Latent tuberculosis infection: Misperceptions among non-U.S.–born-populations from countries where tuberculosis is common

John Parmer[a], **Everly Macario**[b], **Katharine Tatum**[a,c,d], **Alejandra Brackett**[e], **Leeanna Allen**[a], **Rachael Picard**[e], **Nick DeLuca**[a], **Molly Dowling**[a]

[a]National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Division of Tuberculosis Elimination, Centers for Disease Control and Prevention, Atlanta, GA, USA;

[b]IQ Solutions, Inc., Chicago, IL, USA;

[c]Department of Sociology, Emory University, Atlanta, GA, USA;

[d]Oak Ridge Institute for Science and Education (ORISE), Oak Ridge, TN, USA;

[e]IQ Solutions, Inc., Rockville, MA, USA

Abstract

The Centers for Disease Control and Prevention works to eliminate tuberculosis (TB) disease by finding and treating cases of TB disease and expanding latent tuberculosis infection (LTBI) testing and treatment to prevent TB disease. Approximately 70% of reported TB cases in the United States occur among non-U.S.–born persons. We conducted 15 focus groups with U.S. residents born in the six most common countries of birth among non-U.S.–born TB patients: Mexico, the Philippines, India, Vietnam, China and Guatemala. Participants reacted to 39 messages on LTBI and TB disease risk factors, the Bacille Calmette-Guérin (BCG) vaccine, and LTBI testing and treatment. There was low awareness of LTBI, the TB blood test, and how the TB blood test is not affected by prior BCG vaccination. Several participants thought TB disease is contracted by sharing kitchenware. Some felt negatively targeted when presented with information about countries where TB disease is more common than the U.S. Findings highlight the need for communication aimed at increasing LTBI testing and treatment to include messages framed in ways that will be resonant and actionable to populations at risk. Focus groups revealed LTBI misconceptions which highlight areas for targeted education to decrease TB stigma and increase LTBI testing and treatment.

Keywords

Latent tuberculosis infection; tuberculosis; immigrants; message testing; misperceptions

Introduction

Tuberculosis (TB) disease occurs when a person becomes infected with *Mycobacterium tuberculosis* and the body's immune system is unable to stop it from multiplying. Not everyone infected with TB bacteria develops TB disease. From a clinical diagnostic perspective, there are two TB-related conditions: latent tuberculosis infection (LTBI) and TB disease (Lewinsohn et al., 2017) – both of which have distinct and separate ICD-10 codes (Centers for Disease Control and Prevention [CDC], July 17, 2020). Individuals with LTBI do not exhibit any symptoms, do not feel sick, and cannot spread the bacteria to others. Between 5–10% of people with untreated LTBI will develop TB disease – at which point they usually exhibit TB-related symptoms (persistent cough, chest pain) and feel sick, and may become contagious and can spread the bacteria to others. LTBI can be treated to prevent progression to TB disease, reducing the chances of a person becoming sick as well as transmitting the bacteria to others – a strategy vital to achieving TB elimination (Sterling et al., 2020). Previous research has investigated barriers to TB care, including LTBI testing and treatment, from the perspective of various migrant patient populations living in low-burden TB countries (De Vries et al., 2017; Tomás et al., 2013). This research has found a wide range of misperceptions about TB/LTBI among patients, including how TB is transmitted, the effectiveness of the TB vaccine over time and the interpretation of TB skin test results. In addition to examining the misperceptions of TB/LTBI patients, it is important to understand perceptions and understanding among persons at risk for TB/LTBI to increase the effectiveness of LTBI messaging among those outside of a clinical setting.

The CDC works to eliminate TB disease in the U.S. through a dual approach of finding and treating cases of TB disease and expanding LTBI testing and treatment to prevent TB disease. In 2019, the number of reported persons with TB in the U.S. was 8916 (case rate: 2.7 cases per 100,000 population) (CDC, 2020). Approximately 70% of reported persons with TB in the U.S. occur among non-U.S.–born people (CDC, 2020), and more than 80% of people who develop TB disease in the U.S. each year get sick from longstanding, untreated LTBI. The six most common countries of birth among non-U.S.–born TB patients are Mexico, the Philippines, India, Vietnam, China and Guatemala (CDC, 2020).

CDC conducted focus groups with non-U.S.–born individuals from Mexico, the Philippines, India, Vietnam, China and Guatemala to inform the development of understandable, believable, and motivating LTBI messages that will energise LTBI testing and treatment among priority audiences. While the primary goal of this project was to improve messages related to LTBI testing and treatment, several focus group discussion topics focused on TB more generally – including both TB disease and LTBI. Although LTBI and TB disease are two distinct conditions from a clinical diagnostic perspective, it was important to explore participants' familiarity and understanding of both conditions as they relate to their knowledge and perceptions on topics such as who is at risk, transmission and diagnosis.

These discussions generated a wide range of findings that have been presented, or in preparation to be presented, elsewhere (Parmer, 2020; Parmer et al., 2020). The objective of this paper is to focus on the LTBI and TB misperceptions – defined as incorrect interpretations or understandings – that were unveiled in these focus group discussions. The focus on this theme is a result of inductive analysis of the original data. This work contributes to the existing literature on misperceptions as a barrier to TB/LTBI care and includes the additional perspective of persons at risk for TB, but outside of a clinical setting. Finally, we examine associated implications for future LTBI messaging.

Methods

Data for this paper derive from a CDC-funded project that evaluated how well LTBI messages performed among non-U.S.–born persons at risk for TB. In April/May 2019, we conducted 15 focus groups, all in English – in Chicago (Illinois), Houston (Texas), Miami (Florida), New York City (New York) and San Francisco (California) – with U.S. residents born in Mexico, the Philippines, India, Vietnam, China, and Guatemala. The TB case rates in each of the focus group metropolitan areas equalled or exceeded the 2018 national average of 2.8 cases per 100,000 population (Sterling et al., 2020) and represented areas with some of the highest rates of TB within the U.S. Additionally, persons born in the countries of interest are well-represented among these cities. Focus groups were chosen as the most appropriate qualitative research methodology for this project because they allow for an exploration of subtleties in messages being tested and to hear the vocabulary used by participants in their own voices, as well as allowing participants to build-off of one another's ideas to arrive at consensus or disagreement. To reach data saturation, a minimum of two focus group discussions were conducted by country of birth and U.S. city (Hennink et al., 2019).

Theoretical framework

We referred to the Health Beliefs Model (Chang et al., 2007; Jones et al., 2015) for a theoretical framework in informing both the development of the messages to test and the approach for analysing the findings in our study. The Health Beliefs Model suggests that a person's belief in a personal threat of an illness or disease together with a person's belief in the effectiveness of the recommended health behaviour or action will predict the likelihood the person will adopt the behaviour. Ultimately, a person's course of action often depends on the person's perceptions of the following:

- *Susceptibility* (a person's subjective perception of the risk of acquiring an illness or disease).

- *Severity* (a person's feelings on the seriousness of contracting an illness or disease).

- *Benefits* (a person's perception of the effectiveness of various actions available to reduce the threat of illness or disease).

- *Barriers* (a person's feelings on the obstacles to performing a recommended health action).

- *Cue to action* (a stimulus needed to trigger the decision-making process to accept a recommended action).

- *Self-efficacy* (a person's confidence in their ability to successfully perform a behaviour).

Pilot test

Before convening the in-person focus groups, we pilot-tested the data collection instruments (moderator's guide, participant recruitment screener, and informed consent form). We held two web-enabled telephone focus groups, one group with four individuals born in Mexico and a second group with four individuals born in The Philippines. The moderator tested a sample of messages, seeking reactions from participants to at least one message from each of five Message Theme areas.

From the pilot test, we learned that the pace of the overall conversation was appropriate to the length of the moderator's guide. We concluded that it would be most efficient and effective if the moderator read all messages aloud rather than inviting rotating participants to read them. For all questions rated on a Likert scale (1–10), we agreed that participants should first write their individual numbers on a piece of paper prior to the moderator collecting all participant responses in a round robin and inviting participants to articulate reasons behind their answers (The intention was to reduce the influence of other participants on individual responses.) We made some minor text changes to the moderator's guide to enhance clarity. For example, we revised one question to ensure the moderator did not directly ask participants about their personal TB skin or TB blood test experiences, but we worded instructions to welcome participants to share such experiences in a voluntary, organic manner if they chose. The recruitment screener and informed consent form did not need revising, as no issues arose with either of these documents during the pilot test.

Recruitment

The project team engaged a professional recruitment vendor in each of the five metropolitan areas to recruit participants. These vendors manage their own databases of thousands of potential participants, in their local areas, who have voluntarily opted-in to be contacted for potential focus group opportunities. Each vendor administered a standardised recruitment screener to assure eligibility of individuals invited to participate. Eligible focus group participants included birth in the designated countries who were 18+ years of age. We conducted a minimum of two focus groups by country. To secure feedback from a diverse sample of individuals per country of origin, we aimed to recruit a mix of genders, ages, years living in the U.S., education levels, incomes, healthcare usage and health insurance types per each focus group (Appendix). Focus groups ranged in size from 6 to 9 participants each, totalling 126 participants across a total of 15 focus groups (Table 1). Each participant received a token of appreciation for their participation.

Data collection procedures

A trained and experienced moderator with an advanced degree in public health led each focus group session, approximately 90 min each. The moderator is also an immigrant and

mentioned this to participants in her introductory script to develop rapport. All discussions were audio-recorded.

Messages

The moderator provided participants a written message packet, in English, containing messages divided into Message Themes. Each theme represented a category for organising various topics related to LTBI and for crafting public health messages with targeted information and calls-to-action. Each theme below is accompanied by a sample message tested in the focus groups. (The authors can provide the focus group moderator's guide and a full list of messages tested upon request.)

1. Theme A: Basic LTBI information. (Sample message: Anyone can get TB. TB germs are spread through the air from one person to another.)

2. Theme B: Risk factors for LTBI developing into TB disease. (Sample message: Most TB disease in the United States of America is caused by reactivation of latent TB infection.)

3. Theme C: Bacille Calmette-Guérin (BCG) vaccine. (Sample message: People who were vaccinated with BCG can get infected with TB and become sick with TB.)

4. Theme D: LTBI testing and diagnosis. (Sample message: Anyone can get infected with TB germs. However, some people have a higher risk of getting infected with TB germs.)

5. Theme E: LTBI treatment. (Sample message: Taking TB medication is the only way to kill the TB germs in your body.)

Although we developed 39 messages to test, each focus group reviewed 25 of the 39 messages representing all five message themes. We rotated messages across focus groups so that each message received equal attention.

The aim of seeking feedback on a large number of messages was to eventually narrow them down to a few key messages that resonated most among participants for maximising effectiveness in reach and impact during post-project communications.

Discussion flow

The moderator first explored participants' overall health concerns, followed by their familiarity with TB/LTBI. Then, the moderator presented a brief presentation on TB/LTBI. After this educational activity, the moderator reviewed messages with participants. The moderator spent the bulk of the discussions listening to participants' comments on the clarity, understandability, appeal of, and suggestions for improving the messages. The discussions concluded with an inquiry around trusted health information sources.

Analysis

Professional transcription services were used to transcribe – verbatim – all focus group discussions. At least two project team members took notes during each of the live focus

group discussions (one at the focus group facility observation room and a second in a remote location using live video streaming). Verbatim transcripts were divided among three data analysts – all with advanced degrees in public health – and analysed using an inductive approach, following the structure of the focus group guide. Each analyst read their transcripts, placing synthesised information into a table organised by message theme and the six countries. The reason the data analyst team segmented findings by country of origin was to explore across-country similarities as well as unique country-by-country differences, such as population-specific preferred and trusted sources of health information and communication channels. Next, two analysts coded the synthesised information for recurring themes (both within and across countries), identified trends, patterns, and extracted illustrative participant quotes. The analysts summarised information on participants' comprehension of messages, questions/concerns, and understanding of terminology. Throughout the analysis, the project team discussed findings and arrived at consensus on conclusions.

On 13 December 2018, CDC's Associate Director for Science (ADS) deemed this project 'not human subjects research' and thus found the research to be exempt. On 28 February 2019, we received Office of Management and Budget (OMB) approval for this project (OMB Control number: 0920–0840). We obtained written informed consent from all focus group participants.

Results

The results presented here focus on LTBI and TB misperceptions – defined as incorrect interpretations or understandings – that were unveiled as part of the wider focus group discussions described above. Table 2 provides a summary of focus group participants' demographic characteristics.

TB knowledge

Although participants across focus groups correctly pointed to TB as affecting the lungs, causing coughing, and being spread through the air, participants showed some misunderstandings around transmission. (Note: While TB can occur outside of the lungs, because of this project's public health lens and concomitant primary concern of preventing person-to-person TB spread we focused on pulmonary TB.) For example, the use of the word 'air' as the method of spread was confusing to a few participants. One participant associated 'germs' with tangible surfaces rather than air. A few participants, moreover, did not believe that TB is an airborne disease.

Participant A [Message: '…TB germs are spread through the air….']

What do you mean by 'air'? Is it the air from the person?

Participant B I'm not sure whether it's through the air, but I thought it's maybe saliva or something like that. That's how you spread the TB germs.

Participant C When I think of germs, I would think it's on a surface rather than having it through the air ….

Participant D I don't think you can catch TB by inhaling the air that the infected person has.

A prominent and incorrect belief – raised by at least one participant in three of the focus groups – is that TB can be contracted via the sharing of food/drinks or shared use of utensils/ dishware. Some participants indicated learning about TB from family members; a common belief was that TB was contracted from shared utensils. In two focus groups, participants expanded this idea with further comments on sharing a glass of water or exchanging saliva as ways to spread TB.

Participant E Going back to my experiences with my family, my aunt [who had TB], every utensil she used [was] basically separate. So, from what we were told when we were little, 'Never use the utensils that she used', even her plates. Because, then, through bodily liquids is how you're going to catch it.

TB skin test, TB blood test and the BCG vaccine

In each of the 15 focus groups, at least one participant reported having had a TB test. There are two types of TB tests, a skin test and a blood test. Almost all participants only had knowledge and experience with the TB skin test. Most participants were unfamiliar with the TB blood test. In at least two focus groups, participants had mixed certainty about what a 'positive TB test' indicates. Some were confused about whether a 'positive' test result indicates a 'good' or 'bad' result in terms of TB disease and one's health. For both types of tests, in fact, a 'positive' result indicates a person has likely been infected with TB bacteria.

Many participants confused the TB skin test with the BCG vaccine as they both use injections. Furthermore, across focus groups, participants expressed a lack of knowledge, and potential misperceptions, regarding the impact of the BCG vaccine on TB skin test results. Several participants believed that their positive TB skin test reaction was due to their vaccination with the BCG vaccine as a child. Participants expressed little knowledge that the BCG vaccine's protection wanes over time. That BCG vaccine may cause a false-positive TB skin test (TST) reaction, and there is no reliable way to distinguish a positive TST reaction caused by BCG vaccination from a reaction caused by true TB infection, was a source of confusion among participants.

Participants had an overall low level of knowledge of the TB blood test; none were aware that the TB blood test is not affected by prior BCG vaccination (Mazurek et al., 2010). Once participants were educated on this fact, overall understanding improved. Participants did show some knowledge that prior BCG vaccination affects skin test results.

Participant F When I became a citizen, I had to … do that skin test. The doctor told me, 'You're positive'. So, you're positive. You have that in your system. I knew I had it because I had the vaccine when I was a kid.

Some participants' confusion around BCG vaccination not conferring protection for life probably stemmed from comparing this vaccine with many immunizations that do provide lifelong protection.

Participant G I had [the TB vaccine] when I was a baby. I don't know, maybe within the first three months when I was born. When I came here [the USA] when I was 18, that's when they insisted [that] I had to get it again, because, 'Even though you had it 18 years ago, that vaccine can be less effective after years of aging'.

Participant H Because I had a shot. It was my understanding that when you have all the shots as a kid that you don't have to keep going.

Participants in one focus group questioned the veracity of messages communicating the fact that individuals with prior BCG vaccination can still become sick. This focus group, along with participants from a second focus group, found this message to be contradictory, leading some to question the point of the BCG vaccine and others to become concerned about getting sick from this vaccine itself.

Participant I Basically, [the message is] trying to tell you that if you get the vaccine, you will get infected because you received the vaccine, you might get sick afterwards.

Participant J Because if you have the vaccine, you should be protected. You feel like every time you get vaccinated you're protected. So, if you're protected, why would it get weak over time?

Participant K Even if I saw this in a medical source, I would doubt it. It just sounds weird. It sounds counter-intuitive. Like you're getting vaccinated, and then you can still get this disease and become sick. So, what is the point of getting vaccinated?

Countries where TB is common

Participants reacted with mixed levels of acceptance and offence to messages communicating countries where TB is common. They wondered why certain countries have higher TB prevalence than the U.S. In attempting to explain TB prevalence disparities across countries, participants referenced genetic, racial and cultural factors. However, some participants pointed to differences in structural factors in explaining differences in TB across countries.

Participant L I have another very basic and dumb question. Is TB disease genetic? If it is not genetic, then why does it matter if someone is born there?

Participant M Maybe the disease control isn't as it is here in the USA. Because here we actually have … clinics and you're going in for immunizations … compared to … somewhere else. Mexico—you know it's not really a big concern [there] as it is here in the USA.

When the moderator asked participants to react to messages listing countries where TB disease is more common, several participants interpreted these messages as blaming, and singling out, immigrants for bringing disease into the U.S.

Participant N Is this a nice way of saying that immigrants bring in TB? It's like they're trying to spin it to say that if you're natively born in the USA, you're not going to really have a TB issue.

Participant O I have a negative feeling about [this message]. I think it basically profiles you racially. Because all of a sudden, 'You're from the Philippines, you're high-risk', or 'You're from Guatemala, you're high-risk'. So, it's like I feel like I'm being racially profiled.

Participant P This administration [is saying that] illegal aliens are bringing in disease. 'They're bringing in disease', and it's not the case. I think it's the government.

Other participants expressed that they did not find these messages to be offensive and thought it important to highlight the increased risk among their group, but in a sensitive and non-stigmatizing way. These participants recognised the importance of educating themselves about all countries where TB is common.

Moderator Is [the message] offensive?

Participant Q No, there must be some reason for [people born in countries where TB disease is more common] to get it. I think it's malnutrition and living conditions.

Participant R I'd want to know which countries, because there's so many countries.

Participant S Even if they identified the countries, I wouldn't be offended because it's fact.

A few participants expressed increased motivation to get tested once learning they were at increased risk.

Moderator How motivational is this statement to get you, you personally, to get tested for TB infection?

Participant T I think it increases my probability much more because I might not be going back to Vietnam, but I might go to Mexico for a vacation, maybe some place else … like China or India.

Participant U I'm not gonna [sic] run out of the door and do it, but next time I'm gonna [sic] be at the doctor's, I'm like, 'Hey, can you do it?'

LTBI familiarity

Very few participants had heard of latent tuberculosis infection (LTBI) prior to the focus groups. Participants who offered a guess at defining 'latent', a term unfamiliar to them, did a relatively good job at guessing. Participants used terms like 'dormant', 'incubation/incubated', 'inactive', 'not active', 'initial phase', 'delayed', 'remission', and 'carrier'.

Participant V 'Latent' means that somebody has the TB—the germ in your body is inactive. TB disease is active.

Participant W 'Latent'? I kind of know what it means, but it's one of those words that is not clear enough … or may not be clear enough for people that may not know.

In attempting to define 'latent tuberculosis infection', however, participants also communicated aspects of LTBI that are incorrect, including that you can 'pass it onto someone else', there is 'no medicine for treatment', and it is a 'later stage'.

Participant X Is it tuberculosis that you passed onto your baby by lactating?

Participant Y You don't have the medicine for the treatment.

Participant Z I would say it's probably the later stage of tuberculosis.

One participant who asked about the distinction between a carrier and having LTBI generated additional concerns that the 'carrier' terminology could lead to misperceptions about culpability.

Participant AA What's the difference between a 'carrier' and a latent TB infection? Are they the same concept?

Participant BB I would add that calling somebody a 'carrier' sounds like placing the blame on the person versus facts, and it's just like, 'It's a disease. It's not my fault'.

LTBI treatment

Participants in almost every focus group were initially shocked to learn that treatment for LTBI can take up to 9 months, depending on the regimen. Even though 'shorter' regimens of 3–4 months are now available, many participants felt it was still unusually long. Discussions on the meaning of 'regimen' revealed inconsistent and many incorrect definitions. Some participants linked the word to the course of treatment, while others spoke of the word in terms of the disease itself, such as 'how serious' or 'aggressive' the disease is, or the different phases/stages of the disease. These varied definitions engendered more questions about LTBI treatment in general (Why is treatment so long? What is the treatment cost? What are the short- and long-term treatment side effects and how severe are they?). Some participants reported that they would not seek LTBI treatment without symptoms, while others were relieved to learn there was a prevention option and would consider taking medication, especially when recommended by a healthcare provider.

Trusted health information sources

Each focus group concluded with an inquiry around trusted health information sources. The most common trusted source for health information cited in all focus groups was a participant's personal doctor. Participants across focus groups echoed each other in their suggestion to place information on LTBI in traditional media outlets, such as television, radio and newspapers – in languages other than English.

To address sentiments shared by participants in early focus groups, the moderator began exploring feelings related to outreach efforts by CDC – specifically ads on social media that are customised to a certain population – in remaining focus groups. In other words, would

customisation be perceived and received as appropriately attention-grabbing and beneficial or as unnecessary 'profiling' with the potential unintended consequence of singling out or marginalising the targeted group? In general, participants across focus groups reported welcoming information on LTBI, stating that it is appropriate to tailor outreach to specific populations. A small minority, in comparison, expressed a preference for delivering LTBI information 'in general terms'. The Philippines group stood out as strongly opposed to tailoring. Some Filipino participants in San Francisco equated targeted outreach as 'being profiled' or 'singling out Filipinos', recommending 'making information relatable to other people [such as through] travelling [the topic of travel]', 'including all Americans', or 'listing all countries together'.

Discussion

In this paper, we sought to examine TB-related misperceptions that were unveiled as part of larger focus group discussions on LTBI and TB aimed at improving LTBI messages to energise LTBI testing and treatment among priority audiences. Because incorrect interpretations and misunderstandings of TB/LTBI messages can limit perceived risk, as well as healthcare-seeking motivation and behaviours such as the willingness to get tested and treated for TB/LTBI, our aim here is to provide areas for enhancing TB/LTBI messaging. We present below several themes that emerged from these incorrect interpretations and misunderstandings, as well as recommendations for addressing them in future efforts.

TB skin test, the BCG vaccine, and a false sense of protection and hesitancy around testing.

Of all topics discussed in the focus groups, the conversations on the BCG vaccine, and the impact of it on TB skin test results, caused the most confusion. Conflating a TB skin test with having received the BCG vaccine, as they both use injections, appeared to influence the understanding of subsequent TB testing and perceived protection against TB. (The TB skin test uses injected tuberculin to elicit an immune response, while BCG vaccine is often given to infants and small children in other countries where TB is common, to prevent TB meningitis) (A Joint Statement by the Advisory Council for the Elimination of Tuberculosis and the Advisory Committee on Immunization Practices, 1996). Confusion over the meaning of a 'positive TB test' result, and unawareness of the TB blood test (and that it is not affected by prior BCG vaccination), moreover, added to this topic's complexity. Misperceptions about the BCG vaccine could give people a false sense of relief. The common, yet incorrect, belief that the BCG vaccine confers immunity for life might prevent people at risk of TB from getting tested or may alter interpretations about the importance of a positive TB test and the decision to take LTBI treatment. Future messaging should clearly explain that prior BCG vaccination can affect TB skin test results, potentially yielding false-positive results; clarify that prior BCG vaccination does not affect TB blood test results; and, explain why BCG vaccine protection wanes over time and why testing is necessary even for those with prior BCG vaccination.

Stigmatisation of those at highest risk.

One major concern is the stigmatisation of those at highest risk for LTBI – in this case, non-U.SA.-born people, especially those newly arrived to the U.S., who already may feel singled-out and stigmatised for other reasons (Degeling et al., 2020; Lönnroth et al., 2009). Previous studies among migrants in other low TB incidence countries suggest that TB programme activities and representations of migrants in media reporting of TB are implicated in the stigmatisation of migrant groups (Craig et al., 2017; Horner, 2016). In addition, studies have shown TB stigma to be a barrier to early diagnosis and a deterrence to TB treatment adherence (Davidow et al., 2015; Gao et al., 2015; Gebreweld et al., 2018; Murray et al., 2013; Sommerland et al., 2017; Wieland et al., 2012). In the context of these concerns, interventions aimed at reducing TB stigma and improving TB testing and treatment adherence should involve community members in discussions about key issues that can guide message development and programme design. In addition, unfamiliarity with the term 'latent' may lead to incorrect interpretations and stigmatisation, such as when participants described it as meaning you can 'pass it onto someone else' and expressed concerns that the 'carrier' terminology could lead to misperceptions about culpability. Including a definition or examples next to 'latent' when the word is used in messages or considering alternative language such as 'inactive', may help address the unfamiliarity of this term in LTBI messaging. Overall, communications should be careful to develop and provide information that is accessible, particularly for audiences who may have limited health literacy skills and experience other language barriers, with particular focus on the health literacy demand of the materials and information (Berkman et al., 2011).

Misperceptions of perceived risk.

While several participants expressed that they did not find offensive messages about countries where TB disease is more common than the U.S. and thought it important to highlight the increased risk among their group, others expressed misperceptions about what may explain TB disparities across countries. The belief that higher TB rates in certain countries must have something to do with genetics or culture, rather than differences in investment in public health infrastructure and coordinated efforts in TB programme activities and prevention, might lead some people to avoid getting tested for concern of being racially profiled (Degeling et al., 2020; Lönnroth et al., 2009). Negative reactions to messages about countries where TB disease is more common could engender ill-will with the message source. Communicators should consider developing nuanced messaging around describing common countries of birth among non-U.S.–born TB patients. This could include clarifying that these countries are not necessarily those with the highest rates of TB, but rather that they contribute the most cases to the U.S. because of immigration patterns. Additionally, identifying more than one country where TB is common may be one way to message about this topic in a sensitive and non-stigmatizing way.

Education can improve knowledge and accuracy of information-retention, which is an important step in the procession towards motivating behaviour change. For example, as a result of viewing the educational presentation and reviewing messages in the focus groups, an earlier belief that TB disease can spread through the sharing of an infected person's kitchenware was debunked for several participants. Participants across focus groups also

grew in their understanding of the concept of being infected with TB bacteria and not feeling sick or exhibiting symptoms, with several likening this condition to HIV/AIDS, herpes, and human papillomavirus. Other investigators have also found that TB stigma can be attenuated by TB education (Gebreweld et al., 2018; McEwen, 2005; Rodríguez-Reimann et al., 2004). Any communications or outreach efforts aimed at increasing LTBI testing and treatment must include messages framed in ways that will be resonant and actionable to priority audience segments, and directly address misperceptions that could potentially suppress healthcare-seeking behaviours. Variations in non-U.S.–born populations at risk for TB must also be considered in the development of targeted culturally sensitive messages and interventions aimed at reducing TB stigma and improving TB testing and treatment adherence (Chang & Cataldo, 2014).

The TB/LTBI misperceptions presented here, as well as insights, learned as part of the wider focus group discussions about TB/LTBI knowledge, attitudes, risk perceptions and beliefs, inform continued inquiry with these priority audiences. In 2020, CDC conducted additional formative evaluation with these audiences using the Social-Ecological Model as the overarching multilevel theoretical framework that incorporates constructs from several health behaviour models and theories to examine individual, interpersonal, health setting, diagnosis and treatment, and societal and social structure levels of influence on LTBI testing and treatment decisions (Sallis et al., 2008). The results of these activities are being applied to the planning and development of a multipronged communication strategy and targeted messaging campaign to increase LTBI testing and treatment.

Limitations

This assessment has limitations, including a nonrandomly drawn sample and self-selection bias. Therefore, the final sample is not representative of any specific non-U.S.–born population. On the whole, participants had lived in the U.S. for many years, had a high level of English fluency, and were disproportionately skewed toward higher education and income levels. Because three-quarters of the participant sample had been in the U.S. for more than 10 years, results may not fully reflect the experiences of individuals who have recently immigrated to the U.S. Some messages, furthermore, may not have been as easy to understand if we had recruited participants with lower levels of English fluency. That said, this assessment provided insights at the root of participants' TB/LTBI-related knowledge, attitudes, beliefs, intentions and practices – in non-U.S.–born focus group participants' own words – and allowed for an exploration of subtleties in messages tested.

Funding

Appendix

Appendix

Appendix

Focus group participant demographics.

Country of Birth	China	Guatemala	India	Mexico	The Philippines	Vietnam	Total
Focus Group City							
Chicago 29 April 2019	1 focus group; 9 participants		1 focus group; 7 participants	1 focus group; 9 participants			*3 focus groups*; 25 participants
Houston 8–9 May 2019				2 focus groups; 18 participants		1 focus group; 9 participants	*3 focus groups*; 27 participants
Miami 11 April 2019		2 focus groups; 15 participants					*2 focus groups*; 15 participants
New York City 14–15 April 2019	1 focus group; 9 participants		2 focus groups; 17 participants		1 focus group; 6 participants		*4 focus groups*; 32 participants
San Francisco 17–18 April 2019					2 focus groups; 18 participants	1 focus group; 9 participants	*3 focus groups*; 27 participants
Total participants by country of origin	*2 focus groups*; 18 participants	*2 focus groups*; 15 participants	*3 focus groups*; 24 participants	*3 focus groups*; 27 participants	*3 focus groups*; 24 participants	*2 focus groups*; 18 participants	*15 total focus groups*; 126 total participants
% of total Participants	14.3% Chinese	11.9% Guatemalan	19.0% Indian	21.4% Mexican	19.0% Filipinos	14.3% Vietnamese	
Gender							
Female	10 participants	7 participants	15 participants	13 participants	13 participants	11 participants	69 Total Females; *55%* of total participants
Male	8 participants	8 participants	9 participants	14 participants	11 participants	7 participants	57 Total Males; *45%* of total participants
Age							
	36.3 average age (22–66, range)	36.5 average age (20–68, range)	36.2 average age (25–75, range)	32.5 average age (18–49, range)	40.9 average age (21–80, range)	48.7 average age (26–67, range)	*38.5 average age (18–80, range)*
Race							
White/Caucasian		15 participants		27 participants			42 Total; *33%*
Black/African American							0 Total; 0%
Asian/Asian American	18 participants		24 participants		23 participants	18 participants	83 Total; *66%*

Country of Birth	China	Guatemala	India	Mexico	The Philippines	Vietnam	Total
American Indian or Alaska Native							0 Total; 0%
Native Hawaiian/ Other Pacific Islander					1 participant		1 Total; *1%*
Ethnicity							
Yes, Latino/a		15 participants		27 participants			42 Total; *33%*
Not Latino/a	18 participants		24 participants		24 participants	18 participants	84 Total; *67%*
Length of time in U.S.							
Less than 10 years	6 participants	2 participants	9 participants	8 participants	8 participants	1 participant	34 Total; *27%*
More than 10 years	12 participants	13 participants	15 participants	19 participants	16 participants	17 participants	92 Total; *73%*
Level of Education							
< High School/No Diploma			1 participant	2 participants	2 participants		5 Total; *4%*
High School Graduate/GED	1 participant	1 participant		18 participants		3 participants	23 Total; *18%*
Some College or Technical School	3 participants	9 participants		4 participaints	4 participants	2 participants	22 Total; *17%*
Four-year College Degree	10 participants	5 participants	11 participants		15 participants	11 participants	52 Total; *41%*
Post-graduate Studies or Advanced Degree	4 participants		12 participants	3 participants	3 participants	2 participants	24 Total; *19%*
Total Household Income							
< $25,000		2 participants	2 participants	3 participants	2 participants	5 participants	14 Total; *11%*
$25,000–$49,999	6 participants	6 participants	2 participants	14 participants	3 participants	3 participants	34 Total; *27%*
$50,000–$74,999	6 participants	4 participants	2 participants	6 participants	8 participants	6 participants	32 Total; *25%*
$75,000	6 participants	3 participants	18 participants	4 participants	11 participants	4 participants	46 Total; *37%*
Health Insurance Type							

Country of Birth	China	Guatemala	India	Mexico	The Philippines	Vietnam	Total
Private	10 participants	8 participants	19 participants	5 participants	20 participants	15 participants	77 Total; *61%*
Medicare	2 participants	1 participant	1 participant	1 participant	1 participant		6 Total; *5%*
Medicaid		2 participants	3 participants	5 participants	2 participants		12 Total; *9%*
Military						1 participant	1 Total; *1%*
Other government	1 participant					1 participant	2 Total; *2%*
Self-purchased plan	5 participants	4 participants	1 participant	2 participants	1 participant		13 Total; *10%*
No insurance				15 participants		1 participant	16 Total; *13%*
Usual Medical Care Setting							
Doctor's office	15 participants	11 participants	17 participants	15 participants	19 participants	13 participants	90 Total; *70%*
Clinic/ health centre	1 participant	2 participants	5 participants	9 participants	3 participants	3 participants	23 Total; 18%
Health department		1 participant	1 participant				2 Total; *2%*
Emergency room			1 participant	3 participants			4 Total; *3%*
Hospital outpatient	1 participant	1 participant	2 participants		2 participants	1 participant	7 Total; *5%*
VA clinic						1 participant	1 Total; *1%*
Holistic/ Alternative							0 Total; *0%*
Did not report						1 participant	1 Total; *1%*
Provider Respectful of Culture							
Always	7 participants	14 participants	22 participants	24 participants	20 participants	17 participants	104 Total; *83%*
Almost always	10 participants	1 participant	2 participants	3 participants	2 participants	1 participant	19 Total; *15%*
Sometimes	1 participant				2 participants		3 Total; *2%*
Almost never							0 Total; *0%*
Never							0 Total; *0%*

REFERENCES

Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, & Crotty K (2011). Low health literacy and health outcomes: An updated systematic review. Annals of Internal Medicine, 155(2), 97–107. 10.7326/0003-4819-155-2-201107190-00005 [PubMed: 21768583]

Centers for Disease Control and Prevention. (2019). Reported tuberculosis in the United States 2018. CDC. Retrieved December 4, 2020, from https://www.cdc.gov/tb/statistics/reports/2018/default.htm

Centers for Disease Control and Prevention. (2020). Reported Tuberculosis in the United States, 2019. US Department of Health and Human Services, CDC. Retrieved December 4, 2020, from https://www.cdc.gov/tb/statistics/reports/2019/default.htm

Centers for Disease Control and Prevention. National Center for Health Statistics. (2020, July 17). International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM). Retrieved December 4, 2020 from https://www.cdc.gov/nchs/icd/icd10cm.htm

Chang SH, & Cataldo JK (2014). A systematic review of global cultural variations in knowledge, attitudes and health responses to tuberculosis stigma. International Journal of Tuberculosis and Lung Disease, 18(2), 168–173. 10.5588/ijtld.13.0181

Chang LC, Hung LL, Chou YW, & Ling LM (2007). Applying the health belief model to analyze intention to participate in preventive pulmonary tuberculosis chest X-ray examinations among indigenous nursing students. The Journal of Nursing Research, 15(1), 78–87. 10.1097/01.JNR.0000387601.24908.45 [PubMed: 17370235]

Craig G, Daftary A, Engel N, O'Driscoll S, & Ioannaki A (2017). Tuberculosis stigma as a social determinant of health: A systematic mapping review of research in low incidence countries. International Journal of Infectious Diseases, 56, 90–100. 10.1016/j.ijid.2016.10.011 [PubMed: 27810521]

Davidow AL, Katz D, Ghosh S, Blumberg H, Tamhane A, Sevilla A, & Reves R, & Tuberculosis Epidemiologic Studies Consortium. (2015). Preventing infectious pulmonary tuberculosis among foreign-born residents of the United States. American Journal of Public Health, 105(9), e81–e88. 10.2105/AJPH.2015.302662

Degeling C, Dip Sci G, Carter S, Dale K, Singh K, Watts K, Hall J, & Denholm J (2020). Perspectives of Vietnamese, Sudanese and South Sudanese immigrants on targeting migrant communities for latent tuberculosis screening and treatment in low-incidence settings: A report on two Victorian community panels. Health Expectations, 23(6), 1431–1440. 10.1111/hex.13121 [PubMed: 32918523]

De Vries SG, Cremers AL, Heuvelings CC, Greve PF, Visser BJ, Bèlard S, Janssen S, Spijker R, Shaw B, Hill RA, Zumla A, van der Werf MJ, Sandgren A, & Grobusch MP (2017). Barriers and facilitators to the uptake of tuberculosis diagnostic and treatment services by hard-to-reach populations in countries of low and medium tuberculosis incidence: A systematic review of qualitative literature. The Lancet Infectious Diseases, 17(5), e128–e143. 10.1016/S1473-3099(16)30531-X [PubMed: 28291721]

Gao J, Berry NS, Taylor D, Venners SA, Cook VJ, & Mayhew M (2015). Knowledge and perceptions of latent tuberculosis infection among Chinese immigrants in a Canadian urban centre. International Journal of Family Medicine, 546042(1). 10.1155/2015/546042

Gebreweld FH, Kifle MM, Gebremicheal FE, Simel LL, Gezae MM, Ghebreyesus SS, Mengsteab YT, & Wahd NG (2018). Factors influencing adherence to tuberculosis treatment in Asmara. Eritrea: A Qualitative Study. Journal of Health Population and Nutrition, 37(1), 1. 10.1186/s41043-017-0132-y [PubMed: 29304840]

Hennink M, Kaiser B, & Weber MB (2019). What influences saturation? Estimating sample sizes in focus group research. Qualitative Health Research, 29(10), 1483–1496. https://pubmed.ncbi.nlm.nih.gov/30628545/. https://doi.org/10.1177/1049732318821692 [PubMed: 30628545]

Horner J (2016). From exceptional to liminal subjects: Reconciling tensions in the politics of tuberculosis and migration. Journal of Bioethical Inquiry, 13(1), 65–73. 10.1007/s11673-016-9700-x [PubMed: 26757725]

A Joint Statement by the Advisory Council for the Elimination of Tuberculosis and the Advisory Committee on Immunization Practices. (1996). The role of BCG vaccine in the prevention and control of tuberculosis in the United States. Morbidity and Mortality Weekly Recommendations and Reports, 45(RR-4), 1–18. https://www.cdc.gov/mmwr/preview/mmwrhtmL/00041047.htm.

Jones CL, Jensen JD, Scherr CL, Brown NR, Christy K, & Weaver J (2015). The health belief model as an explanatory framework in communication research: Exploring parallel, serial, and moderated

mediation. Health Communication, 30(6), 566–576. 10.1080/10410236.2013.873363 [PubMed: 25010519]

Lewinsohn DM, Leonard MK, LoBue PA, Cohn DL, Daley CL, Desmond E, Keane J, Lewinsohn DA, Loeffler AM, Mazurek GH, O'Brien RJ, Pai M, Richeldi L, Salfinger M, Shinnick TM, Sterling TR, Warshauer DM, & Woods GL (2017). Official American thoracic Society/Infectious Diseases Society of America/Centers for Disease Control and Prevention clinical Practice guidelines: Diagnosis of tuberculosis in adults and children. Clinical Infectious Diseases, 64(2), 111–115. 10.1093/cid/ciw778 [PubMed: 28052967]

Lönnroth K, Jaramillo E, Williams BG, Dye C, & Raviglione M (2009). Drivers of tuberculosis epidemics: The role of risk factors and social determinants. Social Science & Medicine, 68(12), 2240–2246. 10.1016/j.socscimed.2009.03.041 [PubMed: 19394122]

Mazurek GH, Jereb J, Vernon A, LoBue P, Goldberg S, & Castro K, & Division of Tuberculosis Elimination, National Center for HIV, STD, and TB Prevention, CDC (2010). Updated guidelines for using interferon gamma release assays to detect Mycobacterium tuberculosis infection–United States, 2010. Morbidity and Mortality Weekly Recommendations and Reports, 59(RR-5), 3–6. https://www.cdc.gov/mmwr/preview/mmwrhtml/rr5905a1.htm.

McEwen MM (2005). Mexican immigrants' explanatory model of latent tuberculosis infection. Journal of Transcultural Nursing, 16(4), 347–355. 10.1177/1043659605278943 [PubMed: 16160197]

Murray EJ, Bond VA, Marais BJ, Godfrey-Faussett P, Ayles HM, & Beyers N (2013). High levels of vulnerability and anticipated stigma reduce the impetus for tuberculosis diagnosis in Cape Town, South Africa. Health Policy and Planning, 28(4), 410–418. 10.1093/heapol/czs072 [PubMed: 22945548]

Parmer J (2020, March 18–20). Applying a stage-based model to address the latent tuberculosis infection conundrum: 'I don't feel sick, so why should I get tested?' [paper presentation]. Society of Public Health Education Annual Conference, Virtual. https://virtualsophe.elevate.commpartners.com/agenda-week-1

Parmer J, Allen L, Dowling M, Tatum K, Macario E, Picard R, & Brackett A (2020, February 26–29). '"Latent"? It's one of those words that is not clear enough' [Poster presentation]. Annual TB Conference of the Union-NAR, Chicago, IL, United States. https://bc.lung.ca/health-professional-info/annual-tb-conference-union-nar/2020-meeting-archives

Rodríguez-Reimann DI, Nicassio P, Reimann JO, Gallegos PI, & Olmedo E (2004). Acculturation and health beliefs of Mexican Americans regarding tuberculosis prevention. Journal of Immigrant and Minority Health, 6(2), 51–62. 10.1023/B:JOIH.0000019165.09266.71

Sallis JF, Owen N, & Fisher EB (2008). Ecological models of health behavior. In Glanz K, Rimer BK, & Viswanath K (Eds.), Health behavior and health education: Theory, research, and practice (pp. 465–486). Jossey-Bass.

Sommerland N, Wouters E, Masquillier C, Engelbrecht M, Kigozi G, Uebel K, Rensburg AJ, & Rau A (2017). Stigma as a barrier to the use of occupational health units for tuberculosis services in South Africa. International Journal of Tuberculosis and Lung Disease, Nov 1, 21(11), 75–80. 10.5588/ijtld.17.0030

Sterling TR, Njie G, Zenner D, Cohn DL, Reves R, Ahmed A, Menzies D, Horsburgh R Jr., Crane CM, Burgos M, LoBue P, Winston CA, & Belknap R (2020). Guidelines for the treatment of latent tuberculosis infection: Recommendations from the National tuberculosis controllers association and CDC, 2020. Morbidity and Mortality Weekly Recommendations and Reports, 69(1), 1–5. https://www.cdc.gov/mmwr/volumes/69/rr/rr6901a1.htm. https://doi.org/10.15585/mmwr.mm6901a1

Tomás BA, Pell C, Cavanillas AB, Solvas JG, Pool R, & Roura M (2013). Tuberculosis in migrant populations. A systematic review of qualitative literature. Plos One, 8(12), e82440. 10.1371/journal.pone.0082440 [PubMed: 24349284]

Tsang CA, Langer AJ, Kammerer JS, & Navin TR (2020). US tuberculosis rates among persons born outside the United States compared with rates in their countries of birth, 2012–2016. Emerging Infectious Diseases, 26(3), 533–540. 10.3201/eid2603.190974 [PubMed: 32091367]

Wieland ML, Weis JA, Yawn BP, Sullivan SM, Millington KL, Smith CM, Bertram S, Nigon JA, & Sia IG (2012). Perceptions of tuberculosis among immigrants and refugees at an adult education

center: A community-based participatory research approach. Journal of Immigrant and Minority Health, 14(1), 14–22. 10.1007/s10903-010-9391-z [PubMed: 20853177]

Table 1.

Summary of focus groups by U.S. city and participant country of birth.

Case rate per 100,000 population[a]	U.S. Focus Group City					
	San Francisco, California 8.5	Chicago, Illinois 3.2	Houston, Texas 4.8	New York City, New York 4.7	Miami, Florida 3.6	
TB Case Rate by Country of Birth, United States, 2012–2016[b]						Total
Mexico *Case rate: 10.6*		1 focus group	2 focus groups			*3 focus groups*
Guatemala *Case rate: 20.8*					2 focus groups	*2 focus groups*
China *Case rate: 20.0*		1 focus group		1 focus group		*2 focus groups*
Vietnam *Case rate: 36.4*	1 focus group		1 focus group			*2 focus groups*
Philippines *Case rate: 38.5*	2 focus groups			1 focus group		*3 focus groups*
India *Case rate: 24.0*		1 focus group		2 focus groups		*3 focus groups*
Total	*3 focus groups*	*3 focus groups*	*3 focus groups*	*4 focus groups*	*2 focus groups*	*15 focus groups*

[a]TB case rates by U.S. city per 100,000 population in 2018 from Table 53 of CDC (2019).

[b]Tsang et al. (2020).

Table 2.

Summary of focus group participant demographic characteristics.

Demographic characteristic	Per cent of total sample (15 focus groups; 126 total participants)
Gender	
Women	55%
Men	45%
Age (years)	38.5 average (18–80, range)
Race	
White/Caucasian	33%
Black/African American	0%
Asian/Asian American	66%
American Indian or Alaska Native	0%
Native Hawaiian/Other Pacific Islander	1%
Hispanic Ethnicity (yes/no)	
Hispanic origin	33% (this includes selection of a race[s])
Not of Hispanic origin	0%
Length of Time in U.S.	
<10 years	27%
> 10 years	73%
Level of Education	
<High school/No diploma	4%
High school graduate/GED	18%
Some college or technical school	17%
4-year college degree	41%
Post-graduate studies or advanced degree	19%
Total Household Income	
<$25,000	11%
$25,000–49,999	27%
$50,000–74,999	25%
$75,000	37%
Health Insurance Type	
Private	61%
Medicare	5%
Medicaid	9%
Military	1%
Other government	2%
Self-purchased plan	10%
No insurance	13%

Note: Due to rounding, not all percentages in each demographic category add to 100%.