the Diagnosis and Treatment of Tuberculosis

Participants did not verbalize any overt prejudice or negative attitudes about people with TB: “It’s not their fault.” In addition, the majority of those who responded to the question “Who gets TB?” answered that anyone can get it: “I think society in general can get it,” and “I would say that if you are exposed to anyone in the general public you are at risk, it doesn’t discriminate.” While few participants expressed any negative attitudes towards someone with TB, some participants stated that certain groups of people were more likely to have TB than others. For example, the men in the alcoholic recovery group said that “street people” and the “homeless” are more likely to be infected. Many participants commented that persons with AIDS and depressed immune systems are at increased risk of acquiring TB. Several Spanish-speaking participants said that “people from other countries,” and people of other races tend to have it. Other groups more likely to have TB mentioned by the participants were older people, asthmatics, those who smoked or drank alcohol, those who lived in big cities, those with a low income, those who did not receive the vaccine, those who lived in “harsher environments,” and those who were malnourished.

Many participants voiced that their first inclination was to “stay away” from someone diagnosed with TB. Few participants acknowledged having known anyone with TB. A few participants had childhood memories of persons with TB:

I remember my momma saying to me not to let certain people cough on me or spit on me ’cause he got TB stuff so we used to stay away from him because he was a cougher and a spitter ’cause he was contagious, so she told us to stay away from him ’cause he was contagious.

Trust of the Health Care System and Health Care Professionals

Participants in all groups stated that in general they trusted medical professionals to provide appropriate care. Furthermore, participants indicated they had greatest trust in physicians who were specialists in treating their specific illness. A few participants expressed negative feelings and distrust toward specific medical institutions but not toward physicians or other medical providers in general. Despite this trust, participants were not enthusiastic about having a nurse come to their home for TB testing. Several participants were afraid of an unknown person coming to their door, and some participants also voiced fears of being stigmatized by neighbors because a nurse was visiting the house.

Participants in the Spanish-speaking focus groups were asked whether they would seek out a traditional healer (“curandero”) for medical care. Participants were skeptical of the ability of curanderos to treat medical illness and did not express a great deal of trust for traditional healers. However, several Spanish-speaking participants stated they would go to a “naturalist” to supplement traditional medical care.

The cost of health care was an important issue for participants and was mentioned in all 11 focus groups. In all focus groups, health care costs were felt to be too high and represented a significant barrier to seeking care. However, Spanish-speaking participants also stated they knew they would receive health care in the United States regardless of their ability to pay for it, which was not true in some of their countries of origin.

Prejudice and Stigma

While most participants explicitly stated that TB could affect anyone and did not discriminate on the basis of race or socioeconomic factors, TB was usually described as a disease that affected persons belonging to a social group different from that occupied by the speaker. For example, members of the men’s alcoholic recovery group stated they were at risk of being infected with TB because they were regularly in contact with “street people” and unknown people in Alcoholics Anonymous meetings. The homeless women said that people of “low income” and “low social status” were more susceptible to being infected with TB. One nonimmigrant participant said the incidence of TB has increased because immigration has increased. A Hispanic immigrant described a Chinese acquaintance being ill with TB. This projection of disease onto other social groups, particularly groups perceived as less desirable in the eyes of the participant, is evidence for the persistent stigma associated with TB:

There was a drunk in my town that died and he was lying on the corner coughing. That is, but he wasn’t anyone I knew… we just knew he had TB, but…Oh, he was so skinny, you could see his skeleton. He didn’t… he just had his skin hanging off, but I don’t remember… I was little. I remember that we weren’t to go near him. He was always on the corner.

Participants also expressed a strong aversion to persons with TB. Many participants responded “Stay away” to the question “What would your reaction to someone who you found out has TB?”

Willingness to Take Medication

Most participants responded when asked that they would be willing to take 9 months of oral medication to prevent TB (LTBI treatment). However, when the question was rephrased,
emphasizing that LTBI treatment would consist of taking medication when one did not feel sick, the responses changed. For example, when subjects at one of the homeless shelters were asked “Would you be willing to take a drug every day for 9 months to prevent TB?” they answered unanimously in the affirmative. However, when asked, “Would you be willing to take a drug every day for 9 months if a doctor told you that you had TB even though you felt well and not sick?” they answered “it depends” or “not without a lot of tests.”

Participants had various suggestions to improve patient adherence to LTBI therapy. Suggestions ranged from showing graphic pictures of people dying with TB to offering education about TB. One participant suggested that bringing LTBI therapy to the patient, rather than making the patient pick it up at the health department, would improve adherence. Many participants stated that incentives, including food and money, would be effective for increasing rates of LTBI treatment adherence. Emotional support by health care providers also was mentioned: “Give them encouragement for taking the pills” and “Spend time with the person so they don’t feel so alone.”

Several participants felt that persons who were in the habit of taking medications or vitamins every day would be more able to remember to take LTBI therapy. Conversely, participants were skeptical that persons who do not have regular, healthy practices could be expected to take medication every day:

I think the biggest problem is, is that right now a lot of people who would have to take it [the TB treatment], their lifestyle doesn’t really coincide with doing things at a normal time, like taking the medicine every day is like taking a bath every day, well a lot of people on the street don’t take a bath every day it would be hard to get them to do something on a regular basis all the time.

Locus of Responsibility for Health

Participants’ perceptions of who is primarily responsible for their health had important effects on attitudes toward TB prevention and treatment. Many participants felt responsibility for health care rests primarily with the individual:

Of course you are going to have people who aren’t going to take it [treatment for LTBI] no matter how bad it is, ‘cause they are just that way. But people who care about themselves and their health and their family are going to do it. You can’t make people care, but they either care or they don’t but the ones who do I think if they have the right information, if they were educated, they would.

However, other participants placed the responsibility for TB prevention with health care providers and the health care system. For example, one participant said that she distrusted a local hospital, and when she was asked if this could ever affect her seeking out treatment there if necessary for TB, she responded “No, I would still go, but it would be up to them to do it all.” Several participants believed that it is the health care professional’s job to convince, coax, and bribe persons with LTBI or active TB into making healthful choices: “Society loves money, pay them.” A summary of emergent themes with illustrative quotations is provided in Table 1.

Discussion

Misconceptions About Tuberculosis

As in reported studies,8,11,15,18,19 we found participants had many inaccurate perceptions of TB cause and transmission. They frequently believed TB was transmitted by fomites, direct contact with another person’s skin, and sharing eating utensils. These beliefs have been reported in a number of different populations including migrant farm workers34 and Vietnamese refugees.9 Participants inappropriately applied what they knew about other common diseases to TB. In particular, participants often applied what they knew about the spread of HIV to TB, and several participants said TB was transmitted “like AIDS.” Like the present study, homeless persons surveyed in San Francisco similarly applied HIV concepts to TB transmission.13 Participants appeared to apply knowledge of other diseases to TB; for example, “TB is only curable if caught early” may reflect knowledge about cancer. Although these statements attest to the efficacy of public health education efforts for other diseases, the resultant misinformation may have unintended deleterious consequences for TB control efforts. If TB is perceived (as it was by at least one participant) as an incurable disease (like HIV at present), patients will be discouraged from seeking care, thus delaying diagnosis with resultant increased transmission and morbidity.12 Furthermore, perceptions that hand washing or other general hygienic measures prevent TB infection may give persons a false sense of security that they are protected from TB disease.9 Tuberculosis education should stress the distinctions between TB and other diseases and must include information about cause, transmission, and treatment of LTBI and active TB.

Stigma

Stigma may have a significant impact on a person’s willingness to be tested and treated for TB.14,19 In a Chicago survey of African Americans with TB, study participants overwhelmingly reported feelings of embarrassment and isolation among their community, family, friends, and coworkers.20 In another survey of Latinos receiving LTBI treatment, 17% of participants reported having TB was an embarrassment in their country of origin.8 Stigma may result in severe social consequences; in one study in Mexico City 50% of hospitalized TB patients were not received back into their homes after hospital discharge.21 Fear of being stigmatized by family, friends, coworkers, and community may be an important potential predictor for whether the patient initiates and completes therapy for LTBI.

Participants’ Ideas on Adherence to Latent Tuberculosis Infection Therapy

Participants’ ideas of what would affect an individual’s likelihood to complete LTBI therapy can be divided into 3 groups: habits, social factors, and motivation. Health care-related
habits may play a significant role in LTBI treatment adherence. A recent study of adherence to LTBI noted a positive univariate association between having a primary care physician and completion of LTBI treatment, and the belief that seeing a health care worker regularly keeps one healthy was also associated with treatment completion. Social factors, including availability of stable housing, have been associated with likelihood to complete LTBI treatment. Motivation is also clearly important when considering likelihood to complete LTBI treatment. Patients who feel they are at risk to develop active TB are more likely to complete LTBI treatment whereas those who expressed aversion to venipuncture (used in some patients for liver function monitoring) were less likely to complete treatment. Understanding where different patient groups place responsibility for their health may be a key factor in designing strategies to improve adherence to LTBI treatment in these groups. The emotional dynamics between a particular health care provider and patient play an important role in patients’ perceptions of responsibility for their health and resultant motivation to adhere to a treatment plan. A study of Haitian immigrants demonstrated the importance of emotional needs related to the treatment of LTBI, and the authors concluded that a “personal approach” was an important aspect of treatment. Some studies suggest that directly observed therapy, which provides for frequent one-on-one encounters between patients and health care workers, increases completion rates for LTBI treatment. At least one study demonstrated that monetary incentives improve adherence to LTBI therapy among homeless persons. The current study suggests the hypothesis that patients’ attitudes toward emotional or financial incentives could predict initiation and completion of LTBI treatment.

Strengths and Limitations
The findings of this study are strengthened by the fact that our focus groups were assembled from 3 different high-risk populations and conducted in diverse settings. The demographic mix was also diverse with a balance of gender and ethnic groups. A standardized set of questions was used to guide the groups. In addition, the focus group transcripts were reviewed independently by 4 persons to identify recurring themes.

There were several limitations of this study. The subjects represented a convenience sample and may not be representative of their respective populations. The number of participants in each focus group was relatively small, with a small number of total participants from the drug/alcohol treatment centers, which may result in suboptimal theme saturation and reduced generalizability of the results. Furthermore, persons participating at the homeless shelters and drug rehabilitation facilities refused to provide demographic data. The 8 English-speaking focus groups were conducted by a white female, which may have affected the group dynamics. A focus group facilitator of a different sex, race, or age might possibly have provided a more conducive environment to talking about such a sensitive subject. Obviously, there are many high-risk populations that were not represented in this study (eg, non-Hispanic foreign-born persons, prisoners), but the 3 populations chosen are frequently targeted by TB control programs in the United States.

Implications
The information presented here regarding TB knowledge, attitudes, and behaviors in 3 key high-risk populations is a first step in understanding how to reduce the burden of TB in these populations. This study of 3 populations at relatively high risk for LTBI has identified several possible predictors of initiation and completion of LTBI therapy: (1) knowledge of cause, transmission, and treatment of LTBI; (2) stigma associated with TB; (3) health maintenance practices; and (4) financial and emotional needs. We intend to use these potential predictors to develop a survey that will be administered to persons with LTBI prior to initiation of LTBI treatment. Survey responses can then be correlated with adherence to LTBI treatment, and specific interventions can be developed to improve LTBI adherence when specific knowledge deficits, attitudes, or beliefs are expressed.
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