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New strategies for an old disease: the social barriers to targeted testing and treatment of latent tuberculosis infection

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Abstract

New strategies for an old disease: the social barriers to targeted testing and treatment of latent tuberculosis infection

By Katharine Tatum

Tuberculosis (TB) is a bacterial infection that primarily affects the lungs and can be deadly if untreated. Although TB rates have significantly declined in the U.S., rates of decline have stalled. The primary driver of continued TB cases in the U.S. is due to longstanding, untreated latent tuberculosis infection (LTBI) among non-U.S.—born persons who have immigrated to the U.S. In response to these trends, the Centers for Disease Control and Prevention's Division of Tuberculosis Elimination has updated its TB elimination strategic plan to include targeted testing and treatment of LTBI among non-U.S.—born populations, in addition to traditional monitoring and treatment of active disease. This dissertation provides an in-depth analysis of the social barriers to targeted testing and treatment of LTBI from two key perspectives: non-U.S.—born persons at-risk for LTBI and healthcare providers working in community health clinics (CHCs) who serve a large proportion of non-U.S.—born persons. Each chapter addresses one of the new TB elimination strategies: the focus on LTBI (Chapter 1), the focus on non-U.S.—born persons (Chapter 2), and the focus on shifting LTBI care to primary care settings (Chapter 3). The first chapter shows that participants disagree on how to classify LTBI, with some participants defining it as an illness state (infected with TB germs) and others defining it as a healthy state (not sick). These conflicting definitions lead to conflicting views on appropriate health behavior for someone diagnosed with LTBI. The second chapter shows that messages describing a link between country of birth and TB risk may be met with defensive responses, including challenging the logic of the link, or seeing oneself as exempt from risk messages because of TB tests taken for immigration. The third chapter shows that community health clinic staff still perceive the health department as the expert on LTBI, but see a benefit in keeping LTBI care in a patient's medical home. Using sociological theories and frameworks, these papers identify key barriers that emerge in response to these shifting strategies while also highlighting fruitful areas for future interventions that can target these barriers.

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CHAPTER 3. TABLES AND FIGURES

INTRODUCTION

Many public health articles formulate research questions using a similar structure. They ask: "what are the barriers to X?" For example, what are the "barriers to care-seeking," "barriers to buying healthy foods," "barriers to HIV testing," "barriers to vaccine uptake", or "barriers to guideline implementation" (De Figueiredo et al. 2020, Fischer et al. 2016, Horowitz et al. 2004, Kelly et al. 2005, Vermund and Wilson 2002)? This common phrasing highlights an important problem in population health: scientific and medical advancements do not always translate into better health outcomes. Having effective tests or vaccines has little value if people won't use them. Having state of the art healthcare technology won't improve health for people who can't access it. Having up-to-date screening guidelines won't affect clinical practice if providers don't apply them. This gap between medical knowledge and health behavior has led researchers to focus on identifying the social barriers that prevent people from taking advantage of medical advancements.

As these article titles suggest, social factors play an important role in whether and how medical advancements are put into practice. This phenomenon has been described as the "social shaping of population health" (Link 2008) and "fundamental cause theory" (Link and Phelan 1995). According to these theories, the role of social factors in disease control and eradication becomes *more* important once a condition becomes preventable and treatable. By contrast, when we know little about the etiology of a disease or have no treatments, social factors matter less. Link (2008:367-8) explains as follows:

> "Social factors have become more important precisely because epidemiological and biomedical knowledge has shifted the causes and consequences of disease from fate, accident, and bad luck to factors that are under some human control. When humans obtain control, it is their policies, their knowledge, and their behaviors that shape the consequences of epidemiological and biomedical accomplishments, and thereby extant patterns of disease and death. In earlier eras, when we knew less about prevention or

> cure, the social factors that are currently so critical in the spread of life-saving knowledge and technology mattered less. There was less knowledge to diffuse, less useful information to assist in constructing a healthy lifestyle, and fewer potentially effective initiatives around which to form policy. It is in this sense that social factors have become more important over time."

Social factors include socio-economic status, which might influence access to medical innovations; cultural capital, which might influence whether and how someone knows to advocate for that access; education and health literacy, which might influence awareness of medical innovations; and attitudes and perceptions, which might influence willingness to apply medical innovations (Gage-Bouchard 2017, Jackson et al. 2014, Margolis 2013, Polonijo and Carpiano 2013, Rubin, Clouston and Link 2014, Weiss et al. 2018). These social factors play an important role in explaining health disparities between groups, and in explaining the persistence of preventable diseases and associated deaths.

The Case of Tuberculosis in the U.S.

The case of tuberculosis in the U.S. is an excellent example of this social shaping phenomenon. Tuberculosis, also known as TB, is a bacterial infection that primarily affects the lungs, but can affect other parts of the body such as the spine. TB is treatable and preventable via prophylactic treatments (Centers for Disease Control and Prevention 2019). Although rates have significantly declined in the U.S., TB has not reached the elimination threshold[1] and rates of decline have stalled (Schwartz et al. 2020), suggesting the need to focus on the social barriers preventing successful elimination.

[1] Elimination is defined as approximately 330 cases or <1 case per 1,000,000 population Division of Tuberculosis Elimination. 2020a. "Tuberculosis in the United States, 1993-2019." PowerPoint Slides.

TB is an old disease with a long history. Although it was not until 1882 that Robert Koch discovered *M. tuberculosis*, the bacterium that causes the disease, remnants of the bacteria were discovered in Egyptian mummies dating back to 2400 BCE (Tripathi et al. 2005). TB was once a leading cause of death in the United States. In 1900, it was second only to influenza (Jones, Podolsky and Greene 2012). The discovery of effective treatments at the end of World War II marked a new era in TB control (Daniel 2006). While globally TB remains the leading infectious disease killer by a single pathogen (World Health Organization 2020), in the U.S., TB control efforts have been especially effective. In 1953, when systematic TB case reporting began, a total of 84,304 TB cases were reported for a case rate of 52.6 per 100,000. In 2019, the most recent year for which data is available, 8,916 TB cases were reported for a case rate of 2.7 per 100,000 (Division of Tuberculosis Elimination 2020b).

[Figure 1 here]

While the advent of effective medicines allowed the U.S. to make substantial progress towards TB elimination, social factors also played an important role and help to explain continued disparities in TB burden across the world. TB control programs, supported through government funds, have played a major role in reducing TB incidence in the U.S. (Taylor, Nolan and Blumberg 2005). TB programs screen high-risk populations, track and treat infected persons, and respond quickly to TB outbreaks. In addition, routine screening implemented in certain high-risk institutional settings has also aided in controlling TB (Cummings 2007).

The Final Frontier: Testing and Treating Latent Tuberculosis Infection

As the epidemiology of TB in the U.S. shifts, new strategies are required to continue moving towards elimination. The main driver of continued TB cases in the U.S. is not from recent

transmission of active disease, but from longstanding untreated latent tuberculosis infection, or LTBI (Yuen et al. 2016). LTBI is asymptomatic and is only detected via a positive reaction to a TB skin test (TST) or a TB blood test (IGRA). 5-10% of persons with untreated LTBI will progress to active TB disease, which can be contagious (Centers for Disease Control and Prevention 2016). Furthermore, the majority of TB cases occur among non-U.S.—born persons, who likely have been exposed to TB germs in their countries of origin but show no signs or symptoms. In 2019, of the 8,916 reported TB cases, 6,364 were among non-U.S.—born persons, or 71.4% of all reported TB cases (Schwartz et al. 2020). In fact, while cases among the U.S.—born have been steadily declining over the past 30 years, cases among the non-U.S.—born have remained steady. In 1993, there were 7,404 TB cases among non-U.S.—born and in 2019 there were 6,364. Figure 2 provides an overview of these different trends.

[Figure 2 here]

Experts now believe that achieving TB elimination in the U.S. will require increased focus on LTBI among non-U.S.—born populations in addition to traditional monitoring and treatment of active disease (LoBue and Mermin 2017, Menzies et al. 2018). In response to these trends, the U.S. Centers for Disease Control and Prevention (CDC) and their Division of Tuberculosis Elimination (DTBE) have outlined a set of goals and strategies for their 2016-2020 strategic plan, which includes “targeted testing and treatment of persons with latent TB infection” as well as efforts to “mobilize and sustain support for TB elimination by engaging policy and opinion leaders, health care providers, affected communities, and the public” (Division of Tuberculosis Elimination 2016). These strategies are profoundly social in nature and will require social research to carry out successfully. Convincing non-U.S.—born persons to get tested, and then treated if positive, requires effective messaging around the nature of the

condition “LTBI,” what it means to be asymptomatic, why they are at-risk due to country of birth, and the benefits of treatment. Mobilizing the support of healthcare providers working in settings that see high-risk populations requires a firm understanding of their ability and willingness to take on tasks traditionally performed by the public health sector. In short, targeted testing and treatment of LTBI will require the buy-in of at-risk populations and the healthcare providers who serve these populations. This, in turn, will require a firm understanding of their perceptions of and attitudes towards testing and treatment for LTBI.

Current Literature on Social Barriers to Latent Tuberculosis Infection Testing and Treatment

The literature on social barriers to LTBI testing and treatment in the U.S. has focused extensively on barriers from the patient perspective, but less so on barriers from the provider perspective. While studies in both areas have identified important barriers, the research has remained descriptive and largely devoid of theory, suggesting the need for additional research.

Numerous studies have investigated barriers to LTBI and TB care from the patient perspective, focusing on various migrant populations living in low-burden TB countries. A systematic review published in 2013 identified 30 such studies using qualitative methods (Tomás et al. 2013). Another systematic review published in 2017 found 12 additional studies (De Vries et al. 2017). This body of research has focused primarily on identifying the various patient barriers to TB care, including testing and treatment of LTBI. This research has found that patients may come in with existing ideas about TB that conflict with the information they receive in a U.S. medical setting. For example, a systematic review of varying beliefs about TB showed a wide range of misperceptions on how TB is transmitted, including via utensils or genetics (Chang and Cataldo 2014). Many patients have received a vaccine for TB (the Bacille Calmette Guerin vaccine

or BCG) and believe that this confers immunity from TB, even though the vaccine loses its effectiveness over time (Mangan, Galindo-Gonzalez and Irani 2015). Patients may also interpret positive skin test results as a false positive due to their vaccination and are therefore less receptive to positive diagnoses and treatment (McEwen and Boyle 2007).

In terms of specific barriers to LTBI care, patients tend to be less familiar with LTBI compared to TB disease (McEwen 2005). Due to the lack of symptoms and contagiousness, at-risk populations report low levels of motivation for getting tested or treated for LTBI (Wieland et al. 2012). Even when at-risk groups recognize the importance of getting tested, they often do not see themselves as at-risk groups or do not want to personally get tested (Narayanan et al. 2019, West et al. 2008). In an important comparative analysis between U.S.—born and non-U.S.—born persons currently seeking treatment for LTBI, researchers observed a significant difference in how the two groups understood their diagnosis, with non-U.S.—born patients more likely to describe themselves as "protected" from future TB disease, possibly because of their BCG vaccination (Colson et al. 2010). Other barriers to TB prevention and care include limited or no health insurance, lower likelihood of seeking healthcare in general, fear of deportation, stigma from the community, long and arduous treatment regimens, and financial considerations such as time off from a job (Chang and Cataldo 2014, Colson et al. 2014, De Vries et al. 2017, Joseph et al. 2008, Katrak and Flood 2018, Wieland et al. 2012).

Less research has been conducted on barriers to testing and treatment decisions among healthcare providers. This dearth of research may be due, in part, to the more recent call for healthcare providers, especially primary care providers, to become involved in LTBI testing and treatment efforts (Balaban et al. 2015, LoBue and Mermin 2017). Two studies comparing internationally trained and U.S.—trained medical graduates found a significant difference in their

views on the appropriateness of prescribing LTBI treatment in various scenarios. Overall, both studies found that internationally trained physicians were less willing to prescribe LTBI treatment, less likely to believe LTBI treatment would protect against future TB disease, more concerned about the risks associated with LTBI treatment, and more likely to believe the BCG vaccine would offer protection (Hirsch-Moverman et al. 2006, Salazar-Schicchi et al. 2004). Another study examined healthcare providers' beliefs about barriers to TB care, including LTBI, and found that providers were mainly concerned about resource barriers, patient barriers, and problems with "fragmented care" between health departments and primary care settings (Zelnick et al. 2016).

Rationale for Current Research

These studies have yielded important insights on the current landscape of barriers to LTBI testing and treatment, particularly barriers from the patient perspective. However, there are several limitations to these studies that suggest the need for additional research.

First, many studies appear to focus exclusively on barriers that are explicitly mentioned by participants. While this provides an important part of the picture, using this approach alone will miss key barriers. Research has found that people often struggle to articulate their motivations or rationale for behavior and that even when they do provide explicit explanations, the stated reason may contrast with other statements (Vaisey 2009). This phenomenon, described as "cultural incoherence," has highlighted the importance of analytical approaches that translate "one kind of content (explicit talk) to another (implicit cultural content)" (Vaisey 2014). This type of translation requires analysis that moves beyond the identification of explicit reasons or points furnished by participants and instead analyzes speech as representations of social systems. This type of analysis involves attention to the use of language, the use of categories or concepts,

beliefs that appear "obvious," recurring expressions, and other types of implicit cultural content that participants may not be consciously aware of but are still enacting in their speech (Lamont and Swidler 2014, Ryan and Bernard 2003, Vaisey 2014).

Second, these studies have primarily focused on cataloging barriers. This focus on enumerating barriers prevents researchers from better understanding how each barrier functions and ultimately what can be done to remove barriers. In fact, much of the analysis produced thus far takes a "thematic" approach in which the end goal is to outline themes. A crucial next step is to analyze how these themes connect and operate in actual behavior. Research needs to go beyond simply *describing* the barriers and towards *explaining* how those barriers prevent certain desired health behaviors.

Relatedly, most of the studies are atheoretical – either failing to derive theoretical implications from their findings (i.e. inductive theory building) or failing to link findings to existing theories or frameworks (e.g., testing or applying a theory).[2] The point, however, is not to simply "add" a theory from a menu of options, but to articulate the hypothesized explanation for a particular phenomenon. In fact, research has found that public health interventions grounded in theories tend to be more effective (Glanz and Bishop 2010). These theories provide the concepts, mechanisms, and pathways that can help explain how various social factors prevent or facilitate desired health behaviors. Furthermore, the ability to situate barriers in a theory allows researchers to understand the interactions and sequencing of various constructs, and to thereby target the barriers that will most effectively alter behavior (Michie et al. 2008). For example, if a certain type of perception is associated with a reduced willingness to take a desired health behavior, then messages can attempt to pre-empt or correct that perception. Placing barriers into

[2] By theory, I mean an explanatory framework that links constructs in a sequence, identifying causal pathways that can be tested.

a theory or explanatory framework stands in contrast to the typical approach of producing a list of common barriers to a desired health outcome.

However, even TB research that does draw on theories tends to borrow from the behavioral sciences, which takes a psychological and individual-level approach (Davis et al. 2015). Sociological theories and concepts offer an additional important vantage point, emphasizing the role of supra-individual concepts such as social norms, symbolic boundaries, social control, and social categories – concepts that elucidate how individual perceptions and behaviors are enabled and constrained by larger social processes. This theoretical sensitivity to sociological theories and concepts, however, should be tempered with an emic perspective. To overcome social barriers related to LTBI testing and treatment, research must focus on understanding the perspectives of those who are at-risk for TB and those who will be instrumental in caring for TB.

A grounded theory approach offers an important bridge between these two demands. On the one hand, grounded theory focuses on identifying issues relevant to participants, and linking constructs together in a way that describes observed patterns (Glaser and Strauss 1967). Practitioners of grounded theory often talk about letting the data "speak for itself" and focusing on issues that "emerge" from the data. On the other hand, researchers using grounded theory come in with existing "theoretical sensitivities," and can continue to develop ideas by reading through the literature (Kelle 2007, Strauss and Corbin 1998). This interplay between inductive and deductive theory building is a common approach in grounded theory. Crucially, however, the theory that comes out of the analysis should be grounded in the data and this can be verified via different validation techniques (Hennink, Hutter and Bailey 2020). Together, the combination of

a grounded theory approach with a sociological sensitivity can augment current efforts at identifying key social barriers to testing and treatment of LTBI.

Overview of Three Papers

This dissertation provides an in-depth analysis of the social barriers to targeted testing and treatment of LTBI from two key perspectives: non-U.S.—born persons at-risk for LTBI and healthcare providers working in community health clinics (CHCs) who serve a large proportion of non-U.S.—born persons. Each paper addresses one of the new areas of focus outlined in DTBE's new approach to TB elimination: the focus on LTBI (Chapter 1), the focus on non-U.S.—born persons (Chapter 2), and the focus on shifting LTBI care to primary care settings (Chapter 3). These papers outline key barriers that emerge in response to these shifting strategies and link them to existing social theories, providing insights on the underlying social processes that explain the barriers while also highlighting fruitful areas for future interventions that can target these barriers.

The first paper (Chapter 1) investigates barriers associated with the concept of "latent" and the confusion around how to categorize this asymptomatic condition in relation to existing health and illness categories. Specifically, the purpose of this paper is to understand how at-risk persons define the condition LTBI and how different definitions influence intended health behaviors. The paper draws on an original qualitative dataset comprised of 15 focus group discussions with persons born in the 6 countries that contribute most to the non-U.S.—born TB case count in the U.S. Discussions centered around a series of messages on LTBI to which participants reacted, sharing their perceptions, concerns, and intended health behaviors regarding LTBI testing and treatment. To explain varying definitions around LTBI and their effect on

health behaviors, the paper applies the concept of liminal health categories (Timmermans and Buchbinder 2010) and the sociological concept of the "sick role" (Parsons 1975). On the one hand, liminal health categories suggest the emergence of a new middle category between health and illness, spurred by the expansion of screening efforts that identify asymptomatic people as "at-risk" for future disease (Armstrong 2012). On the other hand, people often think in terms of binary categories of health and illness and want to know whether they should or should not take on the "sick role" (Hallowell et al. 2015). This paper situates LTBI within these debates, suggesting that LTBI is typically presented as a liminal category, but that at-risk persons may reject that category and instead try to recategorize LTBI into a binary framework.

The second paper (Chapter 2) investigates barriers associated with targeting non-U.S.—born persons for LTBI testing and the various defensive strategies that participants use to distance themselves from this at-risk category. It uses the same dataset comprised of 15 focus groups with at-risk persons, focusing on non-U.S.—born persons' perceptions of the link between country of birth and TB risk. The paper draws on the concept of "defensive processing," which finds that people who are most at-risk for a condition are often the least receptive to health risk messages (Liberman and Chaiken 1992, McQueen, Vernon and Swank 2013). This "defensive" response likely occurs because health risk messages often threaten an individual's positive self-concept by asking them to identify with an "at-risk" or "sick" category (Sherman, Nelson and Steele 2000). Given that the majority of TB cases in the U.S. occur among non-U.S.—born persons (Schwartz et al. 2020), public health messaging efforts are focusing on increasing awareness and motivation among this target population. However, the overlapping categories of "non-U.S.—born" and "at-risk for TB" may be particularly stigmatizing, potentially reinforcing existing notions of TB as an "immigrant" or "third world" disease (Kehr

2012, Taylor 2013), suggesting the need for careful research on the most effective messaging that can avoid or pre-empt these defensive responses.

The third paper (Chapter 3) investigates barriers associated with shifting some LTBI testing and treatment responsibility from the public health sector to primary health care providers and whether providers are willing and able to take on this new responsibility. The data comes from a large mixed-methods multi-site study assessing barriers to testing and treating LTBI at community health clinics across the U.S. The paper uses a sub-sample of the qualitative data, 77 interviews across 8 clinics, and focuses on clinic staff perceptions of the current and desired role of the health department in LTBI testing and treatment efforts. The paper uses the literature on professional identities and boundaries, which suggests that professionals constantly negotiate the boundaries of their work and expertise, offering opportunities but also possible barriers to expansion of their professional duties (Abbott 1988, Larson 1979). Professionals may resist changes to their professional jurisdiction if it involves low-value tasks or tasks perceived to be outside their job duties, but they may also embrace an expansion of their jurisdiction if it involves the addition of high-value tasks or if it can be framed as part of their existing expertise (Kellogg 2014, Nancarrow and Borthwick 2005). The public health sector has historically managed LTBI cases, in addition to active TB disease, suggesting that primary care providers may continue to see LTBI as a public health issue and not part of their job duties. At the same time, primary care providers in community health clinics who see a high-proportion of non-U.S.—born persons, who are at increased risk for LTBI, may be more inclined to take on increased responsibility if it means they retain greater medical autonomy over their patients. Understanding how primary care providers perceive these shifting boundaries will help to develop models of public-private partnerships that are successful and sustainable.

Together, these three papers provide a sociological lens on barriers and possible solutions to a current public health problem – continued TB cases in the U.S. caused primarily by untreated LTBI. While the motivation for the project is clearly situated in public health, the methods, analytic approaches, and theories all draw on sociological research. Sociological theories and concepts provide key insights on barriers to TB prevention and care. At the same time, the specific case of LTBI offers a unique opportunity to apply and refine existing sociological theories and concepts. As a result, this dissertation contributes both to the literature on TB and to the literature on sociology and the sociology of health.

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Tables and Figures

Figure 1. Reported TB Cases in the U.S.

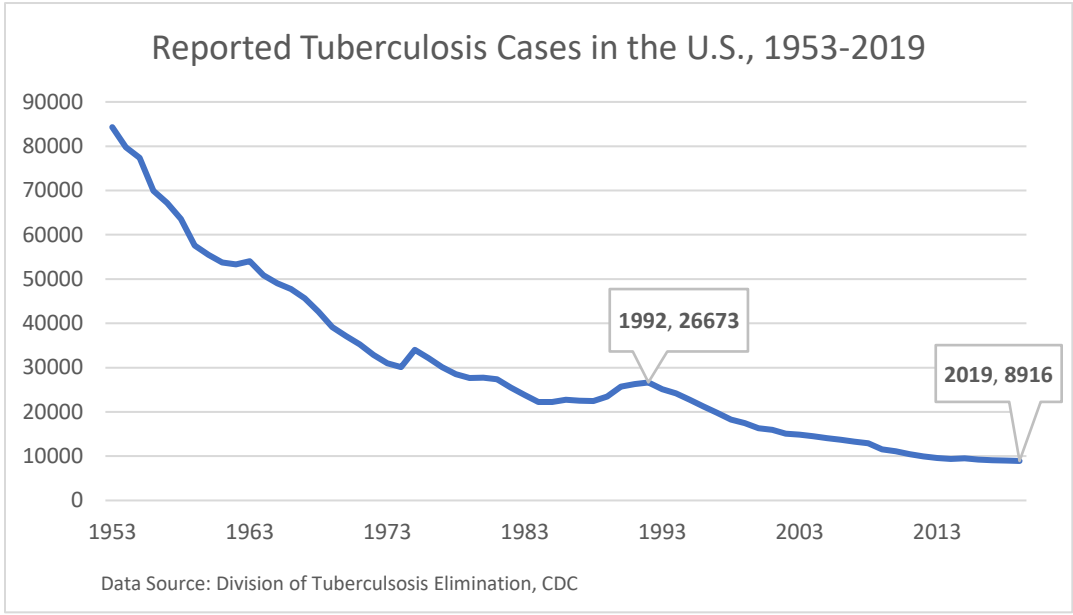
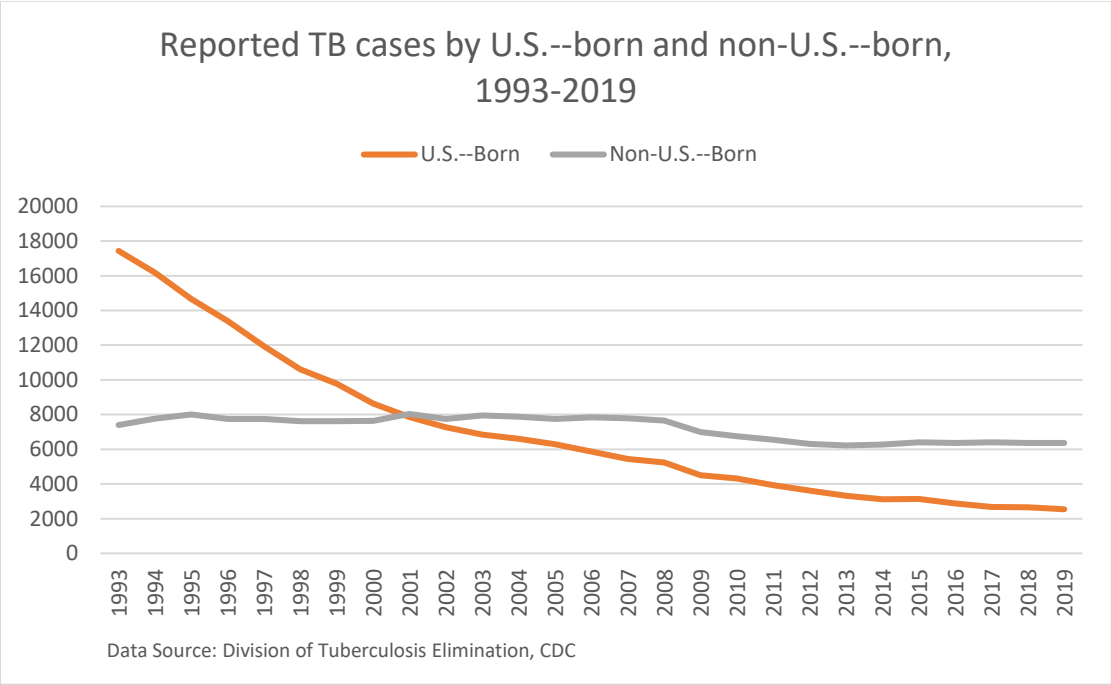


Figure 2. Reported TB Cases by U.S.—born and non-U.S.—born



CHAPTER 1: Do I have it or not? Latent tuberculosis infection and the consequences of liminal health categories

Abstract:
The phenomenon of screening healthy people for various diseases has given rise to a new "liminal" health category between health and illness: people at-risk for future disease. People who fall into this liminal category may experience medical uncertainty, unsure of how to classify themselves and whether to take on the sick role. This paper considers the issue of medical uncertainty through the case of latent tuberculosis infection (LTBI) – an asymptomatic phase of tuberculosis (TB) that, if untreated, can become symptomatic and infectious. Drawing on focus group discussions with populations at increased risk for LTBI, we ask two related questions: how do at-risk persons define the condition LTBI and how do different definitions influence intended health behaviors? We find that participants reject the liminal category and instead attempt to re-classify LTBI into a binary framework of health and illness. However, participants disagree on the appropriate classification. One set of participants placed LTBI into an illness category by conceptualizing the binary as "not infected" and "infected." Another set of participants placed LTBI into a healthy category by conceptualizing the binary as "not sick" and "sick." These differing definitions lead to conflicting views on appropriate health behavior for someone diagnosed with LTBI. We argue that liminal categories may be counterproductive since people seem prone to using a binary framework of health and illness.

Keywords: Medical uncertainty, liminal, screening, sick role, latent tuberculosis infection, tuberculosis

Introduction

Do I have it or do I not have it? Am I sick or am I healthy? How can I be infected but not sick? These types of questions emerge in contexts of medical uncertainty when laypersons struggle to define their health status. A significant body of work has emerged addressing the uncertainty that arises when asymptomatic persons are classified as having a disease or being at-risk for a disease. This phenomenon tends to occur as a result of screening processes in which medical algorithms identify otherwise healthy persons as candidates for diagnostic testing for various conditions (Armstrong 1995, Armstrong 2012, Armstrong and Eborall 2012, Kreiner and Hunt 2014). Patients who test positive on these tests are given a disease classification or deemed "at risk" for a disease, despite no apparent signs or symptoms. The uncertainty of the diagnostic category carries over into uncertainty about appropriate health behavior. Those who find themselves in a liminal position between health and illness are unsure of whether or not they should take on the "sick role" and associated role expectations (Parsons 1975).

This paper considers medical uncertainty in relation to one of the leading infectious disease killers worldwide – tuberculosis (TB) – focusing on the latent non-infectious state of TB called "latent tuberculosis infection" or LTBI (World Health Organization 2020b). It is estimated that more than 80% of TB cases in the U.S. are due to longstanding LTBI rather than from recent transmission (Yuen et al. 2016). Using 15 focus group discussions (FGDs) with at-risk populations for LTBI, the purpose of this paper is to understand how at-risk persons define the condition LTBI and how different definitions influence intended health behaviors.

Background:

Medical uncertainty

Researchers have addressed medical uncertainty in different contexts, but tend to frame the issue around a key mismatch between providers and patients: on the one hand, providers put forth disease classifications based on diagnostic tests, on the other hand, patients put forth an illness experience based on symptoms (Grob 2008). When these two perspectives align, a patient is granted a diagnosis that matches their symptoms, or simply deemed "healthy." When these two perspectives diverge, patients either experience symptoms with no disease classification – often called "contested illnesses" (Dumit 2006, Lillrank 2003, Nettleton 2006) – or a disease classification with no symptoms (Kreiner and Hunt 2014). Figure 1 provides an illustration of these 4 possible scenarios.

[Figure 1 about here]

The phenomenon of asymptomatic patients being diagnosed with various disease classifications has been tied to the process of screening (Armstrong 1995, Armstrong 2012, Armstrong and Eborall 2012, Kreiner and Hunt 2014). Screening refers to "the presumptive identification of unrecognized disease in an apparently healthy, asymptomatic population by means of tests, examinations or other procedures that can be applied rapidly and easily to the target population" (World Health Organization 2020a). Screening can involve both the process of identifying a target population for tests and the administration of diagnostic tests to that target population. Social scientists and historians have argued that screening has produced a new health category, variously called an "at-risk health status," (Kenen 1996) "liminal" status (Scott et al. 2005), or "patients in waiting" (Timmermans and Buchbinder 2010). According to one author:

> "The at-risk health status differs from just being at risk from a specific health hazard. While everyone is at risk from some health peril, everyone is not expected to adhere to

> socially approved at-risk health behavior patterns and actions. It is only after at-risk health statuses have been negotiated and accepted that they can be considered as social positions accompanied by expected role performances and norms." (Kenen 1996:1545).

Although this middle category is intended to reduce medical uncertainty by specifying who is most likely to progress to illness, research suggests that it can actually increase uncertainty. This uncertainty emerges in part because patients may be offered treatment or instructed to monitor their health more closely in a way that produces the experience of being ill even though they are told they are at-risk (Gillespie 2012, Kreiner and Hunt 2014).

Parson's sick role

The uncertainty produced by this liminal diagnostic category carries over into uncertainty about appropriate health behavior. Although the subject of ongoing debate, Parsons's sick role theory (Parsons 1975) continues to serve as a touchstone for discussions around health behavior including behavior in light of a liminal health status. In Parson's formulation, the sick role functions as society's way of regulating illness by laying out specific obligations and exemptions for this temporary "deviance." When someone is sick, they can be exempted from some duties, such as work, in exchange for taking on some obligations, such as seeking medical care (Parsons 1975, Williams 2005). Parsons' theory has been criticized for its inability to account for various health experiences such as people living with chronic conditions, who cannot enter the sick role on a temporary basis (Varul 2010).

At first blush, Parsons's formulation might also appear inadequate for explaining the experience of those "at-risk" for a condition. Parsons sets up a dichotomous relationship between health and illness with no apparent "at-risk" role. However, several studies suggest that the medical community as well as laypersons tend to operate in a binary framework of health and

illness. Rather than treating “at risk” as a middle category between “health” and “illness,” people may reproduce a binary framework of health and illness by simply expanding the criteria for what constitutes “illness” (Kreiner and Hunt 2014). For example, Gillespie (2012) examined patient reactions to health risk information on elevated levels of cholesterol and prostate-specific antigen (PSA) levels. Although healthcare providers offered information of elevated numbers as a way to encourage participants to mitigate risk, participants often perceived the news as an indication of “spoiled identity” or a loss of good health. Likewise, in an investigation of parent reactions to abnormal newborn screening results, Grob (2008) finds that parents change their perception of their child’s health status and treat them as if they were sick rather than simply at-risk of becoming sick. Finally, a study of women at-risk for breast cancer found that some actively sought out an image as “sick” and tied this to their decision to seek preventive surgery (Hallowell et al. 2015).

This pattern of using a binary framework to understand health is consistent with sociological and cognitive research on categorization, which suggests that people use categorization as a way to reduce uncertainty (Fiske and Taylor 2013) and exercise social control (Douglas 1966). Some people may be particularly inclined to use binary classifications, producing a “binary bias” (Fisher and Keil 2018, Oshio 2009).

We extend current discussions on medical uncertainty and the sick role by examining how medical uncertainty operates in the case of a potentially infectious disease. Although the sick role functions as a form of social control and regulation, the stakes for adopting a sick role take on increased social importance when the condition is potentially contagious. We consider the case of latent tuberculosis infection (LTBI), which is the early asymptomatic and non-infectious stage of tuberculosis (TB).

Case study: latent tuberculosis infection (LTBI)

Tuberculosis (TB) is a bacterial infection caused by the bacterium *Mycobacterium tuberculosis.* If left untreated, TB can be fatal. TB germs can affect many parts of the body, but most cases of TB are pulmonary TB, which affects the lungs. Pulmonary TB spreads from person to person through the air via coughing, singing, or speaking (Centers for Disease Control and Prevention 2019).

Not everyone infected with TB germs becomes sick. TB germs can lay dormant in the body for years without causing any symptoms. This is a condition called "latent tuberculosis infection" or LTBI. A person with LTBI has TB germs in their body, but their immune system has produced an effective response and stopped the infection from spreading. LTBI is diagnosed via a positive reaction to a TB skin test (called a TST or occasionally a PPD test) or a TB blood test (interferon-gamma release assay) *and* a clear x-ray (used to rule out pulmonary TB) (Centers for Disease Control and Prevention 2019). An estimated 5% of the U.S. population (approximately 13-15 million people) has LTBI (Miramontes et al. 2015). For most people, LTBI will never progress to TB disease. However, estimates suggest that 5-10% of people with untreated LTBI will progress to TB disease, at which point it becomes infectious (Centers for Disease Control and Prevention 2016).

Globally, TB remains the leading infectious disease killer, ahead of HIV (World Health Organization 2020b). However, in the U.S., Canada, and much of Western Europe, TB rates have been declining for decades. Despite this progress, the rate of decline has started to slow in the U.S. (Schwartz et al. 2020, Talwar et al. 2019). It is estimated that more than 80% of TB cases in the U.S. are due to untreated LTBI acquired many years prior (Yuen et al. 2016). Predictive modeling suggests that the only way to reach TB elimination in the U.S. is through

increased targeting of LTBI (Menzies et al. 2018). Further, in the U.S., TB disproportionately affects non-U.S.—born persons. In 2019, 71% of TB cases in the U.S. were among non-U.S. born persons (Schwartz et al. 2020). Together, these data have led the Centers for Disease Control and Prevention (CDC), as well as the U.S. Preventive Services Task Force (USPSTF), to issue recommendations for targeted testing and treatment of LTBI among non-U.S.—born persons (LoBue and Mermin 2017).

Previous research suggests that perceptions of TB and LTBI may present a key obstacle to scaling up testing and treatment of LTBI. Non-U.S.—born persons, a key at-risk group, are often familiar with TB and come to the U.S. with existing ideas about the etiology and meaning of TB that conflict with information they receive in a U.S. medical setting (Mangan, Galindo-Gonzalez and Irani 2015, McEwen 2005, McEwen and Boyle 2007, West et al. 2008). Further, many associate the disease with dirtiness, promiscuity, malnutrition, and poor health behavior, rendering a TB diagnosis potentially stigmatizing (Chang and Cataldo 2014, West et al. 2008). With respect to LTBI, several studies have found low general awareness of LTBI among at-risk populations and confusion once the condition is explained. Patients struggle to classify the condition within their existing knowledge of TB disease (McEwen 2005, McEwen and Boyle 2007, Tomás et al. 2013, Wieland et al. 2012).

The purpose of this paper is to understand how non-U.S.—born persons, who are at increased risk for TB, define the condition LTBI and how different definitions influence intended health behaviors. This paper contributes to existing TB literature by examining perceptions of LTBI among multiple high-risk audiences and by connecting varying perceptions to intended health behaviors. In addition, we situate the case of LTBI within the larger literature on medical

uncertainty, demonstrating how this phenomenon operates in the case of a potentially infectious disease.

Design and methods

Data

The data for this paper comes from 15 focus group discussions (FGDs) with non-U.S.—born populations living in the United States. The project was funded by the CDC's Division of Tuberculosis Elimination (DTBE) and was carried out by their Communications, Education, Training, and Behavioral Studies branch (CEBSB). The primary purpose was to improve internal programmatic efforts related to educational materials and messaging. The project was considered non-research and therefore IRB exempted. OMB approval was secured.

Sample

The sampling design was based on current TB epidemiology. FGDs were conducted with non-U.S—born persons from the 6 countries with the highest TB case count in the U.S.: China, Guatemala, India, Mexico, the Philippines, and Vietnam (Schwartz et al. 2020). To facilitate recruitment of the 6 target audience groups and allow for geographical variation within the sample, FGDs were held in 5 different U.S. cities: Chicago, Houston, Miami, New York, and San Francisco. Figure 2 provides an overview of the sampling strategy.

[Figure 2 about here]

Each FGD was comprised of people from a single country. Within each group, the team aimed for a mix of other key dimensions, such as education, years in country, age, and sex. To ensure saturation, at least two FGDs were conducted per immigrant population and city (Hennink, Kaiser and Weber 2019).

Recruitment

A professional recruitment vendor carried out recruitment, pulling from existing market research recruitment lists. The recruiters used a 12-item screener to identify eligible participants. The ability to read and speak in English was a requirement for participation – a limitation we address in the conclusion. Participants were not told the discussion would be about TB to prevent participants from "studying" beforehand. Following recommendations in the literature, the study team limited FGDs to 9 participants (Hennink, Hutter and Bailey 2020). The team over-recruited to account for no-shows. All participants who showed up were given $40 to thank them for their participation.

Data collection procedures

Data collection occurred in April and May of 2019. FGDs were 90 minutes and were held in the evening at professional focus group facilities. A professional moderator led all discussions. In the opening script, the moderator mentioned that she was an immigrant to assist in developing rapport with participants. All discussions were conducted in English and audio recorded. A live streaming option was available for remote observation, but only the audio was preserved for transcription. Each room had a one-way mirror for local observers.

The moderator used a discussion guide comprised of 4 topics. The first section was brief and asked participants to share their current health concerns. TB was not mentioned here to see whether it came up unprompted. The second section introduced the topic of TB and asked participants to share any prior TB knowledge or experience. This section also introduced the topic of LTBI. The third section centered around a series of messages on TB and LTBI. For each message, the moderator read the message aloud and then asked participants to "verbalize" or

"restate" the message "in their own words." The moderator probed on any words or ideas that were confusing, whether a message was motivating, and any questions the message might have generated for participants. Overall, the study tested 39 messages, with 25 messages tested per FGD, rotating across sessions so that each message was tested at least twice. The fourth and final section asked participants about trusted health information sources.

Analysis

Audio recordings were transcribed verbatim. Participant names were included to track the flow of conversation. We used the qualitative software NVivo Plus version 12.5.0 for data management and analysis. Our analytic approach followed a combination of grounded theory (Glaser and Strauss 1967, Strauss and Corbin 1998) and discourse analysis. We employed a linguistic approach to discourse analysis by focusing on how semantics and syntax illustrated participant perceptions of LTBI (Bernard, Wutich and Ryan 2017, Cheek 2004).

Analysis began during data collection by writing up fieldnotes after focus groups and outlining emerging themes, using Ryan and Bernard's eight observational techniques for identifying themes (Ryan and Bernard 2003). This process generated a list of possible codes and highlighted the repeated use of certain phrases, indicating the utility of a linguistic analysis. To develop a codebook, we selected three distinctive transcripts for memoing: a Chinese group, a Mexican group, and a group with high TB knowledge (a Filipino group). We wrote memos on issues salient to participants and patterns in language use. This process led to an initial codebook of 25 codes, comprised of both deductive and inductive codes, as well as linguistic-based codes. Linguistic-based codes included a code called "in you/have/infected," which captured language about compromised health and a code called "finding out/knowing," which captured language about knowledge of health status. We further refined the codebook after testing it on a fourth

transcript (an Indian group). The final codebook was comprised of 35 codes. All 15 transcripts were then systematically coded using this codebook.

Once all data was coded, we conducted searches of relevant individual codes (e.g., "LTBI definition," "symptoms," "finding out/knowing") across the 15 FGDs and documented emerging patterns in analytic memos. The purpose was to assess the range of perceptions around LTBI, including various discourses around LTBI as a health or illness category, and to identify various intended health behaviors related to getting tested and treated for LTBI. We also conducted searches of overlapping codes ("symptoms" and "finding out/knowing"), searches of responses to specific messages (e.g., a person with LTBI is infected but not sick), and key word searches (e.g., "but"). In addition, we used a linguistic-focused discourse analysis. To analyze semantics, we reviewed discourse-based codes and noted the repeated use of certain words. To analyze syntax, we focused on linguistic connectors such as "but" – which was used to create a contrast between no symptoms and a diagnosis – as well as modifiers such as "actual" or "real" – which was used to distance LTBI from active TB disease. We also conducted structured comparisons to identify any patterns in data by country of origin.

To explain different perceptions of LTBI and how these differing perceptions influenced intended health behavior, we used a combination of inductive and deductive approaches to theory building (Hennink, Hutter and Bailey 2020). We examined participants' explicit reasoning for why they defined LTBI in one way versus another. We also developed analytical matrices to assess links between a participants' LTBI classification and their discussion on intended health behavior. In addition, we reviewed the research literature on screening and risk. This review led us to the concept of "medical uncertainty" and Parsons's "sick role," which were used to organize and interpret the findings. Neither of these concepts were used in the design or

data collection of the project. To ensure these concepts were grounded in the data, we used the concept-indicator model (Hennink, Hutter and Bailey 2020). This process involved organizing findings around these categories and verifying the appropriateness of the framework.

Findings are organized around perceptions of LTBI and then how these varying perceptions influence intended health behavior. Quotes are included as illustrations of larger themes. No names are used to protect participant confidentiality.

Findings

Demographic characteristics

Focus group participants were born in one of the six countries that contribute most to the non-U.S.—born TB case count: Guatemala, Mexico, Vietnam, the Philippines, India, and China. Figure 3 provides an overview of key demographic characteristics of participants.

[Figure 3 about here]

In 10 of the 15 groups, over half of participants had completed at least a college degree. Hispanic groups reported lower levels of educational attainment than Asian groups. For example, among the two Mexican groups in Houston no one had completed a college degree. Participant ages ranged from 18 to 80, and most groups had a 40-year spread. Finally, a majority of participants had been living in the U.S. for more than 10 years. Only one group (an Indian group in NYC) had a majority of participants living in the U.S. for fewer than 10 years.

Prior knowledge of and experience with TB and LTBI

To contextualize the findings related to perceptions of LTBI, we begin by reviewing participants' prior familiarity with TB and LTBI. Participants were generally familiar with TB. In all 15 FGDs

someone reported having heard of TB, and in several FGDs *all* participants had heard of TB. Participants also had personal experience with TB. In 14 groups someone reported knowing someone diagnosed with TB. This included family members such as parents, cousins, aunts, and uncles, as well as neighbors and co-workers. TB was also a top of mind health concern for some participants. In 7 groups someone mentioned TB as a health concern unprompted at the beginning of the discussion.

By contrast, for most participants, LTBI was an unfamiliar medical condition. In all 15 FGDs, participants were asked if they had ever "heard" of LTBI. In 3 of the groups, one or two participants mentioned having heard of LTBI. Two of these participants had a medical background. One participant, a Filipino man in San Francisco, reported not only having heard of LTBI but also having been diagnosed and treated for it. Strikingly, throughout the course of conversation, 6 total participants in 6 different groups revealed what appeared to be a probable LTBI diagnosis earlier in their life. This number is noticeably higher than the number who reported having heard of LTBI. Figure 4 shows the mismatch between those who had "heard" of LTBI and those who reported a probable LTBI diagnosis.

[Figure 4 about here]

Only the Filipino participant in San Francisco appeared to know and recognize LTBI as a condition for which he had been diagnosed and treated. All other participants revealed medical information about taking pills for a positive TB test, but did not recall that this was for "LTBI." Two people connected their condition to LTBI only after hearing information in the FGD. This mismatch highlights the confusion surrounding LTBI as a condition, which colored much of the discussion.

The medical uncertainty of LTBI

Throughout the discussion participants struggled to define LTBI and to categorize it within an existing framework of health and illness. This struggle emerged in response to the presentation of LTBI as a liminal status between health and illness.

First, the name "latent tuberculosis infection" introduces two modifiers to the word "TB," which generated questions among participants about the relation between "LTBI" and the unmodified "TB." Because so many participants were already familiar with TB, they tried to categorize LTBI in relation to TB. Many participants zeroed in on the word "latent," and indicated that this word suggested LTBI was a condition prior to TB. One Indian participant described LTBI as a "pre-disease" while a Mexican participant described it as "stage one" TB. In 6 groups, participants initially guessed that LTBI might mean "delayed." In 5 groups participants used the word "later" to describe LTBI, likely believing it was the stem of the word "latent." While some correctly guessed that "latent" meant symptoms might appear at a later period, others incorrectly guessed that "latent" was a stage that followed TB disease. In a Mexican focus group in Houston, two participants explicitly stated that the modifiers "latent" and "infection" influenced their perception of LTBI:

> ***MODERATOR: What do you think latent tuberculosis infection is?***
> *P1: I think it might just be a virus?*
> ***MODERATOR: A virus. Okay.***
> *P1: But, you know, you can get it and then maybe you're [INAUDIBLE]. I'm not sure. Because it's latent – it makes it sound like it's not the real infection, or however your -- it just feels like it's a virus. So I'm not sure.*
> ***MODERATOR: So the word latent is making you think --***
> *P1: -- It might just be a virus.*
> ***MODERATOR: A virus. Okay.***
> *P2: I think it's – I don't know. Infection makes it seem like it's not so bad. That it can go away. So… I don't think it's too bad. But I don't really know.*
>
> (Mexican Houston #1)

After having guessed what LTBI might mean, participants then read a series of statements on LTBI. The first two statements, read back to back, depicted LTBI as a liminal status between health and illness.

> Statement 1: "People who are infected with TB, but are not sick have a condition called latent TB infection."
> Statement 2: "People with latent TB infection do not feel sick, do not have symptoms and can not spread TB germs to others. This is because the TB germs are latent or inactive in their body. If their TB germs become active they can develop TB disease."

The state of being "infected" but "not sick" is consistent with the concept of a liminal status described in the literature. Persons with LTBI have been infected with TB germs, but they are still asymptomatic and are therefore not yet ill. In addition, the possibility of a serious future condition is consistent with the concept of "patients in waiting." LTBI may potentially develop into TB disease later in life. This statement suggests the possibility of future disease while also implying that LTBI itself is not a disease. Many participants struggled to understand this liminal position of LTBI, which came through in clarification questions participants posed about how to classify LTBI given its asymptomatic nature.

> *It's just kind of somewhat contradicting to me when you say infected but then not sick. So, what does that mean?*
>
> (Filipino group #1, San Francisco)

> *So you're not sick but you have a TB infection. Is it the same thing?*
>
> (Mexican group #2, Houston)

> *I think I'm just confused on you're infected, but you're not sick part.*
>
> (Chinese group, Chicago)

Ultimately, most participants rejected this liminal categorization and instead attempted to sort LTBI into a binary framework of health and illness. However, participants disagreed on where to place LTBI within this framework. One set of participants used a binary framework of

"not infected" and "infected" to argue that LTBI fell into the illness category and was an early stage of TB. Another set of participants used a binary framework of "not sick" and "sick" to argue that LTBI fell into the health category and should be entirely distinguished from TB. Figure 5 illustrates this conflicting conceptualization.

[Figure 5 about here]

In a majority of groups, participants expressed both types of classifications. There was no clear pattern on which type of participants tended to make each type of classification. Further, all 6 countries of origin had at least 1 case of each type. We discuss both patterns in more detail below.

LTBI is a sickness

In all 15 FGDs, at least one person made the argument that LTBI constitutes an illness even though it does not present any symptoms. To make this argument, participants drew a boundary between infection and no infection, characterizing LTBI as an early version *of* TB rather than a separate condition. By classifying LTBI *under* TB as a "latent stage" of the infectious disease, these participants increase the gravity of LTBI by narrowing the conceptual gap between the two terms.

This argument emerged via four discursive strategies that often occurred in a single statement: the use of the conjunction "but" to explain how it was possible to not have symptoms but still be ill, the use of the words "have" and "there" to describe a contamination of the body, the use of the adverb "still" to emphasize LTBI as a component of TB, and the use of the pronoun "it" to refer to TB in a way that encompassed LTBI. Figure 6 illustrates the similarity of this language across groups.

[Figure 6 about here]

To illustrate all four discursive strategies, consider a single sentence from a Filipino participant describing LTBI: "You don't show the symptoms, but you still have it." First, the participant uses the conjunction "but" in an attempt to acknowledge and simultaneously resolve an inherent tension between the absence of typical signs of illness (i.e. symptoms) and the presence of an illness state. Second, the participant uses the verb "have," suggesting a breach or contamination of the body with TB germs. The verb "have" further illustrates the binary framework through which this, and many other participants, are operating: you either do or don't "have" it. There is no middle category. Third, the participant uses the adverb "still" to show how LTBI is a part of TB because both involve TB germs. Finally, the participant uses the pronoun "it" to refer to TB in a more encompassing manner. Here, "it" refers to "TB" not "LTBI" since the point is that you can "still" have TB even in an asymptomatic state.

An exchange in a Mexican group illustrates these discursive strategies well. While one participant suggests that LTBI is "just an infection," other participants argue that LTBI is an illness state.

> *P1: What I understood is that whenever you're starting the infection of TB, it's called this instead of just TB because it's before -- so you're not showing any symptoms, you're not showing anything. It's just an infection.*
> *P2: You still have, yeah.*
> *P3: Probably just delayed, delayed.*
> ***MODERATOR: Just an infection. Delayed, ok. Just an infection, it's delayed, ok. Any other thoughts about that?***
> *P4: Still the same thing. You still have tuberculosis.*
> ***MODERATOR: You still have tuberculosis. Okay.***
> *P5: Yeah.*
> *P4: You're just not sick.*
> *P6: Yeah you don't have any symptoms. You're not showing – you're not showing the sickness. You just have TB.*
> ***MODERATOR: Any words you don't understand or are not clear in that statement?***
> *P1: Yeah, the -- I think people would misunderstand… because they're like, do I have it or do I not have it?*

> ***MODERATOR: Yeah. What part um would be the --***
> *P1: It says people who are infected with TB but are not sick have a condition called latent… TB infection. So you're not sick but you have a TB infection. Is it the same thing?*
> (Mexican group #2, Houston)

The first comment draws a temporal distinction between "TB" and the thing that comes "before." She says this thing that comes before is "just an infection." This argument illustrates the other categorization of LTBI – as a healthy state. Many participants, however, chime in and caution against this interpretation. They use the words "still" and "have" to challenge the distinction between LTBI and TB. To them, LTBI is "still" TB. One participant says LTBI is "still the same thing. You still have tuberculosis. You're just not sick." Another participant refines this statement, saying "you're not showing the sickness." This statement further cautions against treating LTBI as a healthy state. Rather than saying "you're not sick," this participant says you have the sickness (i.e. the germs), but you are not showing any signs.

LTBI is not the real thing

By contrast, in 12 FGDs, someone made the argument that LTBI does not rise to the level of sickness and is therefore not a real condition. Rather than subsume LTBI *under* TB, these participants underscored the distinction *between* LTBI and TB and used this as evidence that LTBI was not the "real" thing.

This argument was expressed via three discursive strategies. First, participants used modifiers such as "actually," "actual," or "real" to suggest that LTBI was a pseudo-illness. This represents the flip side of the adverb "still" used by the other group of participants. Instead, participants contended that LTBI was not the "real disease" or the "real infection." Second, similar to the other group, they used the verb "have," but instead argued that someone with LTBI does *not* have it. Third, and relatedly, this group also employed the simple pronoun of "it."

Again, in many of their statements, "it" referred to TB, but here participants made the argument that someone with LTBI does not have "it" (i.e. TB). Figure 7 illustrates how people described LTBI as a pseudo-illness.

[Figure 7 about here]

A statement from a Guatemalan participant illustrates all of these discursive strategies: "Not actually have it but to be exposed to it." This participant uses the word "actually" to suggest LTBI is not the real thing. "Actually" modifies the verb "have," implying that LTBI doesn't mean you "have" TB. The participant also uses the word "it" to refer to TB, but here emphasizing that LTBI should not be confused with TB.

A Chinese group provides a nice illustration of this type of argument. The majority of participants contend that LTBI should be classified as a healthy status and clearly distinguished from TB, but one participant, with a fair amount of experience getting tested for TB, pushes back.

> *P1: Latent TB is you don't have any symptom. You feel you are a normal person. But the TB disease, you feel you are sick.*
> ***MODERATOR: OK thanks. And Chen, what would you say?***
> *P2: Yeah latent isn't that like uh-- like you're healthy. Looks good.*
> *P3: Looks healthy.*
> *P2: Yeah, looks healthy, yeah. (LAUGHS). But if you have the real TB disease, you get – you get sick. So that's different.*
> ***MODERATOR: Anyone add –***
> *P4: Yeah, one is hiding. One exists.*
>
> (Chinese group, NYC)

Most of the participants accentuate the difference between LTBI and TB, describing LTBI as a state in which you are "normal" and "healthy." TB, on the other hand, is a "disease" that is "real" and "exists." When one participant argues that with LTBI "you're healthy," another participant pushes back by saying "*looks* healthy." By emphasizing the word "looks," this participant underscores the idea of misperception – not seeing symptoms does not rule out illness. Although

the other participant acknowledges this, repeating the statement "yeah looks healthy," he continues to draw a distinction between the two, now describing TB as the "real" thing and saying "that's different" than LTBI.

Ultimately, this fundamental disagreement on "what" LTBI is leads to subsequent disagreements about how someone diagnosed with LTBI ought to act. Should they take on the sick role?

Taking on the sick role

The disagreement on how to classify LTBI led to subsequent disagreements regarding appropriate health behavior. When someone is deemed at-risk for LTBI or diagnosed with LTBI, should they take on the sick role? As described earlier, the sick role constitutes a type of social role and therefore comes with attached social expectations. Being sick triggers a series of social obligations and exemptions. On the one hand, you must seek medical attention. On the other hand, you are exempted from typical responsibilities, such as work (Parsons 1975). When the health status is not clearly defined or people hold different definitions, it creates a downstream effect, producing uncertainty about whether norms associated with the sick role apply in this situation.

Across FGDs, we observed disagreements over appropriate behavior for someone who might be at-risk for LTBI or for someone who was diagnosed with LTBI. These disagreements did not clearly cluster around any one group or country of origin. However, people who characterized LTBI as an illness were more likely to advocate that someone take on the sick role. Likewise, people who characterized LTBI as "not the real thing," were more likely to suggest no action was needed.

Importantly, the possibility that LTBI could become contagious led participants to engage in social control. Participants attempted to directly influence others' intended health behavior and expressed concern at those they felt were being too cavalier. Most cases of social control involved verbal admonition in which worried group members tried to increase concern among participants who appeared to not be taking LTBI seriously. Participants directly questioned others who seemed unmotivated or unconcerned about getting tested and treated.

For example, a Guatemalan participant states that people shouldn't worry about those infected with LTBI because the person is not contagious or sick. This statement causes other group members to chime in and challenge her, cautioning her against an overly rosy picture.

> *P1: The issue is that if it's latent in me it not mean that I am sick. And you don't have to be like --*
> *P2: But it doesn't necessarily mean that you're going to be safe all the time. If it's staying here, if the TB germ becomes active that means that there's a probability that it could become active.*
> *P3: Exactly.*
> *P1: Yeah, it could be but it –*
> *P4: It could be in you.*
>
> (Guatemalan group #1, Miami)

While the participant emphasized that being latent meant that she was *not* sick and therefore not a public danger, others in the group cautioned against this perception because there was a possibility she could become active and endanger others.

Similarly, in a Mexican group, participants express concern over one member who says she is unlikely to get tested and treated for LTBI given the lack of symptoms. Several participants quickly try to redress what they perceive to be deviant behavior.

> ***MODERATOR: How likely are you to get tested and treated for a condition if you do not feel sick?***
> *P1: Why would -- If I don't feel sick, why would I go get tested?*
> *P2: Because you still have an illness.*
> *P3: You can have it and not feel sick.*

(Mexican group #2, Houston)

Two participants quickly chime in to challenge the lack of motivation to get tested, reminding her that "you still have an illness" and that you "can have it and not feel sick" (meaning TB). They are therefore attempting to persuade her to see LTBI as an illness category and to subsequently adopt the sick role. The conversation continues on for several minutes with other participants chiming in to challenge the perceived deviant participant.

> *P4: Well, you can still go to your annual check-up so –*
> *P1: I'm just saying, if you didn't know about it, would you go? So if you didn't know you had cancer but you had it, you would go? (GROUP LAUGHTER). If you don't feel symptoms –*
> ***MODERATOR: So if you get tested, you find out you're positive, but you still don't feel sick, but you're told.***
> *P1: Yeah, if I was told that I was positive, then I would go get checked.*
> ***MODERATOR: And would you take treatment?***
> *P1: Yes. But if I didn't feel any symptoms or feel sick then no, I wouldn't go.*
> *P3: How about if they told you: you have it, but you don't feel sick. You wouldn't take treatment?*
> *P1: Yes I would.*
> *P3: Oh.*
> *P1: Do you understand what I'm telling you, right? (GROUP LAUGHTER)*
>
> (Mexican group #2, Houston)

Near the end, the challenged participant attempts to clarify her position. She emphasizes that she would take on the sick role and accompanying health behavior, but that the lack of symptoms would make it hard for her to know that she is, in fact, sick. Her emphatic response ("yes I would," "do you understand what I'm telling you") suggest that she wants to be compliant, but that she sees LTBI as particularly challenging given the lack of symptoms. Ultimately, her responses seem to satisfy the group.

Participants also discussed whether someone with LTBI ought to seek treatment. In a Vietnamese group, a participant admits that he "probably wouldn't take it" if he was diagnosed

with LTBI. He then clarifies, “I don’t need treatment if I don’t feel sick” and that “it’s sleeping and not doing anything. Basically, it’s almost like you don’t have it.” This leads into a group discussion where one participant, who had previously been diagnosed and treated for LTBI, tries to convince this skeptical participant of the importance of getting treated for LTBI.

> *P1: Well I didn’t have any symptoms at all. Until the doctor told me and they told me how serious if I don’t treat. If I don’t treat, any kind of sickness occur in your body in the future, you cannot make it because you have a TB. At that point TB will active and become with the TB whatever disease that you have, it is a lot harder to treat.*
> *P2: Right. But that was what active on you and a lot of people that doesn’t have active, they don’t care.*
> *P1: No, no.*
> *P3: No, it’s not active on her.*
> *P2: Oh.*
> *P1: No it’s not active. Mine’s inactive. But because I have it inactive, which mean if I don't treat nothing wrong with me. But, I had to take the TB medicine because if I don't take it, if anything, if all of a sudden I got pneumonia, the TB would attack me and I might die because the TB already in there. If any sickness, if anything your body get problem it wake up (snaps fingers) right away and attack you.*
>
> (Vietnamese, Houston)

Speaking from her own experience of being diagnosed and treated for LTBI, this participant emphatically describes the importance of taking on the sick role. She talks about her discussion with a doctor, her decision to seek treatment, and the potential dire consequences of not getting treated. In response, the skeptical participant tries to dismiss her explanation by saying she had “active” TB. A third participant corrects this misperception, reinforcing social control. When the moderator asks the skeptical participant to respond, he employs another strategy common among testing and treatment skeptics – he speaks from the position of a third party. This line of argument often acted as a cover for personal beliefs. Rather than disclose personal intended health behavior, some participants opined on the health behavior of the general population. Here, the group interjects and asks the skeptical participant to state what he would do personally. Ultimately, the skeptical participant does not alter his intended behavior.

P2: What I'm saying is not everybody take care of themselves.
MODERATOR: I don't care about –
P4: We talk about you!
MODERATOR: Yeah, you personally.
P2: Oh. Oh me?
MODERATOR: Yeah.
P2: It's not active, I'm not doing anything.

(Vietnamese, Houston)

There were also several cases in which discussions were not hypothetical but actually focused on the possibility of someone being infected. In a Filipino group in New York a participant mentioned that he was now worried about having TB germs because he had just recently traveled to the Philippines, a country with a high TB case rate. Upon announcing this recent visit, another participant says "ughhh" in disgust, as if he might be infected. This leads into a question about whether he will make an appointment to get tested. While the potentially infected participant remains more hesitant on his status, saying "we don't know yet" and that "maybe" he will make an appointment to get tested, others laugh, make noises of disgust as if he were contaminated, and one even pleads with him to make an appointment (saying "please"). The group sees LTBI as a sickness that needs to be monitored and treated and expects those at risk to take the condition seriously.

Similarly, in two groups a participant repeatedly coughed, prompting others to make a joke or a comment about possible infection. In one of these groups, the coughing person volunteered an explanation for his cough, explaining that it was not TB. The participant who made the comment about possible infection then quickly tries to save face.

P1: I have a cough, but I don't have it.
P2: Oh no, no, no, no. (Group laughter). Not at all! I'm sorry. I didn't mean to--
P1: Let me tell you (Laughs). (Group laughter).
P2: No! I'm just -- sorry.
P1: Don't – don't – don't go and worry (Laughs).

(Mexican group #1, Houston)

Whereas many of the cases of social control involve a participant challenging perceived deviant health behavior, here we see a participant who voluntarily explains to the group that he is not engaging in deviant health behavior. He volunteers that he "doesn't have it." His decision to announce his health status illustrates the power of social control because he wants others to know that he is being compliant and does not need to adopt the sick role. Indeed, he states: "don't go and worry," suggesting that he is not a cause for public concern.

One particularly illustrative case occurred in an Indian group in New York in which two participants revealed that they had personal experiences of testing positive with LTBI but had not taken prescribed medication. Both said that they had worked with Indian doctors who had explained that their test results were false positives and that this was common among Indians. Both participants leveraged the doctor's statement as evidence that LTBI was not a true health condition and did not need to be treated.

> *P1: So, doctor say that any person who comes from India would be positive, India, Pakistan, Bangladesh, Sri Lanka region. But actually it's not a positive because the way it is being diagnosed here versus the way it is diagnosed in India is some difference there. So, here there is like this Type 1 and Type 2 diabetes, which is not in India but is here actually. So, same thing happened here. So normally they are put on a medication, pills like for six months and they would have to go for the x-ray. That probably is done the same.*
> ***MODERATOR: So, but who do you know somebody who took the pills for six months like you described?***
> *P1: My son did not took it, honestly (laughs) because we know that it's going to come positive.*
> ***MODERATOR: So, your son was tested positive. The doctor said, "hey, take these pills for six months," and he didn't take them.***
> *P1: Yeah. Well on paper it was prescribed, but we know -- even the doctor knows that no one is going to take it, because it's common for Indian people.*
> *P2: Mmhmm*
> ***MODERATOR: And wait [Participant 2 name]?***
> *P2: Yeah, they gave me the medicine, but I didn't take it, too.*
> ***MODERATOR: You didn't take it? How long ago was that? Just curious.***
> *P2: Five years ago.*
> *P3: What -- I don't know if I can ask.*

MODERATOR: Yeah, yeah, please.
P3: What made you not take it if advised?
P2: I knew that I don't have it, so I knew. My doctor explained to me, too, the Indian doctor. He told me.
P3: Or -- another follow-up question would be, what's the difference?
P2: X-ray. X-ray. The X-ray said clearly that I don't have it.
P1: X-ray's clear, yeah.

(Indian group #1, NYC)

Notably, one of the participants uses the language of "have" and "it" at the end, referring to the fact that he doesn't have TB. These participants who have opted not to follow treatment are able to explain this decision as appropriate behavior by classifying LTBI as a category of health. In fact, one of the participants argues that LTBI is not even a true diagnostic category and is only diagnosed this way in the U.S. Regardless, both want to demonstrate to others that their behavior is appropriate and they do this by explaining how they knew they were not sick. For example, both men mention that their x-ray was clear as evidence of a healthy status. During the course of the discussion, however, participants learn a different perspective on LTBI and two women begin to express concern about these men and their decision to not seek treatment. One of the women asks for clarification on the men's position.

P3: I have a question for the both of you [She references the two men by pointing]. Like now, after reading this and reading what latent means and knowing that, would you – like for your son especially -- would you take a more preventative measure? Would you do this?
P1: No.

(Indian group #1, NYC)

While one participant explicitly says he would not change his position, the other participant says that he would now seek treatment if he tested positive, but it is unclear whether he is simply succumbing to social pressure in the group or whether he has actually changed his perspective.

Finally, while most cases of social control occurred through direct influence of other

participants, there were also instances in which participants appeared to alter their stated health behavior out of conformity rather than direct pressure. For example, when asked how likely each person was to go through all the necessary tests for diagnosing LTBI (i.e. initial test, reading, x-ray), one Filipina participant initially stated that she was unlikely to complete all of the necessary tests because it might be too much of an inconvenience. The moderator then proceeds to ask several others for their responses and three other participants state how important it is to get tested, saying "I'd rather be safe than sorry" and "it's more proactive." When the moderator follows up with the participant who had expressed doubts about her motivation to get tested, she changes her response and says that she would go get tested because she has kids and works around kids.

Discussion

This paper considered the issue of medical uncertainty through the case of LTBI – an asymptomatic condition that, if untreated, can become symptomatic and infectious. We used FGDs with populations at increased risk for LTBI to answer two related questions: how do at-risk persons define the condition LTBI and how do different definitions influence intended health behaviors?

We found that most participants were confused by the initial presentation of LTBI as a liminal health status. In response, most participants chose to reject this liminal category and instead attempted to categorize LTBI into a binary framework of health and illness. However, we show that participants disagreed on how to reclassify LTBI. One set of participants placed LTBI into an illness category by conceptualizing the binary as "not infected" and "infected." Another set of participants placed LTBI into a healthy category by conceptualizing the binary as "not

sick" and "sick." Ironically, this attempt at reducing uncertainty -- by placing LTBI in a binary framework --actually produced additional uncertainty because participants disagreed on how LTBI should be categorized.

We also showed how these differing definitions of LTBI influenced participants' intended health behavior. Using Parsons's sick role framework, we showed that disagreements on whether LTBI constituted an illness spilled over into disagreements on appropriate health behavior. For those who saw LTBI as an illness, they expected people to take on the sick role. This meant taking testing and treatment seriously, even without typical signs and symptoms of illness. For those who believed LTBI did not rise to the level of illness, they felt that it was acceptable to not get tested or treated. Importantly, because of the focus group format, we were able to observe several cases of social control in which participants admonished others for not taking LTBI seriously enough. Although the discussions were often hypothetical in nature, centering on whether people *would* get tested or *would* get treated if positive, the stakes appeared high because people worried about the potential for future contagion.

Limitations

Several limitations of this study should be noted. The recruitment strategy likely skewed the sample in several meaningful ways. English literacy was a requirement for inclusion in the study, which may have excluded participants with lower health literacy. We also limited participants to those already available on existing market research lists, which may have further limited the sample. In addition, the design of the study only allowed for stratification on two variables: country of origin and focus group location. This did not allow us to tease apart the effects of other relevant variables including education, health insurance status, or TB knowledge. Finally,

while the focus group setting provided important analytical leverage for understanding how people make health decisions in social environments, it may have also led to a social desirability bias.

Contributions and implications for messaging

The results of this paper contribute to our understanding of how people interpret liminal health categories -- such as "at-risk" and asymptomatic conditions -- and how divergent interpretations can influence health behaviors. Previous research has shown that liminal categories can cause confusion about appropriate behavior, but that people often opt to take on the sick role. Many of these studies, however, have examined perceptions of patients in a medical encounter. This study, by contrast, assessed perceptions among an at-risk group outside of a clinical context. In doing so, it potentially captured a missing perspective – people who see a liminal status as nothing to worry about are potentially less likely to seek medical care in the first place. This paper therefore provides evidence of people classifying a liminal status into both a sick and a healthy category. The paper also provides support for the continuing relevance of Parsons's sick role framework. While participants disagreed on how to classify LTBI, they agreed on the predominance of a binary framework of health and illness. Furthermore, no one seemed to question the existence of a sick role or associated role expectations – only whether the sick role applied to someone with LTBI.

Our results also have implications for future LTBI messaging. The key takeaway is that presenting a condition as a liminal health category may be counterproductive since people seem prone to using a binary framework of health and illness. On both sides, we saw the repeated use of the language "have" and "not have," illustrating this entrenched idea that health is a

dichotomous variable. Because LTBI was presented as “infected but not sick,” two divergent interpretations appeared plausible – either LTBI was an infection (and therefore the person was ill) or it was not a sickness (and therefore the person was healthy). Rather than leaving LTBI open to interpretation, future messaging can frame LTBI as an illness and an early phase *of* TB. We saw that closing the gap between LTBI and TB increased motivation to get tested and treated. Relatedly, the term LTBI could be simplified to “latent TB,” allowing only one modifier (latent) rather than two (latent and infection). This would further help to give the impression that LTBI is a sub-category of TB rather than an entirely distinctive condition. By eliminating this middle category and characterizing LTBI as an illness, messaging on LTBI can encourage at-risk persons to identify with the sick role and adopt the associated health behaviors.

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Tables and Figures

Figure 1. Conceptualizing health categories

	Patient		
Provider		No symptoms	Symptoms
	No diagnosis	Healthy match	Contested illness mismatch
	Diagnosis	Patient in waiting mismatch	Sick match

Table 1. Sample design

COUNTRY	**LOCATION OF FOCUS GROUP**					**TOTAL**
	Miami	*Chicago*	*Houston*	*San Francisco*	*New York*	
Guatemalan	2					2
Mexican		1	2			3
Vietnamese			1	1		2
Filipino				2	1	3
Indian		1			2	3
Chinese		1			1	2
						15

Table 2. Group demographics

Demographics of focus group participants (n=15)						
Group ID	Country	City	% College degree	Age range	% in U.S. > 10 years	FGD size
1	Guatemalan	Miami	38%	21-68	75%	8
2	Guatemalan	Miami	29%	20-52	100%	7
7	Mexican	Chicago	33%	28-42	78%	9
9	Mexican	Houston	0%	21-57	67%	9
10	Mexican	Houston	0%	18-44	67%	9
3	Vietnamese	San Francisco	89%	26-62	78%	9
11	Vietnamese	Houston	56%	41-67	100%	9
4	Filipino	San Francisco	100%	24-59	78%	9
5	Filipino	San Francisco	56%	21-80	56%	9
15	Filipino	New York	67%	29-64	67%	6
6	Indian	Chicago	100%	25-58	57%	7
12	Indian	New York	89%	21-75	100%	9
13	Indian	New York	100%	25-51	25%	8
8	Chinese	Chicago	78%	22-45	67%	9
14	Chinese	New York	78%	23-66	67%	9

Figure 2. Prior knowledge and experience with LTBI

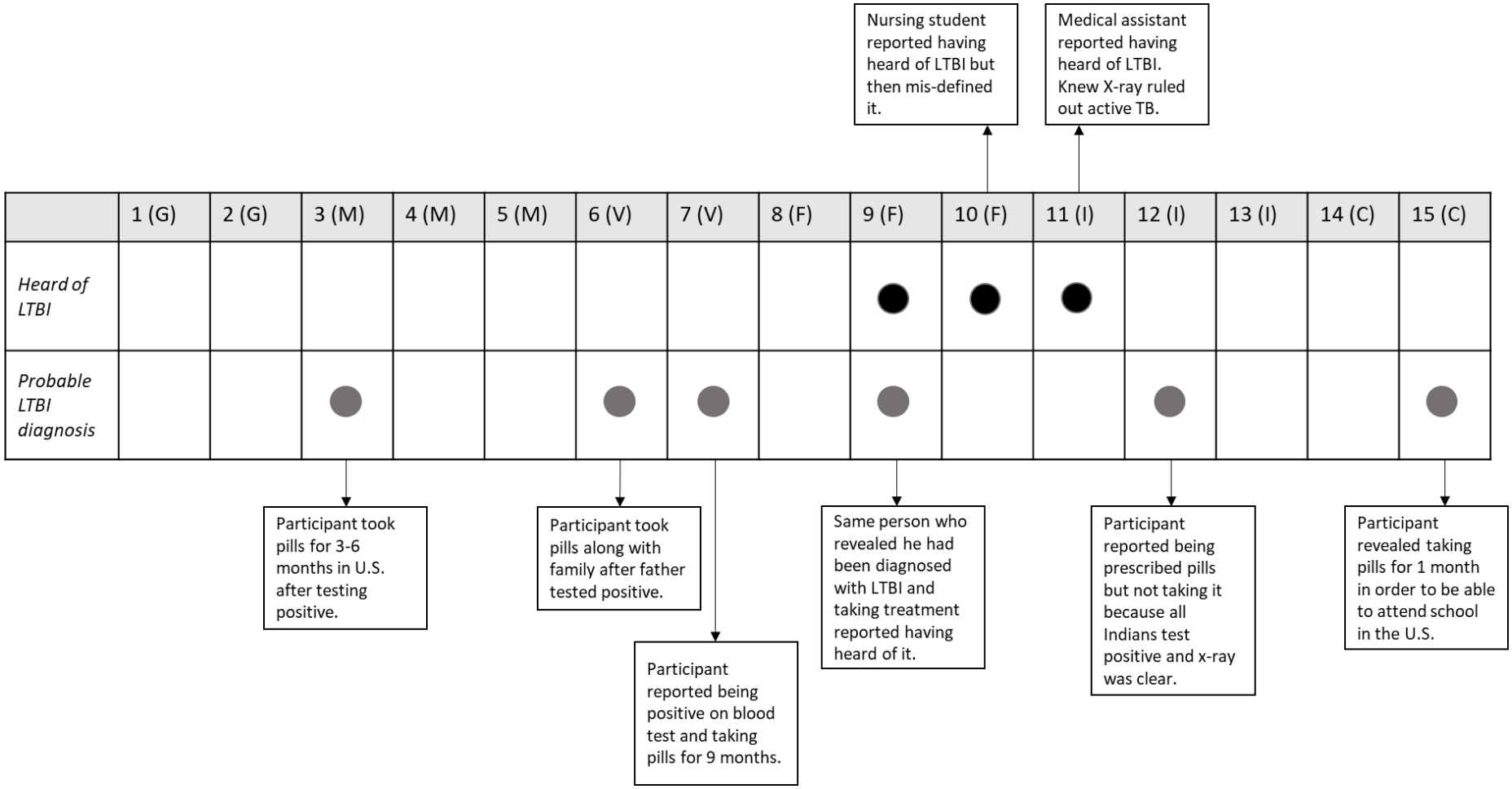

Figure 3. Health and illness frameworks

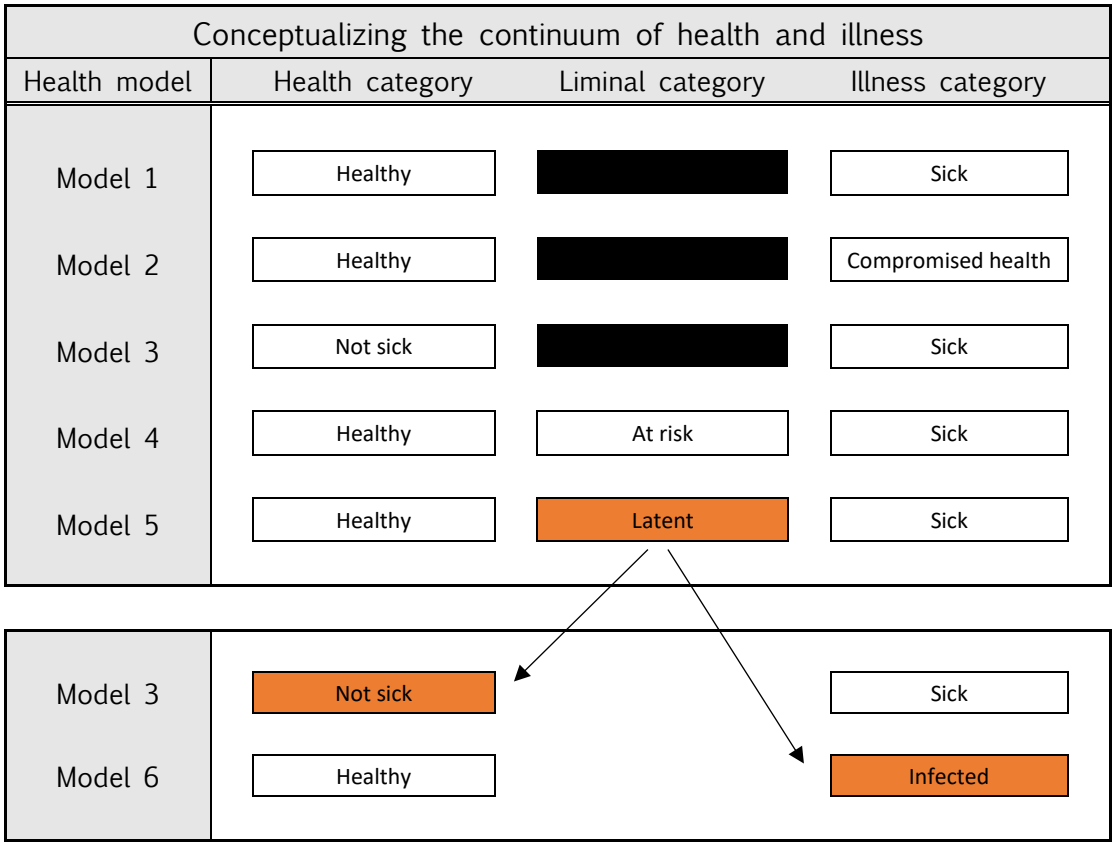

Figure 4. LTBI as illness category

Infected but no symptoms			
Clause 1	Connector	Clause 2	Group
Maybe you have the TB	but	there's **no symptoms**.	CH (NY)
That you're infected	but	you get the **symptoms at a later date** maybe?	GU (1)
Just dormant or something that's there	but	**doesn't come to the surface** until something happens.	GU (2)
It just means that you get it	but	it's in the **latent** stage. You **don't have the symptoms** for it.	VI (SF)
I think that they're saying that you can have the infection	but	it's not like -- kind of what she said -- it's **not making you sick**.	ME (H 1)
P1: I didn't know you had TB. You had TB? P2: Yeah. Yeah	but	it was **dormant**.	FI (SF 2)
You **don't show signs** that you are a sick	but	then you have the infection.	CH (CH)
You **don't show** the symptoms	but	you still have it.	FI (SF 1)
You might not have **any signs** of it	but	you have it on your system.	ME (CH)
Something that **doesn't show** up	but	it's *in* there in your system.	IN (NY 1)
It says that even though your TB don't have **any symptoms**	but	it could be there, that's what it's trying to say.	IN (CH)

Figure 5. LTBI as healthy category

Not the real thing			
Clause 1	Connector	Clause 2	Group
Not **actually** have it	but	to be exposed to it	GU (1)
Somebody develops the **actual** disease	when	it becomes active	GU (2)
So it kind of becomes confusing between having **normal TB**	and	latent TB infection.	IN (CH)
Just being positive means you're just exposed to it,	but	it **doesn't mean you have it**	VI (SF)
It's more like exposed to it,	but	it's **not serious**.	VI (SF)
You have the virus	but	you **don't actually have** the TB	GU (1)
Are you asking about the term latent	or	just the **actual** disease?	FI (SF 2)
They're inactive and only if they get activated	then	you **actually** get the disease	IN (CH)
Because it's latent, it makes it sound	like	it's **not the real** infection	ME (H 1)
Maybe it [LTBI] is not as strong	as	the **regular** one?	ME (H 2)
Latent isn't that like you're healthy. Looks good.	but	if you have the **real** TB disease, you get sick.	CH (NY)
It hasn't hit you completely until it's -- I guess TB	then	that's when it's **actually** the infection.	ME (H 1)
It's a pre-condition. Like **pre**-stages	not	the **late** stage.	IN (NY 2)

CHAPTER 2: Why does it matter where I am born? Defensive processing of health risk messages: The case of TB risk among immigrants

Abstract:
A key problem documented in the health risk literature is that the people most at-risk for a health condition are often the least likely to be persuaded by health risk messages. Instead, at-risk persons may engage in "defensive processing," rejecting or downplaying risk information. This paper considers the case of tuberculosis (TB) messaging directed at non-U.S.—born persons who are at increased risk for TB in the United States. Specifically, we examine non-U.S.—born persons' perceptions of messages describing the link between country of birth and TB risk. Data comes from 15 focus groups with non-U.S.—born persons born in the 6 countries that contribute most to the TB case count in the U.S. Focus groups were transcribed verbatim and analyzed using a grounded theory approach. We find evidence of two types of defensive processing strategies: counter-argumentation and self-exemption. While some participants challenge the link between country of birth and TB risk, many accept the link but perceive themselves as personally exempt from the messages due to passing their immigration screening. Importantly, participants emphasized their status as immigrants as evidence of their lower TB risk. Implications for future TB messaging and contributions to the literature are discussed.

Keywords: Risk, health messages, defensive processing, immigrants, latent tuberculosis infection, tuberculosis

Introduction

Public health agencies design and disseminate health risk messages with the goal of persuading key at-risk populations to protect their health. Yet simply providing information that people are at risk for some health condition is often insufficient for motivating protective health behavior. In fact, health risk messaging may fail to prompt behavior change because it often requires people to identify with a negative social status of compromised health or "at-risk" status. This "at risk" status can be seen as a threat to an individual's positive self-concept and thus triggers a series of "defensive processing" strategies, including the tendency to underestimate one's own risk or see oneself as exempt from risk messages (Liberman and Chaiken 1992, McQueen, Vernon and Swank 2013, Weinstein 1984, for a recent example see: Zhou and Shapiro 2017).

We use the framework of "defensive processing" to explain the reactions of non-U.S.—born persons to public health messages on tuberculosis (TB) and the link between country of birth and TB risk. TB in the U.S. presents an interesting case for understanding defensive processing for three key reasons. First, the risk is tied to a general social group (e.g., immigrants/non-U.S.—born persons) rather than a specific health behavior (e.g., smokers), which may prompt questions about what puts this group at higher risk. In the U.S., TB disproportionately affects non-U.S.—born persons. In 2019, 71% of TB cases in the U.S. were among non-U.S. born persons and non-U.S.—born persons were 15.5 times more likely to have TB than U.S.—born persons (Schwartz et al. 2020). Second, the overlapping statuses of "at-risk" and "non-U.S.—born" may activate negative stereotypes about immigrants, heightening threats to the positive self-concept. TB is already a stigmatized disease in many countries (Chang and Cataldo 2014), but some have argued that in places like Europe and North America it may be perceived as an immigrant disease (Kehr 2012, Taylor 2013). Third, the infectious nature of TB

offers an opportunity to assess whether defensive processing operates differently when the risk in question is communicable. The defensive processing literature demonstrates the tendency for people to acknowledge a general risk while downplaying their own risk, but when the condition is contagious, assessments of personal risk cannot be entirely decoupled from assessments of general risk.

This paper draws on data from 15 focus groups in which key non-U.S.—born audiences living in the U.S. were asked to react to a series of TB risk messages. Using this qualitative data, the purpose of this paper is to understand the perceptions of non-U.S.—born persons to health risk messages describing the link between country of birth and TB risk. We offer specific implications for improving TB messaging to this at-risk audience while also offering implications for the defensive processing literature.

Background

Risk perceptions and defensive processing

Risk perceptions refer to how people process information about risk using both cognitive and emotional channels. Several characterizations of risk perceptions exist and are linked to different research traditions. On the one hand, some characterize risk perceptions as primarily cognitive judgments. For example, this can involve the identification of an event or behavior as risky (e.g., smoking is risky) or calculations of risk probability (e.g., how likely are you to have later health problems if you smoke) (Millstein and Halpern-Felsher 2002). On the other hand, some characterize risk perceptions as combining emotional responses with cognitive reasoning and propose a more dual-process model (for a review, see Leppin and Aro 2009).

In the realm of health, risk information is often presented to the public through various health campaigns. Health campaigns and messages typically highlight some health risk with the goal of motivating target audiences towards protective health behavior that reduces that risk. However, messaging on health risks faces a key problem: the groups most at-risk for a health condition, and therefore most often the target of messaging, are often the most resistant to that messaging (Kessels, Ruiter and Jansma 2010, Liberman and Chaiken 1992, Sherman, Nelson and Steele 2000, Zhou and Shapiro 2017). This is called "defensive processing."

Defensive processing occurs when health messages are both threatening and personally relevant (Liberman and Chaiken 1992). Defensive processing is linked to a fundamental process outlined in social psychology: people are motivated to maintain a consistent and positive self-concept and when that image is threatened, they engage in various defense strategies (Burke 1991, Fiske and Taylor 2013, Markus and Wurf 1987). Upholding a positive self-concept involves claiming identities we want and disavowing identities we do not. The latter has been referred to as a "not me" identity (McCall 2003) and may involve the active rejection of an imposed identity (Killian and Johnson 2006). Health risk messages are often designed to activate an "at-risk" identity with the goal of motivating at-risk persons to neutralize the relevant health threat. But accepting an "at-risk" identity may threaten positive conceptions of the self, leading the most vulnerable people to reject relevant health information (Sherman, Nelson and Steele 2000).

Multiple defensive strategies have been documented in the literature. McQueen, Vernon and Swank (2013) map these various strategies to the four established stages in information processing, which move sequentially from (1) preattention, (2) focal attention, (3) comprehension, and finally (4) elaboration and assessment. In the first stage, defensive

processing takes the form of "attention avoidance," which may involve avoiding risk information from doctors or media sources. In the second stage, called "blunting," people become mentally disengaged after having been exposed to threatening health information. For example, two neurological studies found that the combination of threatening and personally relevant messages reduces attention to those messages. In one study, smokers and non-smokers viewed both threatening and non-threatening images of smoking. Whereas non-smokers paid similar attention to both types of images, smokers held attention for less time on the threatening images, suggesting a conscientious desire to avoid threatening personally relevant information (Kessels, Ruiter and Jansma 2010). A second study evaluated health messages on diet and found that participants paid the least attention to threatening images that were personally relevant, and the most attention to non-threatening images (Kessels et al. 2010). In the third stage, called "suppression," people have chosen to engage with the health information (i.e. rather than avoid it) but they may express self-exemption beliefs such as an "optimism bias." An optimism bias occurs when people acknowledge a general risk but rate themselves as having below average risk (Masiero et al. 2018, Weinstein 1984, Weinstein 1987). This optimism bias appears across a range of different demographic groups, but is more common in response to certain health conditions, such as rare diseases and when the risk appears to have a high level of "controllability" (i.e. capable of being influenced by personal action) (Weinstein 1984). In other words, people tend to assume that they are more capable of controlling their personal health behavior than similar others. In the fourth stage, called "counter-argumentation," people are fully engaging with the health message and evaluating its contents. However, they engage in "counter-argumentation" in which they may reject the message, refute evidence, or downplay severity.

This counter-argumentation has been documented in several studies, including among binge drinkers (Zhou and Shapiro 2017) and caffeine consumers (Kunda 1987).

Case study: non-U.S.—born persons at risk for TB

The present paper considers defensive responses to messages on TB risk. Successful health messaging about TB is particularly urgent. TB is a bacterial infection that can affect the lungs as well as other parts of the body, and is the leading infectious disease killer globally, ahead of HIV (World Health Organization 2019). In many developed countries, including the U.S. and Western Europe, TB rates have been declining for decades and are nearing official elimination status. In the U.S., however, annual declines in TB rates have begun to slow (Schwartz et al. 2020, Talwar et al. 2019) and are slower among non-U.S.—born populations (Iqbal et al. 2018). In the U.S., TB disproportionately affects non-U.S.—born persons. In 2019, 71% of TB cases in the U.S. were among non-U.S. born persons (Schwartz et al. 2020). Predictive modeling suggests that the primary driver of TB cases in the U.S. will continue to be through immigration and that efforts to increase targeted testing and treatment among these immigrant populations is likely to be most effective in attaining TB elimination in the U.S. (Menzies et al. 2018).

In addition, more than 80% of TB cases in the U.S. are due to untreated "latent tuberculosis infection" (LTBI) acquired many years prior rather than from recent transmission (Yuen et al. 2016). LTBI is an asymptomatic stage of TB in which a person is infected with TB germs, but exhibits no symptoms, does not feel sick, and is not infectious. The only indication of LTBI is a positive reaction to a TB skin test or TB blood test. LTBI can lay dormant in a person's system for years, but 5-10% of people infected with LTBI who do not seek treatment will progress to TB disease at some point in their lives (Centers for Disease Control and

Prevention 2016). LTBI can be treated, which helps to prevent the activation and possible spread of TB germs later in a person's life.

Non-U.S.-born persons who come to the U.S. on certain types of visas or who readjust their immigration status must undergo a medical exam either abroad by a panel physician or in the U.S. with a registered civil surgeon. The medical exam includes a TB test. Until 2019, the technical instructions that define the specific responsibilities of civil surgeons for TB testing and referral indicated that a TB test could be administered either via a skin test (often called a "PPD") or a blood test. The skin test is considered less accurate and susceptible to false positives, especially among those who have received the Bacille Calmette-Guérin (BCG) vaccine (Goletti, Sanduzzi and Delogu 2014). The BCG vaccine is often given to infants and small children in other countries where TB is common to prevent TB meningitis (Advisory Council for the Elimination of Tuberculosis (ACET) 1995). It is still widely used in many countries outside U.S. and Europe (Zwerling et al. 2011). Those with a positive test result are then required to get an X-ray to rule out TB disease. This process only attempts to identify those with TB disease and does not identify or report people with LTBI (Centers for Disease Control and Prevention 2018) – the main driver of TB cases in the U.S. Updates to the technical instructions were released in 2019, which require civil surgeons to administer a blood test and to report both TB and LTBI cases to their local health department (Centers for Disease Control and Prevention 2019). Because these updated technical instructions have just recently been implemented, many immigrants have presumably passed their TB test but could still have undetected LTBI. Further, these immigration medical exams do not capture all non-U.S.—born persons, including those on student visas, visiting, or without legal documentation. These trends have led the CDC, as well as the United States Preventive Services Task Force (USPSTF), to

issue recommendations for targeted testing and treatment of LTBI among non-U.S.—born populations in order to better reach this at-risk population (LoBue and Mermin 2017).

Design and methods

Data

The data for this paper comes from a CDC funded study that was designed to evaluate how well a series of LTBI messages performed amongst non-U.S.—born persons who are considered a key at-risk population. Study activities were carried out by DTBE's Communications, Education, Training, and Behavioral Studies branch (CEBSB). In April and May of 2019, CDC conducted 15 focus group discussions (FGDs) with non-U.S.—born persons living in the U.S. FGDs were most suitable for this study to capture a wide range of perspectives on the topic. In addition, FGDs, as opposed to in-depth interviews, enable interaction and discussion therefore better capture areas of consensus and disagreement. The project was considered non-research and therefore IRB exempted. OMB approval was secured.

Sample

FGDs were conducted with non-U.S.-born individuals from the 6 countries that contribute most to the U.S. TB case count: China, Guatemala, India, Mexico, the Philippines, and Vietnam (Talwar et al. 2019). To ensure geographical diversity in the sample, the project team spread recruitment efforts across 5 U.S. metropolitan areas: Chicago, Houston, Miami, New York, and San Francisco. FGDs were stratified by country of origin and metropolitan area. Table 1 provides an overview of the sample.

[Table 1 about here]

Within each discussion, the team aimed to recruit a mix of participants based on other demographic variables: education, years in country, age, and sex. To ensure saturation, a minimum of two FGDs were conducted per immigrant population and city (Hennink, Kaiser and Weber 2019).

Recruitment

A professional recruitment vendor was used to recruit participants. Using existing recruitment lists comprised of individuals who had already agreed to participate in various market research studies, the recruiters used a 12-item screener to identify eligible participants. English literacy was a requirement for participation. Participants were not told the discussion would be about TB, only that it would be a health-related discussion. Consistent with recommendations in the literature, the team limited FGD size to 9 participants (Hennink, Hutter and Bailey 2020). However, to account for possible no-shows, the team over-recruited. When too many participants showed, the team came to a consensus on who to exclude, focusing on maintaining the preferred mix of participant characteristics. All participants who showed up were given $40 to thank them for their time regardless of participation.

Data collection procedures

A professional moderator led all discussions, which were in English and lasted 90 minutes. The moderator was also an immigrant and explicitly mentioned this similarity to participants in her introductory script to assist in developing rapport. Discussions were held in the evening at professional focus group facilities and were audio recorded. To allow for remote observation, the

team enabled a live streaming option. However, the video was not archived and only the audio was preserved for transcription. Each room had a one-way mirror for local observers.

A discussion guide was used which comprised four topics. The first section asked about current health concerns. This section offered the team an opportunity to see whether participants mentioned TB as a health concern unprompted. The second section introduced the topic of TB and asked participants about their knowledge of the disease and any personal experience with it (e.g., questions around testing, knowing someone who had TB). We also asked about any knowledge around LTBI and guesses about what LTBI might be. The third section centered around a series of messages on TB and LTBI that participants read and reacted to. Messages included statements on how TB is transmitted, the asymptomatic nature of LTBI, who is at risk for TB and LTBI, available tests, available treatments, and the TB vaccine. Overall, the study tested 38 messages, with 25 messages tested per FGD, rotating across sessions so that each message was tested at least twice. Messages were written on plain sheets of paper with no CDC heading or logos. The moderator read each statement aloud and then asked participants to "verbalize" or "restate" the statement "in their own words." The moderator asked additional questions such as whether a statement or word was confusing, whether a message was motivating, and any questions that a message might have generated. Participants often engaged in discussions based on questions, confusions, or personal connections to the statements. The fourth section included questions about health information sources.

Analysis

Audio recordings were transcribed verbatim. Participant names were included to follow the flow of the discussion. Non-verbal sounds such as laughter, sighs, coughing, and background noises

were also transcribed. When possible, overlapping speech was indicated via dashes to preserve the back-and-forth nature of many of the exchanges.

We used the qualitative software program NVivo Plus version 12.5.0 for data management and analysis. We used a grounded theory approach to analyze the data. First, we reviewed a selection of transcripts (Chinese, Mexican, and Filipino group) and wrote memos about issues salient to participants, and patterns that occurred within and across FGDs. This memoing led to a list of potential inductive codes. We also included deductive codes with concepts from the discussion guides (e.g., TB vaccine). All codes were listed in a draft codebook comprising 25 codes. We tested the fit of the codebook on a fourth transcript (an Indian group). During this test, the codebook performance was evaluated based on four criteria: 1) gaps in code coverage, 2) overlaps in codes, 3) code (in)frequency, and 4) codes that were difficult to apply. Based on the test, the codebook was refined to aggregate redundant codes, clarify unclear codes, and to add new codes. The final codebook was comprised of 35 codes. All 15 transcripts were then systematically coded using this codebook. All text was coded to avoid losing potentially relevant data in queries. Therefore, functional codes such as “moderator leaves room” were used to ensure all data was indexed (Hennink, Hutter and Bailey 2020).

Once all data was coded, we conducted searches of relevant individual codes (e.g., “health requirements,” “immigrant/immigration”) across the 15 FGDs and documented emerging patterns in analytic memos. The purpose was to assess the range of perceptions around key issues related to the research question. We also conducted searches of overlapping codes, searches of responses to specific messages (e.g., TB is more common among non-U.S.—born), and key word searches (e.g., “third world”). This process was iterative so that emerging issues from one search revealed an important subsequent search. Next, we conducted structured comparisons to

identify any patterns in data by country of origin. To explain the observed patterns in reactions to TB risk messaging, we used a combination of inductive and deductive approaches to theory building. We examined participants' explicit reasoning for why they disliked certain risk messages. We also turned to the research literature on responses to risk messaging. Through this re-reading of the literature, we identified the concept of "defensive processing." We did not use this framework in the design or data collection. To ensure that this framework fit the data, we re-organized the findings around concepts from defensive processing and then used the concept-indicator model to verify that these concepts were grounded in the data (Hennink, Hutter and Bailey 2020). This involved returning to the data and mapping key themes to the core defensive processing concepts. We also identified and assessed an important outlier case –Mexican groups. We reviewed these cases to try to explain the deviation. We assessed the characteristics of these groups and how they differed from the other groups and reviewed relevant literature. We describe this process and the results in greater detail in the findings. Findings are organized around two key defensive processing strategies. Quotes are included as illustrations of larger themes. No names are used to protect participant confidentiality.

Findings

Demographics of Participants

Participants were born in one of the six countries that contribute most to the non-U.S.—born TB case count: Guatemala, Mexico, China, India, the Philippines, and Vietnam. Table 2 provides an overview of the key demographics of participants.

[Table 2 about here]

Participants tended to have high levels of education. In 10 of 15 groups, over half of participants had at least a college degree. However, there was a clear difference between Hispanic and Asian participants, with the former having much lower levels of education. In the two Mexican groups in Houston, no one had received a college degree. There was also a wide range of ages amongst participants, ranging from 18-80 years old. Finally, most participants had been in the U.S. for more than 10 years.

The focus groups fit the conditions for "defensive processing" as they exposed participants to threatening and personally relevant health information about their risk for TB due to their country of birth. Throughout the discussion, participants read statements about how "non-U.S.—born persons" are at higher risk for TB than U.S.—born persons. Mid-way through the focus groups, participants also learned that they had been invited to the discussion because they were born in one of the countries that contributes most to TB cases in the U.S. Participants therefore learned that this information was threatening (possibility of having TB germs) and personally relevant to them (participants were in a high-risk group). We observed two key defensive processing strategies in response to this information: counter-argumentation and self-exemption.

Defensive Strategy #1: Counter-Argumentation

Counter-argumentation is a defensive strategy in which people viewing a health message reject the message outright, refute evidence, or downplay the severity of the health risk. This strategy tends to occur with sustained attention and processing of the message (McQueen, Vernon and Swank 2013). In just over half of the groups (8), at least one participant engaged in this counter-argumentation strategy to question the message that non-U.S.—born persons are at higher risk

for TB. One type of counterargument focused on raising doubts about the logical link between country of birth and TB risk. Another counterargument took issue with the prejudicial consequences of the link. Participants in many groups also accepted the link and even occasionally tried to curb this defensive response among peers. We discuss each theme below.

Challenging the logic

For some participants, a crucial problem with TB risk messages centered around the implausibility that a contagious disease could be linked to an immutable characteristic like country of birth. These participants questioned the relevance of country of birth given that "anyone" could get TB. For example, one participant equated "country of birth" with genetics and inquired whether TB was genetic.

> *P1: Is TB disease genetic?*
> ***Moderator: That's an excellent question.***
> *P1: If it is not genetic, then why does it matter if someone is born in there?*
>
> (Chinese, Chicago)

Participants also pointed out that people born in the United States are not immune to getting TB. For example, in a Guatemalan group, participants suggested that TB was likely common in rural areas of the U.S. In several groups, participants suggested that the link sounded dubious and likely related to nefarious attempts to "blame immigrants" for diseases. During one such discussion in a Mexican group, a participant brought up a personal anecdote as a counterpoint to the argument that immigrants are bringing TB into the U.S. She told a story of her cousin getting TB shortly *after* immigrating to the U.S. Upon hearing this story, another participant asked for clarification on where the cousin contracted the illness.

> ***Moderator: Was your cousin born in Mexico or - ?***
> *P1: Yeah, in Mexico. And he got sick here and then he got TB bacteria.*

P2: And when he got it, was it here?
P1: It was here.
P2: See.

(Mexican, Chicago)

Saying "see" is a way to confirm for the group that TB can be contracted in the U.S. Even if this case does not invalidate the broader trend, from the participant's perspective, this case casts doubt on the link between country of birth and TB risk.

Additionally, in three different groups, someone challenged the link between country of birth and TB risk via a *hypothetical* scenario. All three scenarios call attention to the limits of this high-risk definition by providing situations in which that definition potentially misses key sources of infection. Figure 1 illustrates these three scenarios.

[Figure 1 about here]

In the first scenario, the participant presents a case of someone being born in a low-risk country (England), moving briefly to a high-risk country (China), before settling in a low-risk country (Korea). The participant then asks how this person would be classified in terms of TB risk. By presenting a case of an itinerant lifestyle, the participant calls attention to the role of exposure rather than country of birth in TB risk. Additionally, this case is purposefully convoluted to suggest that "country of birth" is overly simplistic as a risk factor. The second scenario presents a case of someone born in a low-risk country (Iceland) having TB and transmitting it to someone born in a high-risk country (Philippines). The third scenario presents a case of someone from a low-risk country (U.S.) going on a vacation "overseas" and getting TB there. In these last two scenarios, the participants illustrate that people born in low-risk countries can also have, contract, and spread TB germs, further calling into question this link between country of birth and TB risk.

Critical of the consequences

A second counterargument focused on the stigmatizing consequences of the TB-country link. While this argument didn't necessarily invalidate the link between country of birth and TB risk, it refuted the message by suggesting that the message itself was bad or inappropriate. This argument came through in critical language of the health risk messaging such as "unnecessary targeting," "racial profiling," "blaming immigrants," being "singled out," or giving their country and people a "bad name." Participants expressed concern about the negative social status associated with an "at-risk" health status and advocated for a more general approach to health messaging on TB risk.

Accepting the link and reducing threat to the positive self-concept

By contrast, in all 15 groups, at least one participant (but often three or four participants) felt that the link between country of birth and TB risk made sense. Some participants were already aware that TB is patterned by country of origin, rendering the information unsurprising. This prior knowledge of TB epidemiology came through in clarification questions some participants posed to a generic prompt: "How common do you think TB is?" In nine groups, at least one participant asked for clarification on country or made a comment about how TB prevalence ought to vary significantly by country. Below are some examples of this clarification question:

> *Here or in India?* (Indian, Chicago)
> *Again, it's here? You're saying -- asking here or there?* (Indian, NYC 1)
> *Are you asking here or back home?* (Indian, NYC 2)
> *In the States or in China?* (Chinese, Chicago)
> *Here in this country or back at home, in Vietnam?* (Vietnamese, SF)

Other participants were not previously aware of the TB-country link, but still seemed receptive to the information. These participants identified plausible explanations for the pattern that didn't

necessarily challenge their positive self-concept. For example, participants in several groups hypothesized that larger structural factors likely explained the pattern. This included references to TB being more common in "third world" or "poor" countries (5 groups), or TB being more common in countries with less aggressive vaccine programs (3 groups). Emphasizing the role of structural factors reduces the threat to the positive self-concept by decreasing the sense of controllability and taking the focus away from personal attributes. In fact, some participants explicitly framed their arguments to calm fellow participants' concerns that immigrants were being unfairly targeted for TB testing. For example, a Guatemalan participant in Miami tried to assuage the concerns of a fellow participant who had expressed dismay that the message was "attacking foreigners."

> *They're not attacking one country per se. It boils down to –unfortunately—third world countries where medicine or information and education to the people in those countries is not up to par where we're at, for whatever reason. So it's just letting you know, 'Look these other countries that have the highest percentage of this particular disease. So, if you are planning on visiting any of these countries, be aware and be on the lookout and take your precautions, basically.'*
>
> (Guatemalan, Miami 1)

This re-framing was deemed more suitable by the other concerned participant in the group who responded to this new explanation with, "see, that's better." A Chinese group had a similar discussion. While some participants initially expressed concern that the message was "blaming" immigrants, two other participants chimed in to offer another interpretation that was less threatening to the positive self-concept.

> *P1: I would suggest--I think CDC is trying to make a fact politically right without hurt anybody's feeling. (STIFLED GROUP LAUGHTER). So, it's not easy. Maybe we can try that people who are born in a certain area is at higher risk of getting this disease.*
> *P2: I like [name of participant's] suggestion. To me, when I first heard it, this was totally like a "Duh" kind of statement. To me, it's very obvious. I also interpret it as, all right, well, instances of malaria are going to be higher in areas where malaria is prevalent. So, someone from a country or area near the equator is going to be more likely to have malaria, than, say, someone from Iceland, or Norway, or Sweden. So, I didn't quite get*

> *the outsider, immigrant kind of… connotation from it. But I can understand where you could draw that - you could feel that way.*
>
> (Chinese, Chicago)

Overall, there was a mix between participants who engaged in counter-argumentation of the health risk message and participants who accepted it. The next section describes the second defensive processing strategy, which occurred across most groups: self-exemption.

Defensive Strategy #2: Self-Exemption

Self-exemption is another defensive strategy in which people viewing a threatening and personally relevant health message acknowledge the risk to others but perceive their own risk to be comparatively lower. It is sometimes referred to as the "optimism bias." Even though many participants accepted the TB-country link and recognized that they were born in a high-risk country, few perceived themselves as personally at risk for TB. We describe different examples of these self-exemption arguments.

Passed the medical exam

One of the most common self-exemption arguments centered around a distinction between "non-U.S.—born" writ large and "immigrants" who enter the U.S. and undergo a medical examination. Many participants pointed to having passed medical exams for immigration, school, or work – exams that include a TB test – as evidence that they did not have TB. This point did not undermine their acceptance that country of birth could be a risk factor for TB. Instead, they continued to make that argument, but emphasized that immigrants in the U.S. were significantly less likely to have TB because they had to be tested in order to be in this country and participate meaningfully in society (e.g., go to school, work).

> *P1: When we come here and we have to get our documents of residence and all of that, I mean -- to become a citizen, you'll have to go through a test so –*
> *P2: It's not required.*
> *P3: But not everyone does that. I was just going to say that not everyone does … things according to what you're supposed to do, get all your shots, so like that could be, you know.*
> *P4: My concern is the fact that, you know, when you're referring to people migrating to the United States who have to go through the process of getting vaccinated and getting checked out, but then, again, we also have a lot of visitors from all over the world, and then especially Philippines, you know, Guatemala, Mexico. You know that they don't have to go through that uh rigorous, you know, checkup or health checkup -- that they can bring the virus in as a tourist and not necessarily as a migrant.*
>
> (Guatemalan, Miami 2)

Here, a distinction is made between low-risk non-U.S.—born persons (immigrants, due to the immigration medical exam) and high-risk non-U.S.—born persons (non-immigrants, who don't go through this medical exam). The participants, therefore, acknowledge the relevance of country to TB risk, while simultaneously distancing themselves from the risk category by underscoring their adherence to required medical exams.

Many participants reported experience with mandatory TB testing either in the U.S. or for the purposes of immigrating to the U.S. Figure 2 shows an overview of the reason for mandatory TB testing among the 15 groups, using a spectrum display chart (Evergreen 2020).

[Figure 2 about here]

The unit of analysis is group. A single dot implies that at least one participant mentioned getting a test for this reason. More than one person could have received a test for the same reason, but this does not affect the overall count. Reporting was voluntary and not every participant had to respond or had an opportunity to respond. Nonetheless, in all 15 groups at least one participant reported receiving a TB test at some point in their lifetime. Eleven groups (73%) had at least one participant who reported receiving a TB test for their immigration to the U.S. Nine groups (60%) had at least one participant who reported getting a test for admission into school (often

university), 9 groups (60%) had at least one participant who reported a test for a job (often in healthcare), and 12 groups (80%) had a participant whose reason for testing was classified as "other" (2 in the military, 1 for jail, and many where reasons for the test were not specified).

Throughout, when participants mentioned these testing experiences, they often leveraged them both as evidence of very low personal risk and more broadly as evidence that non-U.S.—born persons living in the U.S. should be considered at lower risk. Participants used language such as having been "cleared" or having "proof" of their TB-free status such as signed forms or clear X-rays. More importantly, since the U.S. already has rigorous medical testing in place for immigrants, including a TB test that many recounted during the discussion, their lawful presence in the U.S. was sufficient in showing they were not at risk. If they had been infected, the U.S. immigration authorities would not have let them in. However, prior to 2019, the medical exam only assessed active TB disease and not LTBI (Centers for Disease Control and Prevention 2018). Therefore, it is possible that participants passed their exam but were still infected with TB. Those who mentioned mandatory screening for universities used a similar logic since their lawful presence was tied to their student visa. Figure 3 illustrates the conditional language used by many participants to demonstrate that their presence in the U.S. signified they had already passed a rigorous medical exam.

[Figure 3 about here]

This type of argument was made across all groups except for two Mexican groups in Houston. Many participants used the language of "when" or "before" to demonstrate that their entry into the country was conditional upon them *first* passing the TB test. Others used language such as "if," "or," "in order to" or "otherwise" to further emphasize the consequences of not passing this test – barred entry. Further, while some phrased these statements in terms of personal

experiences, others made general comments that immigrants had to pass a medical exam for lawful residence. For example, in a Vietnamese focus group in Houston, after describing a personal experience of getting a "TB shot" before immigrating, the participant then clarified that "if they are a refugee, they all should get a shot before they come" suggesting that his experience was typical for people wanting to immigrate to the U.S.

Not risky, but at-risk

Another type of self-exemption argument focused on drawing a distinction between those deemed currently "risky" (i.e. infected with TB germs) and those deemed "at risk" of infection through transmission. This argument emerged in response to the tricky nature of assessing personal risk of a potentially contagious disease and illustrates an important variation on the self-exemption strategy. Typically, self-exemption involves acknowledging a general risk while minimizing personal risk. Yet, acknowledging a general risk of a contagious disease implies some personal risk due to the possibility of transmission. To accommodate this variation, participants framed the issue around two possible identities (risky and at-risk) and selected the more favorable one. Doing so allowed participants to maintain a positive self-concept. Rather than acknowledge the possibility that they might currently be infected with TB germs acquired years ago in their country of origin – which is how most TB cases in the U.S. arise – most participants instead suggested that they might get infected with TB in the future from someone else – either here in the U.S. or elsewhere. They therefore engaged in self-exemption by acknowledging the link between country of birth and TB risk but by suggesting their own TB risk stemmed from a possible future infection rather than from a longstanding infection originating in their country of birth. In other words, participants said "I might get it" rather than

"I might have it." This is a less stigmatizing identity to adopt because it characterizes the participant as a possible victim of exposure rather than a source of infection for others.

Participants expressed concerns about future infection in different ways. In three groups, someone mentioned a general concern about getting TB from someone else (for example, in public transportation). In two groups, someone mentioned being concerned about getting TB in an outbreak. In six groups, participants expressed concern about getting TB through international travel. This last argument was particularly interesting because participants often mentioned their country of origin as a place of possible infection but linked this to travel rather than longstanding exposure from early in their life. For example, in a Filipino focus group, the moderator tries to clarify whether being born in a country with high rates of TB is a motivator to get tested for TB.

> *P1: Yes, because I do frequently travel back home.*
> ***Moderator: So, it would motivate you.***
> *P1: Yeah, it would motivate me.*
> ***Moderator: OK. Two different opinions. [Name of participant]?***
> *P2: Your question was, does that motivate us to get tested after we visit these countries or--?*
> ***Moderator: So you read statement YZ and you read the list of countries and you learn that "Oh, the Philippines is in this list." You were born in the Philippines. Does this information motivate you, [name of participant], personally, you, to go get tested for TB infection?***
> *P2: Sort of. I always get tested. (LAUGHS)*
> ***Moderator: You what?***
> *P2: Every time I come back from Asia, I always go.*
> ***Moderator: You get tested here?***
> *P2: Yeah, I get tested here.*
>
> (Filipino, SF 1)

Both participants recognize that the Philippines has high rates of TB infection and that this could put them at risk. However, they both link TB risk to travel. The first participant says she's concerned because she "travels back home" rather than because she spent part of her early life there. The second participant says he gets tested all the time, but links it to regular visits to Asia.

Similarly, two men in a Vietnamese group both report that they are now concerned about getting TB because of possible vacation or international travel for work.

> *P1: 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 to other places like China for -- or India.*
> *P2: I think the statement, like [name of participant] says, encourages you to get tested because for me, I've been to two of these countries for **work** and so when I went, they had me do all these kind of shots and one of them was TB as well, so that's why I knew about all these countries.*
>
> (Vietnamese, SF, emphasis added)

In addition, many of these arguments draw on the issue of controllability. Participants are simultaneously suggesting that TB has low controllability because it is contagious and that they are exerting control by responsibly choosing not to travel to high risk areas or to actively get tested upon return. In doing so, participants set up a sort of identity insurance policy. They don't think they will get TB because they are being responsible and careful, but if they do it's not a sign of personal failure. For example, one participant from a Filipino group states that learning about this list of high burden countries "will make me reluctant to visit these countries." He implies that he has some control over the situation. By contrast, another Filipino participant emphasizes the lack of control you incur when you visit some of these countries.

> *P1: Especially when you go visit those countries -- you don't know who you're talking to or who your people like – conversation...*
> ***Moderator: You might go get tested before you visit a country?***
> *P1: No, after you go back.*
> ***Moderator: After you -- when you return?***
> *P1: When you return. (STIFLED GROUP LAUGHTER).*
>
> (Filipino, SF 2)

The stated concern that "you don't know who you're talking to" implies that TB germs might be common in some of these countries (i.e. a general risk) while simultaneously characterizing oneself as currently not infected (i.e. self-exemption). Ultimately, these types of statements allow

participants to maintain a positive identity of healthy status, while also acknowledging the risk inherent in infectious diseases.

Explaining the outlier

An important exception with regards to the self-exemption strategy occurred among the Mexican groups. Not a single participant in the two Houston Mexican groups disclosed an immigration medical exam. They therefore did not leverage this exam as an exemption from risk messages. Further, none of the three Mexican groups expressed concern about future infection in their country of origin. Both outliers can plausibly be explained by data from other sources.

First, estimates suggest that people born in Mexico make up the largest proportion of undocumented persons living in the U.S. compared to immigrants from other countries (Passel and Cohn 2019). Some of the Mexican participants, therefore, may not have gone through the immigration exam.

Second, these participants also reported lower rates of knowledge and experience with TB compared to other groups, which aligns with TB epidemiology. While TB cases among Mexican-born persons have accounted for the majority of non-U.S.—born TB cases for the past 5 years (Centers for Disease Control and Prevention 2020), Mexico is not considered a high-burden TB country (World Health Organization 2020). The high case count among Mexicans in the U.S. is more a function of immigration patterns in the U.S. than high TB burden in Mexico. This epidemiology helps to explain why participants may have been less inclined to perceive travel back to Mexico as a source of possible TB infection. Importantly, Mexican participants did engage in the other defensive strategy, counter-argumentation, as described in the results.

An alternative explanation to self-exemption

We have shown that many participants did not accept the health risk message that they were in a high-risk group for TB nor did they accept the message that they might currently be infected with latent TB. We have argued that the rejection of the message is due to a common tendency to engage in self-exemption when faced with threatening and personally relevant health information. However, an alternative explanation is simply that participants did not fully understand the concept of a dormant infection. Rather than engaging in defensive processing, participants may simply not have understood that TB germs can stay in the body for years without showing symptoms (LTBI) and that they might currently be infected with TB germs acquired years ago in their country of origin. This would suggest that participants were not *defensive* to risk messages but had not fully *understood* the content of the messages. Additionally, participants likely did not know that the TB exam administered for immigration did not systematically identify or report LTBI until 2019, suggesting they may not have understood that their cleared exam did not exempt them from a potential LTBI diagnosis.

Nonetheless, the messages reviewed in the focus group described the concept of LTBI in detail, including the possibility of long dormancy periods. Many participants, while not initially familiar with the condition, were able to understand the concept of dormancy by comparing LTBI to other conditions with dormancy periods such as chicken pox or HIV. Further, many participants expressed concern regarding the asymptomatic nature of LTBI and how this would prevent them from "knowing" whether someone *else* had LTBI. This fear indicates that participants *did* understand the concept of an asymptomatic condition and supports the self-exemption argument. A fear that one is unable to reliably identify infected others acknowledges a general risk but minimizes the possibility of one's own asymptomatic infection. It indicates a

perception that other people have a higher probability of currently being infected with LTBI compared to oneself. Understanding whether low perceptions of risk are due to defensive responses or lack of understanding is important because it impacts how future health risk messaging is modified to be more persuasive.

Discussion

The purpose of this paper was to understand how non-U.S.—born persons, who are at higher risk for TB, perceive and react to health risk messages describing the link between country of birth and TB risk. We used the concept of "defensive processing" to explain the findings, situating the specific case of TB risk messages within the larger literature on health risk messaging and defensive processing. We highlight TB specific messaging implications as well as broader contributions to the defensive processing literature.

We identified two types of defensive responses that participants displayed in reaction to TB risk messages: counter-arguing and self-exemption. First, we found that some participants engaged in a counter-arguing strategy by challenging the link between country of birth and TB risk. Participants in half of the groups deployed this strategy, either by suggesting the link was illogical or by highlighting the prejudicial implications of such a link. However, participants in all 15 groups stated that the link made sense either because they were already aware of TB epidemiology or because they were able to generate plausible explanations that were not threatening to their positive self-concept (e.g., limited health infrastructure, insufficient vaccine programs). Occasionally, participants made their case to allay concerns of other participants, especially those who felt the link was prejudicial.

Second, we found that participants engaged in a self-exemption strategy. Although many participants ended up accepting the link between country of birth and TB risk and acknowledging that they were from a high-risk country, they continued to characterize themselves as low-risk or "exempt" from the risk messages. Participants pointed to required TB exams for immigration or school as evidence that they were not high-risk for TB. Participants also expressed concern over future infection of TB from someone else rather than acknowledging the possibility that they might currently be infected with TB germs and not know it (LTBI).

These findings contribute to the defensive processing literature in several ways. First, we provide an illustration of how defensive processing plays out in a group setting. Most studies examine defensive processing at the individual level, often through experiments and surveys. We observe different reactions to threatening and personally relevant health information within the same group as well as attempts at inter-group persuasion. Second, we highlight two variations to the self-exemption process. While the literature tends to frame self-exemption as an individual-level process in which people optimistically perceive themselves as uniquely healthy or invulnerable, we observed a more group-based process in which participants pointed to a specific group membership that lowered their risk. Participants emphasized their status as "immigrants" who had passed through a medical exam and compared this to a riskier group of "non-U.S.—born persons" still in their country of origin or who had not gone through the same immigration process (e.g., foreign visitors). This finding is particularly interesting when juxtaposed to a common concern among TB researchers that the overlapping identities of "immigrant" and "at risk for TB" will produce a stigmatizing identity of immigrants as disease carriers (Kehr 2012, Reitmanova and Gustafson 2012, Taylor 2013). While we did observe this type of argument, we

also found that some participants think their status as immigrant stands as evidence of their *reduced* risk for TB. In addition, we find that the self-exemption process operates differently when the health condition is an infectious disease. (Although LTBI is not infectious, participants understood and worried about the potential for progression to TB disease, which is infectious.) Because TB is infectious, anyone can presumably get it, making it difficult for participants to categorically deny an "at risk" status. Instead, participants reproduced the self-exemption argument by drawing a distinction between risky (i.e. infected) and at-risk (i.e. all others) and selected the more favorable of the two identities. This distinction emerged in participants' concern regarding a future infection from someone else rather than concern regarding their own possible latent infection. Making this distinction allowed participants to maintain a positive self-concept as currently healthy while still acknowledging the risks inherent in a potentially infectious disease. This modified form of self-exemption argument appears especially relevant to the current COVID-19 pandemic because people might be more willing to acknowledge a general risk rather than accept their own possible asymptomatic infection.

Limitations

Several limitations of this study should be noted. A condition of participation in the study was the ability to speak and read English. This selection criteria likely skewed the sample in multiple ways, leading to under-representation of less educated participants, those with lower health literacy, and those who are less acculturated. These social determinants of health can impact health perceptions and behaviors, (Raphael 2006), suggesting key missing perspectives. Finally, the design only allowed for stratification on two variables: country of origin and geographic

location in the U.S. This design may have conflated some key variables such as education and country of origin (e.g., low educational attainment among Mexican groups).

Implications for messaging

Identifying which defensive strategies occur and in response to which messages provides insights on how to improve future messaging and outreach. We outline several key implications for LTBI messaging derived from this analysis. First, future messages should avoid creating the impression that recommendations for TB testing unfairly target the non-U.S.—born. We saw that concerns about prejudice led some people to reject the messages. Future messages could combine statements about risk tied to country of birth with statements on risk tied to overseas travel in order to minimize the singular focus on birth location as a risk factor. Second, messages should frame TB exposure as one of low controllability to reduce feelings of personal responsibility or guilt. Participants appeared to be more willing to accept TB risk messages when it was framed as beyond personal control, for example due to larger structural forces such as public health infrastructure or due to transmission from others. Third, messages should provide more detail on what is and is not included in the immigration medical exam. Having passed the medical exam was a common tactic to downplay TB risk, therefore messages should pre-empt this argument. Messages can clarify that an LTBI diagnosis is not grounds for denying entry and that new civil surgeon instructions were put in place in 2019 that now include the mandatory use of a blood test, which provides a more reliable test result. Fourth, messages can include recommendations on specific actions people can take to mitigate TB risk, for example, encouraging people tested prior to 2019 to ask their provider to administer a blood test and check for LTBI. Providing specific actions further helps to reduce feelings of distress that may arise

when reading threatening and personally relevant health messages (Cho and Salmon 2007). Finally, messages can capitalize on other avenues for concern, such as concern about future infection rather than longstanding infection. Ultimately, health risk messages need to identify ways of communicating risk while allowing at-risk persons to maintain a positive self-concept.

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Tables and Figures

Table 1. Sample design

COUNTRY	**LOCATION OF FOCUS GROUP**					**TOTAL**
	Miami	*Chicago*	*Houston*	*San Francisco*	*New York*	
Guatemalan	2					2
Mexican		1	2			3
Vietnamese			1	1		2
Filipino				2	1	3
Indian		1			2	3
Chinese		1			1	2
						15

Table 2. Group demographics

Group demographics					
Group ID	Country	City	% College degree	Age range	% in U.S. > 10 years
1	Guatemalan	Miami	38%	21-68	75%
2	Guatemalan	Miami	29%	20-52	100%
7	Mexican	Chicago	33%	28-42	78%
9	Mexican	Houston	0%	21-57	67%
10	Mexican	Houston	0%	18-44	67%
3	Vietnamese	San Francisco	89%	26-62	78%
11	Vietnamese	Houston	56%	41-67	100%
4	Filipino	San Francisco	100%	24-59	78%
5	Filipino	San Francisco	56%	21-80	56%
15	Filipino	New York	67%	29-64	67%
6	Indian	Chicago	100%	25-58	57%
12	Indian	New York	89%	21-75	100%
13	Indian	New York	100%	25-51	25%
8	Chinese	Chicago	78%	22-45	67%
14	Chinese	New York	78%	23-66	67%

Figure 1. Counter-argumentation: how is country of birth relevant to TB risk?

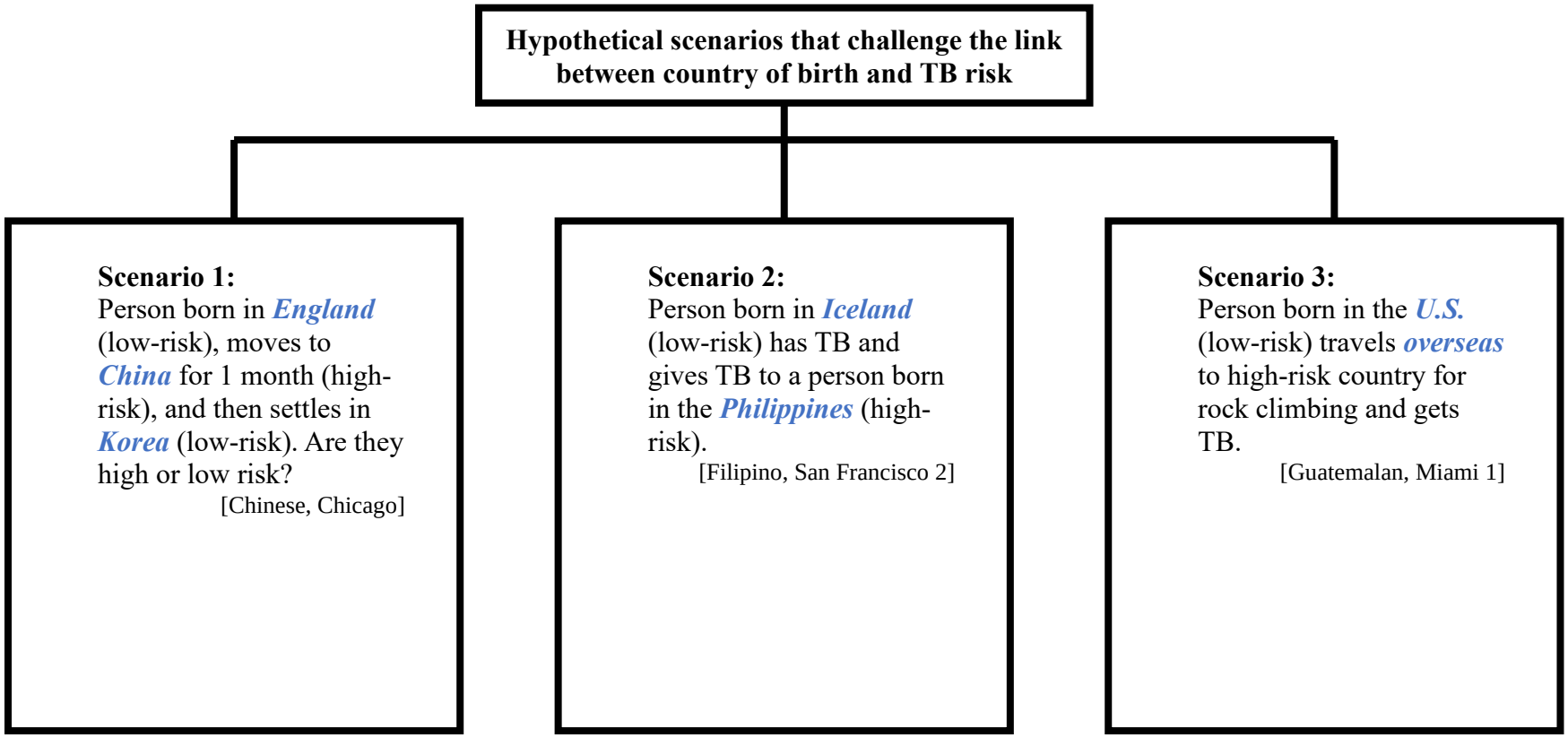

Figure 2. Reason for TB testing among non-U.S.—born populations

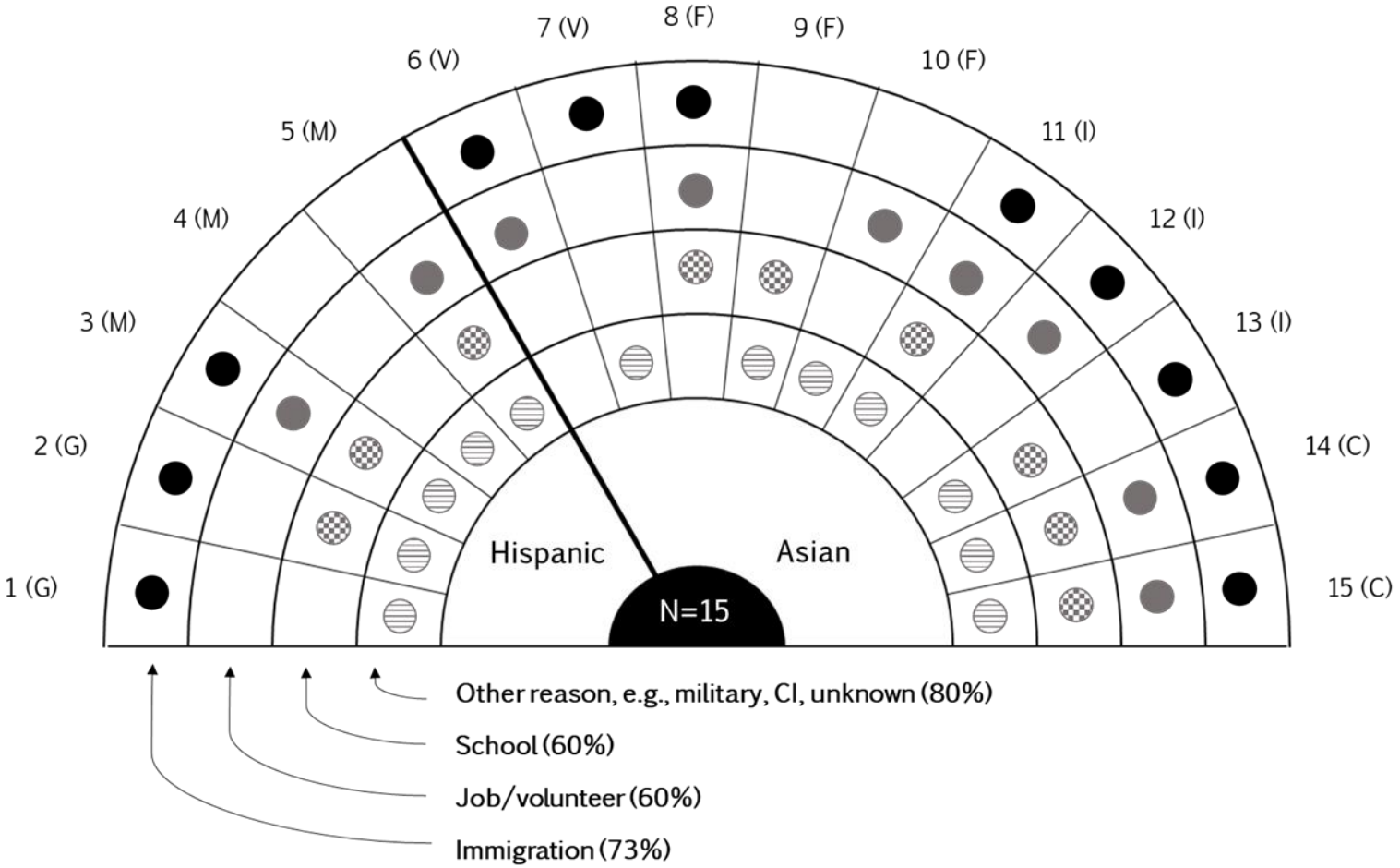

Figure 3. Self-exemption: I passed the TB test before coming here

Example	Group
Before coming to this country, the embassy sent me to have a [TB] test.	GU (M 1)
We both came from Mexico when we were very young – so we were tested for TB when we were going to school. So everything was negative, you know?	ME (CH)
When I came here for the first time, I was doing my master's. It was mandatory to do the tuberculosis skin test.	IN (CH)
When we came from India to here, before the admission for my son you know it's mandatory. My son had to go get the [TB] test.	IN (NYC)
When people coming from China to United States, they must do their TB test. If they find something wrong, they no allow you to come to United State.	CH (NYC)
Before you could actually immigrate to the United States you had to get tested for [TB] to make sure you didn't have it.	FI (SF 1)
Before we came, so were in the refugee camp, everybody had to take a shot before they go to the country, United States or Canada.	VI (H)

CHAPTER 3: To refer or not to refer: Primary care perceptions on shifting professional boundaries in tuberculosis prevention and care

Abstract:
A growing chorus of voices has argued for the need to integrate the fields of public health and healthcare, suggesting that doing so would lead to more efficient care and better patient outcomes. This paper considers the issue of public health and healthcare integration through the case of latent tuberculosis infection (LTBI). While public health currently plays a central role in LTBI testing and treatment, successful TB elimination will require partnerships with primary care providers who are already seeing high-risk patients in clinical settings. Establishing such partnerships requires a firm understanding of primary care provider perceptions of their role in TB care. Using 77 in-depth interviews across eight community health clinics, this paper assesses clinic staff perceptions on the role of the health department in current and expanded LTBI testing and treatment efforts. To analyze the data, we use a thematic analysis approach and link the findings to the literature on professional boundaries. We find that while many participants perceived LTBI as *outside* or at the limits of their professional jurisdiction, they perceived overall patient care as *within* their professional jurisdiction. Participants reconciled this conflict by proposing a shared model approach: clinic staff expressed a preference for keeping care in a patient's "medical home," but wanted assurances of continued health department support through training, resources, and expert consultation.

Keywords: Health department, community health clinics, professions, latent tuberculosis infection, tuberculosis

Introduction

> *"I mean traditionally, you know, active disease is obviously treated in a Public Health Department, but traditionally latent tuberculosis has always been treated in an Infectious Disease Public Health Department as well. I think we're demonstrating that you can offer the services, the treatments in a community health clinic."*
>
> (Pharmacist; Clinic that treats LTBI on-site)

> *"I do not see any barriers. You see, I may not see what the administration sees. Ok. Some people [think] like infectious disease prevention is for infectious disease providers. And some people are territorial and want to keep those patients for themselves. I cannot tell you. We have never been confronted to think like that. I don't see any reason for us to not do it."*
>
> (Physician Assistant; Clinic that refers LTBI treatment to health department)

In the United States, public health and healthcare represent two distinctive arenas of care. While public health tends to focus on population health and prevention, healthcare tends to focus on individual patient outcomes and treatment. This practical, social, and professional division goes back decades and is attributed to differences in professional training and a shift in medical focus from infectious diseases to chronic conditions (Brandt and Gardner 2000, Scutchfield, Michener and Thacker 2012, Starr 2009). A growing chorus of voices has argued for the need to integrate these two fields, suggesting that doing so would lead to more efficient care and better patient outcomes (Berwick, Nolan and Whittington 2008, Hardcastle et al. 2011, Jacobson and Parmet 2018). The Affordable Care Act has already begun to move the needle in this direction, increasing the number of persons with health insurance, and increasing incentives for healthcare service providers to tackle population health issues (Chait and Glied 2018, Erwin and Brownson 2017).

Integrating public health practices into healthcare services will require the buy-in of staff working in these settings. However, the literature on professions shows that healthcare workers may resist organizational changes that threaten their professional identity or that they perceive to

be outside their professional duties (Kellogg 2014, Nancarrow and Borthwick 2005, Powell and Davies 2012, Timmermans 2008). Being asked to take on tasks previously assigned to the public health sector could challenge the professional boundaries of healthcare staff who see it as their imperative to address health issues visible during a clinical encounter. Understanding healthcare staff perceptions of public health-healthcare integrations is a key precursor to any successful partnership.

This paper considers the issue of public health and healthcare integration through the case of expanding tuberculosis (TB) prevention efforts to community health centers. Experts believe that achieving TB elimination in the United States will require changes to current practices including shifting to a prevention and treatment model (LoBue and Mermin 2017, Menzies et al. 2018) and moving some of TB care outside of the traditional public health setting (Balaban et al. 2015, Ehman, Flood and Barry 2014). The shift to tuberculosis prevention has led to an increased focus on identifying and treating persons infected with latent tuberculosis infection (LTBI), which is an asymptomatic condition that can progress to active TB disease. While public health currently plays a central role in LTBI testing and treatment, these efforts need to be scaled-up to reach TB elimination and will require partnerships with primary care providers who are already seeing high-risk patients in clinical settings.

Using in-depth interviews with clinic staff at eight community health clinics, this paper assesses clinic staff perceptions on the role of the health department in current and expanded LTBI testing and treatment efforts. Specifically, this paper asks two questions: 1) What are clinic staff perceptions of the health department's current role in LTBI testing and treatment and 2) What role do clinic staff want the health department to play if they were to scale-up LTBI testing and treatment? Understanding clinic staff perceptions and preferences on the health department's

role in LTBI testing and treatment is key to devising testing and treatment models that are feasible, effective, sustainable at scale, and fit within existing professional identities.

Background

Professional boundaries

The call for better integration of public health and healthcare services implies a current divide between the two sectors. Public health and healthcare are "often conceptualized, organized, and funded as two separate entities" (Levesque et al. 2013:3), tend to function as "two distinct, albeit overlapping systems" (Jacobson and Parmet 2018:941), have "generally functioned independently of each other" (Koo et al. 2012:S307), and "exist in isolation from each other" (Scutchfield, Michener and Thacker 2012:S312). Further, some argue that they follow different health paradigms, with public health following a population health paradigm and healthcare following a biomedical and individual-focused paradigm (Brandt and Gardner 2000, Kuo et al. 2012:e19, Levesque et al. 2013). These divisions can be understood through the lens of professional boundaries, or perceived jurisdictions related to occupations and associated roles. Public health and healthcare may share goals to protect and promote health, but they follow distinctive logics and hold different areas of expertise and control.

We draw on the literature on professions and professional boundaries as a useful framework for understanding these current divisions as well as insights into the types of barriers that might emerge in response to integrations of public health and healthcare services. Professions are occupational groups that require esoteric knowledge and usually credentials or licensing (Muzio, Brock and Suddaby 2013, Timmermans 2008). Social scientists characterize professions as institutions that often appear stable and natural but that are in fact the product of

continuous power struggles in which groups challenge and re-negotiate professional jurisdictions (Abbott 1988, Currie et al. 2012, Muzio, Brock and Suddaby 2013). Professionals engage in a "professional project," attempting to maintain autonomy of their area of expertise from external threats (Larson 1979).

Healthcare providers, and especially physicians, represent a classic case of professionalization: they undergo formalized training, earn credentials, obtain licensing, and lay claim to a specialized area of knowledge. However, different types of clinical changes, often initiated by management, can challenge providers' professional jurisdiction. For example, when clinical guidelines such as protocols are implemented, they may introduce new tasks that some professionals perceive as beneath them or not part of their job duties (Currie et al. 2012, Kellogg 2014, Powell and Davies 2012, Timmermans and Kolker 2004). In addition, tools meant to standardize care such as clinical decision support tools (e.g., electronic medical alert reminders) may be perceived as a threat to a provider's medical autonomy (Boonstra and Broekhuis 2010, Dent 1999, Timmermans and Kolker 2004).

In a review of this literature, Nancarrow and Borthwick (2005) identified four types of professional boundary changes in healthcare settings: diversification, specialization, vertical substitution, and horizontal substitution. Diversification refers to the acquisition of tasks not previously "owned" by any professional group. This change can occur as a result of new technology. Specialization refers to the acquisition of specialized tasks through additional training, post-credentials. Vertical substitution refers to the transfer of tasks to professionals in a different status position. It can include upward movement such as the medicalization of child delivery or downward movement such as the delegation of prescribing duties to nurses (also known as "task shifting"). Finally, horizontal substitution "arises when providers with a similar

level of training and expertise, but from different disciplinary backgrounds, undertake roles that are normally the domain of another discipline" (Nancarrow and Borthwick 2005:911). This final type of boundary change is especially relevant to the potential shifting boundaries between public health and healthcare.

Some examples of collaboration and shifting boundaries between public health and various healthcare settings have already been documented, including partnerships with hospitals and community health centers (Clement et al. 2019, Fairchild and Alkon 2007, Prybil et al. 2014, Shahzad et al. 2019). In addition, changes brought about by the Affordable Care Act are creating opportunities for a shift in professional jurisdictions (Chait and Glied 2018). Primary care providers, in particular, are well suited to partner with public health agencies on key preventive health issues because they are the first point of contact with the healthcare system (Levesque et al. 2013). While some of the traditionally public health tasks that providers might be asked to take on include low-value tasks like screening, others might involve high-value tasks like management of complex treatment regimens and monitoring for side effects (Kellogg 2014). We consider to what extent primary care providers are receptive to this professional boundary change within the context of tuberculosis care.

Case study: latent tuberculosis infection

TB is a bacterial infection that primarily affects the lungs and can be fatal if not treated. Globally TB remains the leading infectious disease killer by a single pathogen (World Health Organization 2019), but in the United States a robust public health control program has led to a significant decrease in TB incidence over the years. In 1953, when systematic TB case reporting began, a total of 84,304 TB cases were reported for a case rate of 52.6 per 100,000. In 2019, the

most recent year for which data is available, 8,916 TB cases were reported for a case rate of 2.7 per 100,000 (Division of Tuberculosis Elimination 2020a). Despite this progress, the rate of decline has slowed. From 2010-2019, the annual percent change in rate dropped from 6% to 1.7% (Division of Tuberculosis Elimination 2020b).

A primary driver of continued TB cases in the U.S. is longstanding, untreated LTBI. A person with LTBI has been infected with TB germs, has a positive TB skin test or blood test and a negative chest x-ray, but is asymptomatic. Five to ten percent of persons with untreated LTBI will progress to TB disease (Centers for Disease Control and Prevention 2016). It is estimated that more than 80% of TB cases in the U.S. are due to untreated LTBI acquired years ago rather than from recent transmission (Yuen et al. 2016). Furthermore, TB cases are concentrated among the non-U.S.—born population. In 2019, 71.4% of TB cases occurred among non-U.S.—born persons (Schwartz et al. 2020). Similar patterns have been documented in other high-income countries (Pescarini et al. 2017). Experts agree that achieving TB elimination will require increased focus on LTBI among high-risk groups in addition to traditional monitoring and treatment of active disease (LoBue and Mermin 2017). The Centers for Disease Control and Prevention (CDC), the American Thoracic Society (ATS), and the United States Preventive Services Task Force (USPSTF) have issued recommendations that non-U.S.—born persons from intermediate to high TB prevalence countries should be tested for and, if positive, treated for LTBI regardless of how long they have lived in the United States (Lewinsohn et al. 2017, LoBue and Mermin 2017, US Preventive Services Task Force 2016).

Currently, state and county health department clinics provide the majority of services for TB prevention and care (Balaban et al. 2015, Ehman, Flood and Barry 2014, Sterling et al. 2006). These clinics focus on provision of clinical care for patients with TB disease and public

health activities such as contact investigations. They also diagnose and treat approximately 80% of reported LTBI cases in the United States (Sterling et al. 2006).

A growing group of experts suggest that the scale-up of LTBI testing and treatment cannot occur entirely within the public health sector, and requires a partnership with primary providers (Balaban et al. 2015, Malekinejad et al. 2017, Stockbridge et al. 2018). Public health departments do not currently have the resources to test and treat the estimated 13 million persons infected with LTBI in the U.S. (Mancuso et al. 2016, Miramontes et al. 2015). In addition, patients do not typically present to public health departments. Instead, they are most likely to go to their primary care provider who can act as an important first point of contact with the healthcare system (Levesque et al. 2013). Therefore, while the public health sector has a deep knowledge about the complex nature of TB prevention and care, primary providers can play an important role in identifying and potentially treating patients with LTBI. Moving screening to areas in which at-risk populations already seek care can help reach key populations. The USPSTF "grade B" rating of LTBI screening (US Preventive Services Task Force 2016) combined with increased insurance coverage provided through the Affordable Care Act will create new incentives for primary care settings to get involved in TB prevention efforts. Insurance coverage increases use of primary care services and insurers are now required under the ACA to cover TB testing for high-risk populations with no patient cost sharing (Chait and Glied 2018, Erwin and Brownson 2017, Stockbridge et al. 2018).

Community health centers (CHCs) may serve as a particularly important site for expanding LTBI care. CHCs are "nonprofit private or public entities that provide affordable health services to underserved and at-risk populations," instituted under the Public Health Service Act of 1944 (Association of State and Territorial Health Officials 2016). Clinics must

meet specific criteria to qualify for CHC status, which provides access to federal subsidies either through grants or additional reimbursements. Criteria include serving un-insured or under-insured populations and providing both primary and population health services. CHCs likely capture populations at-risk for LTBI, including non-U.S.—born persons, and can therefore play an important role in the scale-up of LTBI testing and treatment. A review of community-based approaches to LTBI testing and treatment suggest that pro-active screening programs that draw on community-based approaches may be more effective in identifying and treating high-risk persons than more passive approaches (Malekinejad et al. 2017).

However, given the long tradition of tracking and treating TB within the public sector, primary care providers may perceive LTBI as outside of their professional jurisdiction. They may not feel comfortable taking on some of these specialized tasks, or they may be worried about how these new tasks will force them to give up other high-value tasks. Furthermore, LTBI is still a public health condition and primary care providers can therefore continue to refer LTBI cases to their local health department.

Despite the calls for shifting some responsibility for TB prevention and care outside of the public health sector, little is known about primary care providers' views on their responsibility and capacity for taking on TB prevention efforts. The few studies that have addressed this issue have focused on locations outside the U.S. or single metropolitan areas (Atchison et al. 2015, Benjumea-Bedoya et al. 2019, Zelnick et al. 2016). This paper aims to fill this gap by assessing community health clinic staff perceptions of the current and desired role of the health department in LTBI testing and treatment in the U.S.

Design and methods

Data

The data for this paper comes from a multi-site study funded by the Tuberculosis Epidemiological Studies Consortium (TBESC). TBESC is a partnership between the CDC's Division of Tuberculosis Elimination (DTBE) and academic institutions and TB clinics around the U.S. This study was a mixed-methods investigation designed to identify barriers and facilitators to increasing testing and treatment of LTBI at CHCs. TBESC member sites partnered with local CHCs to participate in the study. CHCs had to be a general practice, non-public health community clinic, that serve an adult population. They also had to serve a large proportion of non-U.S.—born persons, a key at-risk population for LTBI in the U.S. (Schwartz et al. 2020).

In total, 16 CHCs across the U.S. participated in some capacity in the study. Data collection included an overall clinic assessment, extraction of patient data records to create a cascade of care, provider surveys, and in-depth interviews (IDIs) with clinic staff. For this paper, we focus on the interview data. The protocol was approved by CDC IRB and, where applicable, local IRB sites, as well. The study was exempted from OMB review.

Clinic sample

For this analysis, we selected a sub-sample of eight clinics to investigate staff perceptions around the health department's current and desired role in LTBI testing and treatment. To build a diverse sample, we selected four clinics that offered LTBI treatment on-site and four clinics that referred out to their local health department. We also ensured diversity on other key factors such as clinic location, clinic size, patient population, percent uninsured, and current rates of LTBI testing. In

total, the sub-sample was comprised of eight clinics, and 77 IDIs. Table 1 provides an overview of key characteristics of the sub-sample.

[Table 1 here]

In-depth interview data collection

In order to capture a range of perspectives within each clinic, we used a purposive sampling strategy, recruiting participants from three types of clinic staff: leadership (e.g., chief medical officer) providers (e.g., physician, nurse practitioner), and patient services (e.g., medical assistant, front desk clerk). Each clinic carried out this purposive sampling with a goal to reach 10 interviews per clinic. Recruitment methods varied by clinic and included email blasts, announcements at staff meetings, and direct invitations. Incentives were given at most clinics.

Interviews were designed to last 30 minutes in order to accommodate the busy schedules of clinic staff. Actual interview length ranged between 20-40 minutes. All interviews were conducted remotely via Zoom by trained interviewers. Interviewers were outsiders to the project and had no affiliation with the CDC nor any medical background. They emphasized these points in the introductory script to help put participants at ease in discussing the topic. Interviewers used a guide, which was piloted and revised before data collection began. The guide covered background information on participant job duties, interactions with their local health department, experience with LTBI at the clinic, general protocol on LTBI testing and treatment, and potential barriers and facilitators to increasing testing and treatment at their clinic. The interviews were structured, but interviewers probed on relevant areas as time allowed. Data collection occurred over a 11-month period, beginning in January 2020 and ending in October 2020.

Analysis

A professional transcription company transcribed all interviews verbatim. To organize the data and facilitate analysis of the interviews, we used MAXQDA Plus 2020. We used a thematic analysis approach, focusing on identifying key themes related to how staff perceived the health department role in LTBI testing and treatment. Thematic analysis is a systematic approach to qualitative analysis in which the researcher reviews verbatim text, identifies codes and codes the data, and then describes and compares those codes across cases, culminating in the identification of higher-order themes. The process involves many of the same tasks as grounded theory, while stopping short of creating a formal theoretical model (Guest, MacQueen and Namey 2011). We did not use the professional boundaries framework in the initial analysis, instead opting for an inductive approach to analysis and theme generation. However, we re-assessed findings in light of this framework, and connected inductive themes to existing concepts in the literature. We used the concept-indicator model to ensure these concepts were still grounded in the data (Hennink, Hutter and Bailey 2020).

To code the data, we engaged in multiple rounds of deductive and inductive coding. First, we created deductive codes based on the questions on the guide (e.g., interaction with health department, hypothetical testing and treatment needs). Next, we coded all text related to discussions of the health department in order to focus analysis on this particular aspect of the interviews. We did this by conducting different lexical searches using MAXQDA's lexical analytic tool, which allows researchers to identify relevant text using different levels of sensitivity (e.g., whole words, stemmed, case sensitive). For example, we searched for text that mentioned "health department," "department of health," "TB clinic," and proper names of various health departments. We used MAXQDA's auto code feature to auto code all text identified in these searches. We then

read through these segments to identify other words that would pick up discussions of health department (e.g., “TB nurse”) and repeated the lexical search process with these additional terms.

Next, we reviewed all coded health department segments to begin to identify inductive codes, focusing on repeating issues, connections across topics, comparative statements, and in-vivo phrases (Hennink, Hutter and Bailey 2020). This led to the development of codes such as “record sharing,” “HD referral,” “they take over,” and “medical home.” Once all relevant text was systematically coded, we conducted various structured searches of the codes to identify patterns by clinic and staff type. We documented patterns by codes in an 8x3 analytical matrix, facilitating comparisons across the eight clinics and the three staff types. We then wrote analytic memos based on the patterns that emerged in these matrices, identifying broader themes in participant views on the health department’s current and desired role in LTBI testing and treatment.

Results

Clinic staff interviewed at each of the eight clinics included a variety of positions. The leadership category included medical directors, nurse managers, and chief operations officers. The provider category included family doctors, physician assistants, nurse practitioners, and clinical pharmacists. The patient services category was comprised primarily of medical assistants but also included a health coach and social worker, among others. Table 2 provides an overview of the interview participants.

[Table 2 here]

Interacting with the Health Department

To better contextualize the specific discussion around the health department's role in LTBI testing and treatment, we start by characterizing the clinic's overall relationship with the health department. First, we reviewed responses to a standard question on the guide asked across all 77 interviews: "what was the last interaction you had with the health department as part of your role at this clinic?" Figure 1 shows a word cloud of the top 25 words that came up in response to this question. Stop words such as conjunctions and prepositions have been removed.

[Figure 1 here]

The image shows that TB came up quite frequently as did COVID, which makes sense given the timing of data collection. Other common words included references to "positive," "reporting," "patients," and time-related words such as "months" and "years." The word "haven't" also came up frequently, and a closer reading of the responses shows that many participants had not had a recent interaction with the health department or did not consider interactions with the health department to be part of their job duties. In several clinics, participants pointed to a specific staff member who carried out these duties, highlighting a clear professional boundary within the clinic about whose responsibility it was to coordinate with the health department.

Based on a holistic review of each clinic, we characterize half of the clinics as having a close relationship with their local health department. This characterization was based upon explicit statements from participants such as being "closely connected" or having a "really good relationship," mentions of specific health department staff with which they were in contact, and more direct interactions such as phone calls, "chats," and in-person visits. Three of the four clinics with close relationships were those that provide treatment on-site.

We characterize three of the clinics as having an impersonal relationship with the health department, marked by more indirect contact such as reporting and faxes, no references to specific staff at the health department, and explicit commentary about lack of feedback or response from the health department. One clinic had mixed responses among staff, including some who had no interaction and others who described the department as "very reachable." To illustrate the range of health department relationships, consider these two disparate statements from providers at two different clinics:

> *I also have a **direct phone number to the nurse practitioner** that takes care of the latent TB cases that we sent to them.*
>
> (Provider, ID37, Clinic 5)

> *It's not always easy. I think in this day and age period it's **not always easy to get somebody on the phone** when you need them. But eventually, you can **get a hold of somebody usually** and get some pretty good advice from the health department.*
>
> (Provider, ID64, Clinic 6)

While one provider mentions having a direct line to a specific staff member, the other provider talks about struggling to reach someone and then only mentions talking to "somebody" rather than a specific contact at the health department. Overall, the range of relationships between clinics and their respective health departments provides important context for interpreting findings on staff perceptions of current and anticipated role of the health department in LTBI care.

Current Practices: Reporting, Consultation, Supplies, and Referrals

Clinic staff described a number of ways in which their local health department was currently involved in LTBI care. Some of the tasks, such as reporting LTBI and TB cases, are mandated by state and federal laws. Other tasks, such as receiving expert consultation and support, indicate an

informal but important professional boundary related to perceived expertise. Clinic staff, especially providers, described contacting the health department for specialized expertise and advice on various LTBI cases. Overall, there was striking similarity in statements across participants and clinics, again indicating established professional boundaries about the role of the health department in LTBI care. We review some of the key activities described across clinics.

A common interaction with the health department on LTBI care centered around the tasks of reporting cases and sharing medical records with the health department. This included faxing over necessary documents, reporting LTBI and active TB cases, and following up on requests from the health department for current patient medications to avoid toxic drug interactions with LTBI medications.

In two clinics that provide treatment on site, staff mentioned that the health department had or was continuing to supply LTBI medications, which allowed them to provide medications to patients for free or at a highly reduced cost.

Many clinic staff reported using the health department as a resource for expert consultation and advice. Staff saw their local health department as the TB experts who could provide specialized knowledge on various complex cases. Staff might seek consul on specific LTBI cases by calling their local TB nurse for advice or sending questions through their electronic medical records system. For example, one provider talks about calling the health department for "weird cases."

> *That would be the other reason that I communicate with the public health folks is kind of triaging **weird cases** or kind of conflicting [cases]. You know, like a little kid [whose] PPD is positive but they're only two, so like cases like that where I don't necessarily know what to do with.*
>
> (Provider, ID7, Clinic 4)

Finally, a key way in which the health department was currently involved in LTBI care was by taking on referrals of positive LTBI cases. In seven of the eight clinics, participants mentioned referring LTBI cases to the health department for treatment. While half of the clinics in the sample formally referred out all LTBI cases to their local health department for treatment, in three of the four clinics that offered treatment on-site, participants still mentioned occasionally referring patients to the health department for treatment. Participants depicted this process of referring patients as a shift of responsibility and expertise, in which providers let the health department "take over." Participants in all clinics except one employed this language of "handing off" cases or letting the health department "take over." Here are some examples from different clinics:

> *But then, the health department **takes over from there** and manages their care and decides if they need treatment or not.*
>
> (Patient Services, ID40, Clinic 5)

> *So, if we can connect the patient to the health department, they kind of **take it from there**.*
>
> (Provider, ID64, Clinic 6)

> *The skin test comes back positive or they have an abnormal x-ray and immediately we are contacting the health department and they **take over**.*
>
> (Patient Services, ID98, Clinic 7)

> *Then we typically refer to the [name of health department TB clinic] and then they kind of **take over**.*
>
> (Provider, ID55, Clinic 8)

Especially for clinics that always referred out, the perception was that LTBI fell under public health purview and that the health department was the clear expert on the matter. That is, some clinic staff perceived LTBI to fall within the professional jurisdiction of the health department. An unintended outcome of this take-over approach, however, was that staff who might otherwise be interested in increasing their knowledge on LTBI treatment continued to lack confidence in

this area and didn't really know what happened after the hand-off. For clinics that only occasionally referred patients to the health department, the hand-off was characterized as a helpful back-up option. Nonetheless, this perception still suggested that the health department acted as the final experts and could be called in for difficult cases.

Several key problems emerged as a result of this "take over" approach: providers did not keep up to date with their patients' treatment progress, providers did not have incentives to learn about LTBI treatment best practices, and some patients fell through the cracks during the handing off process. These issues emerged during discussions about what it would take to scale up LTBI testing and treatment at the clinic.

Scaling Up: What Role Should the Health Department Play in Scaled-up LTBI Testing and Treatment?

The interview guide asked participants to answer a hypothetical question: what would it take to scale up testing and treatment of LTBI in their clinic to reach 100% of their high-risk non-U.S.—born population? Participants were not specifically prompted to address whether the health department would be involved. We systematically reviewed all 77 interviews and documented the various participant suggestions, categorizing responses by clinic and staff type. Participants in all eight clinics and across all three staff types mentioned the health department in some capacity. We identified seven themes regarding what role the health department should play in LTBI scale-up. Table 3 provides an overview of these seven themes, including example quotes that illustrate the themes.

[Table 3 here]

While six of the themes portray the health department as a key facilitator in the scale-up of testing and treatment – for example providing finances or medications or taking over difficult cases – one of the themes portrays the health department as a barrier to this scale-up. The theme "stay in medical home" expressed concerns about referring patients out to a new location. Instead, participants suggested that keeping a patient in their medical home might facilitate treatment initiation and completion. This theme occurred across all eight clinics and all three staff types. Importantly, participants tended to frame this desire as a way to maintain or regain control of their professional jurisdiction over their patients' care. While much of the interview guide focused on whether participants would accept an expansion of their professional jurisdiction by taking on more responsibilities related to LTBI care, participants highlighted concerns about a loss of professional jurisdiction that had already occurred by referring patients out to the health department. Keeping LTBI care might increase LTBI responsibilities, but it allowed providers to maintain their medical autonomy over their overall patients' care.

Many participants, however, viewed the ideal model as one of shared responsibility between the clinic and the health department. Participants wanted to pair in-house treatment services with continued support from the health department. This was another very common theme across clinics and groups. Taken together, these two themes suggest a general tendency towards expanding the clinic's professional jurisdiction related to LTBI care, but still sharing some responsibilities. We discuss these two themes in more detail.

Relying on Health Departments as resources for expert consultation and support

We found that many participants felt that the health department should continue to play a role in scaled-up LTBI testing and treatment, mainly as a resource for expert consultation and support.

This view occasionally aligned with the "take over" mentality, in which participants perceived LTBI to be more in the professional jurisdiction of public health than primary care. For example, leadership at several clinics felt that LTBI was clearly a public health issue that required close collaboration with the health department. A chief medical officer at a clinic that referred out to the health department described LTBI as "way, way in the public health sector" (Clinic 5, ID36). A medical director at a clinic that provided treatment on site said "public health engagement" was the most important tool for scaling up testing and treatment:

> *Public health engagement, that's probably the most important thing. We have our social workers and our community health, but* ***a tight working relationship with the public health department is critical*** *because as you said, 10% of those with latent…with LTBI go untreated, become active, at which point they become* ***a public health liability*** *and so staying in close contact with the public health department is critical.*
>
> (Leadership, ID1, Clinic 4)

Others felt that their clinic could expand their professional jurisdiction and take on increased responsibility in LTBI care. However, they wanted assurances that the health department would provide adequate resources for consultation and support. This suggests a desire for a shift in boundaries but not a full substitution of responsibilities. For example, participants expressed a desire for a hotline where they could call in for support, they wanted a designated staff member linked up with the health department, or they wanted someone from the health department who could occasionally come into the clinic to provide assistance. Furthermore, while some talked about maintaining current support, others worried about how increasing their testing and treatment would require resources above and beyond current levels. For example, one provider made the fowling comment:

> *So, as it stands, currently we don't treat them here at our clinic. We refer them to the health department. So I would imagine that would be more,* ***require more resources from the health department*** *and more cooperation or maybe having someone from the health*

> *department come to our clinic weekly or, I don't know, depending on how many [patients], daily or something like that.*
>
> (Patient Services, ID17, Clinic 5)

For those clinics that referred all LTBI cases to the health department, clinic staff expressed a need for an initial seminar from the health department that would provide a comprehensive review of LTBI treatment options and best practices. Because these providers always referred patients out, they did not have a lot of experience or confidence with LTBI treatment. In other words, because they relied on others for expertise, they had never had incentives to build up their own. Participants perceived an initial training as a critical first step. Without the training, providers would continue to refer out to the health department since that was easier. For example, one provider made the following comment:

> *Well I guess in the concrete, you know, A to Z of it, I think it's very doable. I think another* ***barrier is lack of provider education****. Most of the people at the clinic don't know how to do it. Don't know the regimens, don't know the updated name. Like they know about it in general, they know where they can look, but you know,* ***if it's trying to figure that out and you know, get the medications and blah, blah, blah, versus just sending them to the Health Department, that's what they're going to do****. I don't think anybody at our clinic knows actually how to do it. So they would need to be educated in some way.*
>
> (Provider, ID55, Clinic 8)

However, many felt that offering a seminar on best practices in LTBI treatment could be a relatively easy task that would then allow clinics to offer care in the patient's medical home, a theme that came up in all eight clinics.

Keeping the patient in their medical home

Across all eight clinics and all three staff types, participants emphasized the benefits of keeping care in a patient's medical home. Participants described problems with linking patients to off-site locations, and the resulting loss of control over their care. This concern highlights an important

nuance in how participants perceived their own professional boundaries. While many participants perceived LTBI as *outside* or at the limits of their professional jurisdiction, they perceived overall patient care as *within* their professional jurisdiction. When these boundaries overlap, as they do with patients who test positive for LTBI, participants must navigate unclear professional boundaries. Ultimately, participants seemed to express a desire for a shared responsibility model, where they could provide care on site but retain the remote expertise of the health department.

Participants described a number of problems with relying on off-site care, many of which involved perceived patient barriers. This included transportation barriers, limited language services at external sites, or a general patient hesitancy to go to a new place. In addition, participants worried about their loss of control as providers in not being able to ensure patients were linked to care. We discuss each of these in more detail below.

At multiple clinics, participants explained that the health department was not in a convenient location for their patient population and that this might prevent patients from following up with their appointments. For example, in one clinic that offered treatment on-site, several providers mentioned that even after offering patients the option for free treatment at the health department downtown, patients still chose to do treatment at their clinic for a small co-pay:

> *Most of our patients struggle with transportation so to get downtown, they might have to take two or three city buses. Yes they got the drug free, but they had to struggle with transportation or be aware that they had to get downtown to get the treatment versus living right next to my clinic.*
>
> (Provider, ID13, Clinic 2)

At the same time, participants also described some solutions to these barriers, including having someone from the health department come to the clinic to perform x-rays and discuss

treatment options (Clinic 5), or assisting patients in identifying transportation options to get to the health department (Clinic 3).

In addition to transportation barriers, participants also felt that patients were not always comfortable with the idea of "going somewhere else" or "going to another clinic." Participants attributed this reluctance to limited language services, the inconvenience of going somewhere else, or a fear of trying to navigate a new medical setting.

> *If they do come back and get it read, and then it's like, 'Okay, now you need to go here,' it's always, 'Okay, I'll get there as soon as I can.' You know, and it might be -- transportation may be an issue. You know, our patients tend to like a one-shop-stop type thing. And so,* ***when they're told they have to go somewhere else, that brings a little bit of hesitance for them****.*
>
> (Leadership, ID102, Clinic 7)

> *We have a clinic at [the Health Department] that they can get TB treatment for free, but some patients even though it's free,* ***going to another clinic is challenging****. Going to another place.*
>
> (Provider, ID23, Clinic 2)

> *I feel like a lot of our patients really love our clinic, and* ***having to go other places for care, I think can be really hard****, especially if you don't speak English. So, if they know, like, "Oh, I'm going to have to maybe go somewhere else, that could be scary, and I don't know if I want to do that," or, "I don't know if I want to follow-up if I'm going to have to go somewhere else to get more care.*
>
> (Patient Services, ID40, Clinic 5)

While many participants felt that *patients* would prefer to have all of their care provided in a single location, clinic staff also expressed a preference for keeping care on-site. Several participants lamented that referring out led to a loss of control. For example, in a clinic that used to refer to the health department for treatment but now provides treatment on site, a provider recalled the earlier difficulties of referring out.

> *It was harder in some ways sending people to the Health Department because we didn't – we kind of* ***lost control*** *as to whether they would go or not.*
>
> (Provider, ID42, Clinic 1)

In clinics that referred out, some providers felt that they didn't have a good handle on patients' treatment completion due to the health department's lack of communication. In one clinic, several providers described learning about their patients' treatment regimen and tolerance from the patients during other appointments. Having to construct their patient's treatment plan and outcomes piecemeal from patient reporting was less preferable to receiving more formal reporting from the health department or even treating on-site. Finally, several participants felt that treatment outcomes would improve if they could keep care on-site because patients could maintain their relationship with their primary care provider. For example, a provider at a clinic that refers out says the following:

> *I would say I think **it's much better if I am the PCP. The patient knows me. I know them. There is a trust.** I can see them. I can look at labs. I can enter labs, and I can take care of anything that is a side effect, like I said. I can look at them and know when to stop if there is big inflammation in the liver, I know to say, okay we stop this medication now and not end up with liver failure. […] Of course, everybody needs education to start something. You know, maybe do some education for everybody and say this is the way we do it and have a template. You know? **Being the PCP, patients can communicate easily with us**. And if they have any questions, if they see any change, if they see any side effects. I would say, yes, we can do it. Of course, I don't decide. Just an opinion.*
>
> (Provider, ID58, Clinic 8)

This provider touches on the key role of patient-provider trust and relationships in patient outcomes. Here, the provider suggests that they might be better at monitoring the patient than a provider less familiar with the patient. That is, by maintaining professional jurisdiction over their patient, the provider can ensure better continuity of care. Similarly, the provider suggests that the patient might be more effective at communicating issues with their primary care provider because they know and trust them. This quote illustrates the trade-off between the health department's expertise on TB and the primary care provider's expertise on the patient. The provider acknowledges the need for initial education to get started offering treatment at the

clinic, but ultimately frames the issue as one of professional jurisdiction over patient care. The theme of keeping care in a patient's medical home expresses the overall desire to maintain the patient-provider relationship, suggesting that TB expertise could be acquired through seminars, HD consultation, and continued experience testing and treating patients for LTBI.

Discussion

Eliminating TB in the U.S. will require innovative methods and new partnerships, including expanding prevention efforts outside of the traditional public health sector and into primary care settings. A key part of this work involves understanding barriers that primary care settings may perceive in taking on some of this new responsibility and expanding their professional jurisdiction. This paper contributes to our knowledge of how primary care settings, specifically community health clinics, believe this scale-up should be designed. Using 77 in-depth interviews across eight clinics and three staff types, we provide an analysis of clinic staff perceptions of the health department's current role in LTBI testing and treatment efforts and their desired role in scaled-up testing and treatment. To contextualize the findings, we draw on the literature of professional boundaries, which suggests that people working within a particular profession continuously negotiate which tasks and responsibilities fall within their professional jurisdiction and which do not (Abbott 1988, Larson 1979, Muzio, Brock and Suddaby 2013, Nancarrow and Borthwick 2005). Previous research has found that providers, in particular, may be resistant to changes that challenge their medical autonomy or that they perceive to be outside of their professional duties (Kellogg 2014, Powell and Davies 2012).

First, we reviewed perceptions of how the health department is currently involved in LTBI testing and treatment. Clinic staff described required reporting and record sharing with

their health department, provision of supplies and resources such as medications, and more direct interactions such as receiving expert consultation on difficult cases or handing over cases to the health department in various scenarios. Overall, we found that many participants, including clinic leadership, continue to see the health department as the clear expert on LTBI. In particular, while only half of the sample formally referred out all cases to the health department, we found that in seven of the eight clinics participants mentioned referring to the health department for treatment in some instances. Importantly, we identified a common refrain among participants about how the health department "takes over" cases. This language exemplifies the perception that LTBI continues to fall under the professional jurisdiction of the health department. Participants felt that they could hand-off cases and that it was no longer a part of their professional duties. Especially for clinics that formally referred all positive LTBI cases to the health department, there was a sense of mystery on what exactly happened once they sent the patients over. As a result, providers in these clinics often expressed a lack of confidence and expertise on LTBI treatment practices, even if they were interested in potentially getting more involved.

Despite this "takeover" language, we found that in all eight clinics many of the participants believed that the clinic could increase their LTBI testing and treatment efforts with some assistance from the health department. We identified seven themes relating to how the health department should be involved in scaled-up LTBI testing and treatment. Six of the seven themes identified the health department as a facilitator, for example by providing medications or other resources, or by continuing to be available as a source of medical expertise. However, we also identified a theme of "keeping care in a patient's medical home," which highlighted the problems that arise when trying to link a patient to another site of care. Participants pointed to

patient barriers in going to a new location and their own desire to maintain control of their patient's care. This theme highlighted two sets of overlapping and potentially conflicting professional boundaries: while many participants perceived LTBI as *outside* or at the limits of their professional jurisdiction, they perceived overall patient care as *within* their professional jurisdiction. However, participants reconciled this conflict through a proposed shared model approach: community health clinics could expand their professional jurisdiction by providing LTBI care on-site at the patient's medical home, but should be able to continue to receive expertise and support from their local health department as needed.

Based on the literature on professional boundaries, one might think that primary care providers and other clinic staff would resist this scale-up of LTBI testing and treatment because it demands an expansion of their professional jurisdiction into unfamiliar territory. The public health department has traditionally tracked and treated both active TB and LTBI cases. We also saw from the interviews that many participants continue to hold on to this traditional view, perceiving LTBI as an area of public health responsibility and expertise. However, the findings revealed an interesting twist: providers already worry about the loss of professional jurisdiction they currently face in sending patients to the health department for treatment. Bringing patients back to their medical home for LTBI care might increase some responsibilities but it would also allow providers to maintain or regain some lost medical autonomy and ensure better overall patient care.

Limitations

Several limitations of the study should be noted. First, the recruitment process for the clinics may have led to a biased sample that skews the data in important ways. Clinics were recruited by the

consortium sites, many of whom are health departments. It is possible that the initial clinics that were targeted already had a good relationship with the health department. In addition, some clinics declined to participate, suggesting additional bias in the types of clinics that may have agreed to participate. These recruitment strategies may have led to the exclusion of clinics that are not engaged with their health department, and may therefore miss perspectives of those who are already independently carrying out LTBI testing and treatment or those who are doing very little but still see a high-risk population. Second, the team decided to limit in-depth interviews to 30 minutes in length in order to ensure the participation of busy clinic staff. However, this limited time frame may have prevented the interviewers from probing in-depth on some issues.

Implications

These findings have implications for future intervention efforts aimed at scaling up LTBI testing and treatment in primary care settings. As these results indicate, clinic staff appear receptive to the idea of scaling up LTBI testing and treatment in their clinical settings and expanding their professional jurisdiction to include LTBI care. However, most of these clinics tended to frame this expanded responsibility as a continued partnership with their health department, in which they would continue to receive resources and expert advice. This finding suggests the need to identify sustainable partnership models that allow clinics to take on more responsibility in treatment, but not feel that they lose health department support. It is unclear, however, to what extent clinics need local support versus a more centralized organization of expertise. Alternative models that centralize expert knowledge could also potentially prove effective.

In addition, clinics that currently refer to the health department for treatment suggested the need for a one-time seminar on LTBI regimens in order to begin to take on this new

responsibility. Implementing a single or short series of courses on treatments will likely be an important part of initiating this shift in care.

Finally, the theme of keeping care in a patient's medical home suggests a potential effective way to positively frame this new responsibility. Rather than highlighting LTBI as a responsibility of primary care providers or a task that the health department can no longer do alone, messaging can echo the language of clinic staff, emphasizing their expertise in overall patient care and the importance of "keeping care in a patient's medical home." This type of message can tap into clinic staff's existing professional boundaries: providing primary care and preventive services to patients right in their community. As public health agencies continue to explore new ways of partnering with primary care providers, they will need to maintain a keen awareness and understanding of the clinic perspective.

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Tables and Figures

Table 1. Clinic characteristics

GENERAL CHARACTERISTICS						LTBI CHARACTERISTICS		
Clinic	**Location**	**Avg patient visits per day**	**Patient population**	**Clinic specialties**	**% uninsured**	**Location of treatment**	**% Eligible tested**	**Diff from study avg**
ID1	East	20	Hispanic	Primary care	>50%	Treat at clinic	58%	+27
ID2	Southwest	67	Hispanic	Family medicine, internal medicine, pediatrics	<25%	Treat at clinic	36%	+5
ID3	Southwest	75	Mix (lots of refugees)	Family medicine	<25%	Treat at clinic	32%	+1
ID4	West	55	Chinese, Vietnamese	Family medicine	<25%	Treat at clinic	20%	-11
ID5	South	15	Mix (lots of refugees)	Internal medicine, pediatrics	>50%	Refer to HD	13%	-17
ID6	South	115	Hispanic, African, Vietnamese	Family medicine, obstetrics/gynecology	<25%	Refer to HD	13%	-18
ID7	South	90	Hispanic	Family medicine, obstetrics/gynecology, pediatrics	>50%	Refer to HD	10%	-20
ID8	Southwest	81	Hispanic	Family medicine	<25%	Refer to HD	9%	-21

Table 2. In-depth interview participants

Clinic staff in-depth interview overview					
Clinic	**Location**	**# of IDIs**	**Leadership examples**	**Provider examples**	**Patient services examples**
ID1	East	7	Medical director, Nurse manager	Physician assistant, Nurse practitioner	Health coach, Lead medical assistant
ID2	Southwest	10	Nursing manager, Team leader	Family doctor, Clinical pharmacist	Medical assistant
ID3	Southwest	10	President of clinic, Manager	Physician assistant	Medical assistant
ID4	West	10	Chief Medical Officer	Family doctor, Clinical pharmacist	Nurse, Patient services supervisor
ID5	South	10	Chief Operations Officer	Lead physician, Nurse practitioner	Social worker
ID6	South	10	Medical director, Senior manager	Family doctor	Clerical team lead, Ambulatory floor nurse
ID7	South	10	Co-medical director	Family doctor	Medical assistant, Nurse
ID8	Southwest	10	Medical director, Nurse program manager	Family doctor, Physician assistant	Medical assistant

Figure 1. Word Cloud of “Last Interaction with the Health Department”

Table 3. Identified themes related to HD role in LTBI testing and treatment scale-up

Theme	Summary	Quotes
HD feedback and communication	Desire to have feedback, reporting on numbers and impact, and overall good communication with health department on LTBI care efforts.	*"As a whole, as an organization, we can see we are making a difference. But, when we are doing all this extra work, and then we are not getting any feedback at all from the Health Department, what impact we are making, then it is a little bit frustrating." (ID22)*
HD financial support	Desire to have health department provide financial resources to carry out scaled up LTBI testing and treatment.	*"Usually community health clinics works very closely with local health departments. If they get support from local health department, we, you know, get funding from them, we will follow this through. That is what it is." (ID6)*
HD supply medications	Desire to have the health department supply LTBI medications, usually dispensed on-site at clinic for easy pick-up.	*"I think just access to the free medicines like the Health Department is able to give. That would be the main thing." (ID31)*
HD maintain treatment management	Desire to have health department maintain their treatment management and for clinic to continue to refer all cases to them.	*"I think when it goes to the Health Department, they have a person where that that's all they do (laughs). They have a TB person. So, you know, that's their job (laughs). So, I don't know if we can. I don't even think we have the time, resources, or, you know, manpower to have one person assigned to that." (ID81)*
HD take over cases	Desire to have the health department available to take over LTBI cases as needed.	*"Sometimes though, we diagnose and it's actually better for public health to actually track and treat because of again, transportation, homelessness, etcetera. Their outreach may be better than ours." (ID1)*
HD expert consultation and support	Desire to have health department as an expert resource for case consultations and educational seminars on LTBI treatment and care.	*"I think that we would need to have a good collaboration with the TB clinic and our health department since, again, they have been the experts and they know how to do this well. That if we have a case that we are concerned about or don't understand or maybe have to change a medication regimen because of side effects then we can consult with them easily." (ID37)*
Stay in medical home	Desire for clinic to be primary source of LTBI care due to the belief that staying in a patient's "medical home" will increase testing and treatment uptake and compliance.	*"I feel like a lot of our patients really love our clinic, and having to go other places for care, I think can be really hard, especially if you don't speak English. So, if they know, like, 'Oh, I'm going to have to maybe go somewhere else, that could be scary, and I don't know if I want to do that.'" (ID40)*

CONCLUSION

Key Findings

This dissertation provided an in-depth analysis of the social barriers to targeted testing and treatment of LTBI from two key perspectives: non-U.S.—born persons at-risk for LTBI and healthcare providers working in community health clinics (CHCs) who serve a large proportion of non-U.S.—born persons. Each paper addresses a different barrier that arises in response to DTBE's new approach to TB elimination: the uncertainty surrounding the concept and classification of LTBI, the defensive responses to messages highlighting the link between country of birth and TB risk, and the changing professional jurisdictions that arise by shifting LTBI care from the public health sector to primary care providers.

The first paper investigated barriers associated with the concept of "latent" and the confusion around how to categorize LTBI within existing health categories. Using the literature on liminal health categories (Timmermans and Buchbinder 2010) and the sociological concept of the "sick role" (Parsons 1975), the paper argues that LTBI is presented as a liminal category between health and illness, but that at-risk persons attempt to re-categorize LTBI into a binary framework. In response to unclear definitions and the asymptomatic nature of LTBI, at-risk persons disagreed on how to classify LTBI, with some placing LTBI in a healthy category ("not sick") and some placing LTBI in an illness category ("infected with TB germs").

This disagreement spilled over into discussions on whether someone with LTBI should take on the sick role (i.e. take precautions, see a doctor, get treated). Because people disagreed on the meaning of LTBI, they also disagreed on socially appropriate health behavior for someone diagnosed with LTBI. These disagreements often led to attempts at social control, in which persons who perceived LTBI to be an illness challenged other participants who appeared to not

be taking LTBI seriously enough. These findings suggest that presenting LTBI as a liminal category between health and illness may sow confusion, preventing the establishment of clear social norms on appropriate health behavior for someone at-risk or diagnosed with the condition.

The second paper investigated barriers associated with targeting non-U.S.—born persons for LTBI testing. The paper draws on the concept of "defensive processing" (Liberman and Chaiken 1992, McQueen, Vernon and Swank 2013), which describes how threatening and personally relevant health messages may produce defensive rather than receptive responses. The paper focuses on participant responses to messages describing a link between country of birth and TB risk. The findings show a mix of both defensive and receptive responses.

Some participants challenged the logic of the TB-country link, asking how country of birth could be related to TB risk given that TB is not genetic, and that "anyone" can get TB. Others found the link potentially prejudicial and rejected the messages due to concerns about its stigmatizing consequences. However, in all groups, at least one but often several participants accepted the general link between country of birth and TB risk. Some participants were already aware of TB epidemiology, making the messages unsurprising. Others learned about risk patterns during the focus group, but were receptive to the information because they focused on structural explanations rather than seeing messages as blaming immigrants.

Despite accepting the general premise of the messages, most participants did not personally see themselves as at-risk. Instead, they engaged in two types of "self-exemption" arguments. Participants pointed to their immigration medical exam as evidence that they were TB-free. This often involved drawing a distinction between non-U.S.—born persons who had successfully immigrated to the U.S. (i.e. passed a TB test) and other non-U.S.—born persons such as visitors or people who had not immigrated, who might be at higher risk for TB. In

addition, many participants downplayed the possibility that they might currently be infected with TB germs acquired years ago in their country of origin – which is how most TB cases in the U.S. occur – and instead, expressed concern over future infection from others. In other words, participants did not want to see themselves as "risky" (i.e. currently infected), but were willing to acknowledge that they might be "at risk" (i.e. could get infected) from others. These various defensive responses highlight specific improvements that can be made to LTBI messaging that can help to preempt these types of arguments.

The third and final paper investigated barriers associated with shifting some LTBI testing and treatment responsibility from the public health sector to primary health care providers. To situate the findings in a broader context, the paper draws on the literature on professional identities and professional boundaries, which shows that people may resist changes to their professional jurisdiction, especially if it involves tasks perceived to be outside their job duties or low-value tasks (Kellogg 2014, Nancarrow and Borthwick 2005). However, this literature also shows people may accept increased responsibility if it can be framed as within their existing duties or perceived as a high-value task.

The findings show that clinic staff perceive the health department as clear experts on LTBI, available for consultations on difficult cases but also available to "take over" cases. However, findings also show that clinic staff, especially providers, see themselves as experts on their patients and their overall care. As a result, for many clinic staff, the ideal model for LTBI care would be to offer LTBI testing and treatment all within the patient's medical home, but retain support (both medical and resource-related) from the health department. For clinics that currently refer out to the health department for treatment, this shift will require sufficient

provider education on LTBI treatment to give them the confidence to handle LTBI cases rather than “hand them over” to public health experts.

Limitations

Several limitations of the two studies and subsequent analyses should be noted.

First, there are several limitations regarding the message testing data that was used for Chapters 1 and 2. The recruitment criteria and strategy imposed several restrictions on participation that may have influenced the types of participants we were able to recruit. The study recruited from existing market research lists, comprised of people who had already agreed to participate in market research studies. This initial recruitment source may have skewed the data in various unknown ways. In addition, participants were required to self-identify as comfortable reading and speaking in English. We therefore did not gather perceptions on LTBI testing and treatment from non-U.S.—born persons who were not comfortable conversing in English. This may have skewed the sample towards those with higher levels of education, more years in the U.S., and with greater levels of acculturation.

The design of the message testing study limited the types of analyses we were able to conduct. Focus groups were stratified by two variables – country of origin and location of focus group – limiting stratification by other important variables such as years in the country, education, or gender.

The focus group format may have further limited some of the types of information we were able to gather. Given the group dynamic, participants may have engaged in self-censorship, keeping perceived socially undesirable comments to themselves (e.g., not wanting to get tested or treated), or they may have engaged in social conformity, agreeing with the group publicly

even if they privately had some reservations. While it is impossible to determine to what extent social desirability and social conformity played a role in these focus groups, we did observe a fair amount of concerns about getting tested and treated as well as open disagreement in groups, suggesting that some participants were willing to air honest opinions.

Second, there are several limitations that affected the community health clinic data used in Chapter 3. The recruitment process for the clinics may have led to a biased sample that skews the data in important ways. Clinics were recruited by the consortium sites, many of whom are health departments. While there were specific eligibility criteria that clinics had to meet, consortium sites could pick to work with clinics with which they already had a good relationship. In addition, some clinics initially approached for the study declined to participate, suggesting additional bias in the sample. These recruitment strategies may have led to the exclusion of clinics that are not engaged with their health department, and may therefore miss perspectives of those who are already independently carrying out LTBI testing and treatment or those who are doing very little but still see a high-risk population.

In addition, the interviews were purposefully limited to 30 minutes to ensure the participation of busy clinic staff. This shorter than usual time frame for in-depth interviews may have prevented the interviewers from probing in-depth on some issues.

Finally, there are several limitations to note regarding the analysis on all three chapters. All analysis was conducted independently without review by a second coder or analyst, increasing the possibility of an individual researcher's bias. This independent process may have led to a focus on issues more salient to the researcher, or interpretation that is not grounded in the data. To guard against this bias, several strategies have been employed. For all three chapters, a formal codebook (comprised of definitions and examples from the data) was developed and has

been shared here – a tool that would allow a second coder to verify code clarity and consistency in application. The specific tasks used to develop the codebook have been documented and reported, again providing transparency in the codebook development process. Most of the codes are concrete in nature, with detailed definitions, requiring less subjective interpretation from a coder. Once coding was completed, various structured searches and analytical matrices were used to ensure systematic review of the data. All queries and notes were documented and are available for review. For Chapter 3 specifically, subsequent focus groups with clinic staff members provided another validation check – member checking. We reported back results to staff and asked for additional feedback on what it would take to scale up testing and treatment. During these focus groups, staff brought up the concept of a patient's "medical home," further supporting the relevance of that theme, which had initially emerged in interviews.

To ensure exiting theory was not inappropriately tacked on and truly explained patterns in the data, we used the concept-indicator model, re-categorizing findings into the framework from the literature and assessing any gaps (Hennink, Hutter and Bailey 2020). Where outliers existed, they were examined to determine whether they challenged the theory being proposed or could be explained within the current framework. In Chapter 2 specifically, an alternative explanation is considered but additional data is presented to cast doubt on this alternative.

For the write-up of results, all findings were initially written without reference to quotes to avoid focusing on captivating or articulate statements that may not be representative of the overall patterns. Findings were organized around the primary themes and written using thick description from analytic memos and matrices. Quotes were added in afterwards as illustrations of the larger patterns. A systematic effort was made to assess whether the same participant or group was being overly relied upon to illustrate a theme.

Contributions and Implications

While this dissertation addresses a current public health issue, the frameworks, theories, and methods draw from sociology and other allied social sciences. As a result, this dissertation contributes to two literatures: TB and sociology. The sociological approach contributes to our knowledge about TB while the specific case of TB, and particularly the fascinating case of LTBI, contributes to our knowledge about sociology and the sociology of health.

Sociological contributions to the TB literature

First, how does a sociological approach contribute to our knowledge of TB? All three papers use analytic approaches that attend to more implicit and overarching barriers, in addition to those that are explicitly mentioned by participants. This attention to taken-for-granted norms, dominant categories, and social customs is a hallmark of the sociological approach and a key method for uncovering the connection between beliefs and behavior (Lamont and Swidler 2014, Vaisey 2009). For example, the first paper used discourse analysis to understand differing perceptions of LTBI. This approach revealed how participants' language reflects their assumptions about LTBI as a condition – whether it is a sickness, no big deal, or an early stage of something more serious. By comparing language patterns across cases, the analysis also revealed conflicting meanings participants held with regards to LTBI – a key barrier that no single participant mentioned explicitly but that clearly emerged through analysis. Despite these differences, the discourse analysis approach also revealed the entrenchment of a binary framework for thinking about health and illness. Through the repeated use of "have," participants demonstrated their belief that health was a dichotomous variable – and that you were either healthy or sick. Again, participants did not explicitly state that they preferred a binary

framework. This preference emerged in *how* participants *talked* about LTBI and *how* they tried to *classify* this new condition into their existing understanding of health and illness.

Relatedly, the use of theory helps to contextualize findings beyond the specific case of LTBI and offers insights into both mechanisms and future possible interventions. For example, in the second paper, the application of the "defensive processing" concept helps to categorize the specific responses to LTBI messages observed in the focus groups within existing defensive strategies documented in the literature. The theory also highlights possible future messaging that might be more motivating for getting tested, including messaging that emphasizes TB exposure as one of low controllability and avoids implications of personal guilt. In the third paper, the application of the professional identity and boundary literature moves the issue outside the specific realm of LTBI care and into the broader issue of shifting professional boundaries. In doing so, the paper highlights an opportunity for facilitating this shift: framing increased primary care providers' involvement in LTBI care as a way of reclaiming medical autonomy over their patients' overall care.

TB contributions to the sociology literature

Second, how does the case of TB, and LTBI specifically, add to our knowledge of sociological frameworks and theories? Each of the three chapters draws on existing sociological theories to make sense of the specific findings related to LTBI testing and treatment. However, these papers go beyond simply applying these theories. Instead, they offer important tests of these theories and even introduce several interesting modifications.

Chapter 1 uses the concept of "liminal" health categories (Timmermans and Buchbinder 2010) and Parsons's "sick role" (Parsons 1975). Previous research has shown that liminal

categories can cause confusion about appropriate behavior, but that people often opt to take on the sick role. Many of these studies, however, have examined perceptions of patients in a medical encounter. This study, by contrast, assessed perceptions among an at-risk group outside of a clinical context. In doing so, it potentially captured a missing perspective – people who see a liminal status as nothing to worry about are potentially less likely to seek medical care in the first place. This paper therefore provides evidence of people classifying a liminal status into both a sick and a healthy category.

The paper also provides support for the continuing relevance of Parsons's sick role framework. While participants disagreed on how to classify LTBI, they agreed on the predominance of a binary framework of health and illness. Furthermore, no one seemed to question the existence of a sick role or associated role expectations – only whether the sick role applied to someone with LTBI.

Chapter 2 applied the concept of "defensive processing" to understand responses to messages describing a link between country of birth and TB risk. We identified two of the four types of defensive processing strategies in the data: counter-argumentation and self-exemption (McQueen, Vernon and Swank 2013). However, we identified two variations to the self-exemption process that emerged through the specific case of LTBI, but that may be applicable in other contexts.

While the literature tends to frame self-exemption as an individual-level process in which people optimistically perceive themselves as uniquely healthy or invulnerable, we observed a more group-based process in which participants pointed to a specific group membership that lowered their risk. Participants emphasized their status as "immigrants" who had passed through a medical exam and compared this to a riskier group of "non-U.S.—born persons" still in their

country of origin or who had not gone through the same immigration process (e.g., foreign visitors).

In addition, we find that the self-exemption process operates differently when the health condition is an infectious disease. (Although LTBI is not infectious, participants understood and worried about the potential for progression to TB disease, which is infectious.) Because TB is infectious, anyone can presumably get it, making it difficult for participants to categorically deny an "at risk" status. Instead, participants reproduced the self-exemption argument by drawing a distinction between risky (i.e. infected) and at-risk (i.e. all others) and selected the more favorable of the two identities. This distinction emerged in participants' concern regarding a future infection from someone else rather than concern regarding their own possible longstanding latent infection. Making this distinction allowed participants to maintain a positive self-concept as currently healthy while still acknowledging the risks inherent in a potentially infectious disease. This modified form of self-exemption argument appears especially relevant to the current COVID-19 pandemic because people might be more willing to acknowledge a general risk rather than accept their own possible asymptomatic infection.

Chapter 3 applied the concept of "professional boundaries" to explain the possible reactions primary care providers and other clinic staff might have to shifting LTBI care from their traditional public health setting to clinical settings. We observed many expected patterns in concerns about additional work or tasks at the bounds of professional expertise. However, we also observed what happens when professional boundaries overlap and conflict. Specifically, we found that while many participants perceived LTBI as *outside* or at the limits of their professional jurisdiction, they perceived overall patient care as *within* their professional jurisdiction. Referring patients out to the health department for LTBI treatment might prevent

providers from taking on new LTBI responsibilities, but it also forces them to give up existing responsibilities as primary provider for their patients. We argued that this conflict provided an opportunity for future framing of LTBI care. Rather than propose LTBI care as new responsibility and expanded professional jurisdictions, messaging could frame it as regaining lost medical autonomy and maintaining care in a patient's medical home. This example provides an important illustration of what happens when professional boundaries overlap, and how boundaries are socially constructed and can therefore be reconstructed to meet new demands.

This dissertation offers an example of how behavioral sciences, especially those with sociologically informed theories, can address important public health problems by considering the social factors that influence population health outcomes.

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EXPLANATION OF ROLE IN COLLABORATIVE STUDIES

Message testing project (CH. 1 and CH. 2)

1. Design
    a. Assisted with review of moderator guide
    b. Assisted with revisions to moderator guide following pilot

2. Data collection
    a. Observed all 15 focus groups, in person or via live streaming
    b. Took fieldnotes at all 15 focus groups, comprised of seating charts, discussion notes, and other information as relevant (e.g., gestures, non-verbal cues)

3. Data cleaning and management
    a. Reviewed, revised, and fully cleaned all 15 transcripts using a standard transcription key
    b. Imported all data into qualitative software program (NVivo) along with relevant demographic variables

4. Data analysis
    a. Created codebook, with input from committee members
    b. Coded all 15 focus groups
    c. Conducted all analysis, with input from committee members

5. Manuscript preparation
    a. Wrote manuscript draft, with input and feedback from committee members

Community health clinic project (CH. 3)

1. Design
    a. Created all 3 interview guides, with substantial input from DTBE staff
    b. Conducted several pilot interviews and revised guide based on feedback
    c. Determined sample design and recruitment strategy for clinics, with substantial input from DTBE staff
    d. Assisted in drafting protocol sections related to qualitative data collection and analysis

2. Data collection monitoring
    a. Conducted weekly check-ins with interviewers to assess data collection progress and troubleshoot any issues
    b. Identified and implemented minor modifications to guide either to improve flow of conversation or understandability of questions or to add in additional areas to probe based on initial data analysis.

3. Data cleaning and management
    a. Conducted quality checks of professionally transcribed transcripts
    b. Imported all transcripts into a qualitative software program (MaxQDA) along with relevant clinic-level and demographic variables

4. Data analysis
    a. Led team-based analysis of entire qualitative data set, using a “rapid analysis” approach that is not used in this dissertation, but that did inform the initial interest in the health department research questions
    b. Created focused codebook for health department analysis
    c. Coded 77 interviews in sub-sample
    d. Conducted analysis for paper

5. Manuscript preparation
    a. Wrote manuscript draft, with input and feedback from committee members

METHODOLOGICAL APPENDIX

Message testing moderator guide

A 90-Minute Focus Group With
Non-U.S.-Born Men and Women
at High Risk for Tuberculosis

MODERATOR'S GUIDE

Spring 2019

BACKGROUND [5 minutes]

Moderator:

- Welcome / thank you for your participation
- My name / not an employee of the Centers for Disease Control and Prevention (CDC) or the federal government / independent researcher
- My role (facilitate discussion and end on time at x:xx a.m./p.m.)
- *The purpose of today's discussion is to:*
  1. Discuss health conditions and diseases common in your home country and in the United States.
  2. Get your feedback on information that the Centers for Disease Control and Prevention (referred to throughout as "CDC") is developing for the general public.
  3. Hear your suggestions for how CDC could best reach you with important health information.
- *Some guidance for our conversation:*
  - Please talk one at a time.
  - Please talk in a voice at least as loud as mine.
  - I need to hear all of your opinions—i.e., everyone should have more or less equal "air time."
  - There are no right or wrong answers—that said, if someone disagrees with what someone else says, please speak up (we are respectful of all opinions).
  - This discussion is confidential—first names only / no names will be used in the summary report.
  - Your participation is voluntary (free to decline to answer a question / free to leave the room at any time).
  - I did not have anything to do with the development of the material we are going to review—if you have constructive criticism, I will not be offended or penalized.
    - Please be honest.
  - Our time together is limited—please don't be offended if I have to interrupt you to turn to the next question; there is simply a lot to cover, and we have to finish on time.
  - If you need to leave the room, please do so one at a time.
  - Please turn your cell phones off or place them on silent.
  - We would like to audio-record this discussion so that when it comes time to write the summary report, we will have the "raw" data to turn to, as needed. Does anyone object to our audio-recording this focus group discussion? *[Dismiss participant(s) if so.]*
  - We will also be live video streaming this discussion so that project staff who couldn't be here in person can view today's discussion. The video streaming is not being recorded; thus, there will be

no video record or archive of this discussion. Does anyone object to our live video streaming of this focus group discussion? *[Dismiss participant(s) if so.]*
- Project staff are sitting behind the one-way mirror viewing the discussion.

PARTICIPANT INTRODUCTIONS [5 minutes]

Moderator:
- One thing everyone here has in common is you were all born in [insert country name]. (Full disclosure—I was born in [insert country name] and came to this country when I was [insert age] years old.)

Participants:
- Go around the table and have participants introduce themselves:
  a. First names only (no last names).
  b. Favorite food from your home country.

GENERAL KNOWLEDGE OF DISEASES AND TUBERCULOSIS [15 minutes]

1. Very briefly, what is one health condition or disease that concerns you greatly, and why? *[Listen for tuberculosis and whether that was/is a concern in the home country and/or is a concern in the United States.]*

2. What health conditions or diseases are most common in your home country?

3. How many of you have heard of "tuberculosis" (sometimes referred to as "TB")? *[Ask participants to raise hands and count out loud for the audio-recording.]*

    a. If you were reading a brochure or fact sheet, would you know that "TB" is short for "tuberculosis," or would you need to see "tuberculosis" spelled out each time?

Please remember that we are not asking you to disclose your health status information. Your participation in the discussion is voluntary.

    b. Among those of you who have heard of tuberculosis, please describe what tuberculosis is.
    c. Where did you hear about tuberculosis/How did you learn about tuberculosis and what it is?

        i. What have you heard about the TB skin test?
        ii. What have you heard about the TB blood test?
        [If applicable for both questions: Has your health care provider told you about the test/how the test is given?]

4. Does anyone know of anyone who had or has tuberculosis?

    a. What do you know about that person's experience with tuberculosis?

5. How much of a concern is tuberculosis for you? *[If needed: On a scale of 1 to 10, where 1 is "Not at All Concerned" and 10 is "Extremely Concerned," how concerned are you about tuberculosis?][Participants to write the number on a piece of paper prior to sharing their response.]*

6. How common do you think tuberculosis is? *[If needed: How many people do you think get tuberculosis, out of 100 people? Or, out of 10 people?]*

7. Who do you think is most likely to get tuberculosis?

8. How contagious do you think tuberculosis is? *[If needed: On a scale of 1 to 10, where 1 is "Not at All Contagious" and 10 is "Extremely Contagious," how contagious do you think tuberculosis is?]*

9. How many of you have heard of "latent tuberculosis infection"? *[Write on flip chart.]*

    a. *[If no one knows what LTBI is]* What do you *think* latent tuberculosis infection is?
    b. *[If applicable]* Among those of you who have heard of latent tuberculosis infection, what do you know about it?
    c. *[If applicable]* Where did you hear about latent tuberculosis infection/how did you learn about it?

EDUCATION ON TUBERCULOSIS DISEASE AND LATENT TUBERCULOSIS INFECTION [5 minutes]

The moderator will review a brief visual PowerPoint by reading notes aloud pertaining to each slide as participants follow along.

Moderator: The reason we have gathered a group of individuals from [country of origin] is that most people diagnosed with tuberculosis disease in the United States were born in Mexico, the Philippines, India, Vietnam, China, and Guatemala. Tuberculosis rates among non-U.S.-born individuals are approximately 15 times greater than the rate among U.S.-born individuals. We will be talking more about these points as we move along in the discussion. *[Moderator to read this section verbatim.]*

MESSAGE TESTING [50 minutes]

The themes and messages that follow will be rotated across focus groups to ensure:

- *Message testing stays within the 50-minute time allotment.*
- *Participants in any one focus group are not cognitively overburdened with message testing questions.*

Please refer to the last two pages of this guide for the rotation of messages by audience.

Participants will review statements printed on paper and placed within a folder in front of them. The statements will be labeled in the order in which they will be discussed.

For all rating questions (e.g., On a scale of 1 to 10 where 1 is "Not at All Concerning" and 10 is "Extremely Concerning," how important does latent TB infection seem to you?) the moderator will ask participants to write down a number on a piece of paper before sharing their response.

Moderator:

- In front of you, there is a folder that contains several statements. I am going to ask for your feedback and thoughts on these different statements. I will read a statement aloud and ask that everyone else follow along as we go.

Theme A: Basic information on latent tuberculosis infection

Statements Y, Q, and B to be discussed with participants BEFORE the moderator reviews the educational PowerPoint.

Statement Y (1): Anyone can get TB. TB germs are spread through the air from one person to another.

1. In your own words, what do you think this statement is trying to say?
2. Are there any words in this statement that you do not understand?

Statement Q (2): People who are infected with TB but are not sick have a condition called latent TB infection.

3. In your own words, what do you think this statement is trying to say?
4. Are there any words in this statement that you do not understand?

Statement B (3): People with latent TB infection do not feel sick, do not have symptoms, and cannot spread TB germs to others. This is because the TB germs are latent, or inactive, in their body. If their TB germs become active, they can develop TB disease.

5. In your own words, what is this statement saying?
6. Are there any words in this statement that you do not understand?
    a. What does "symptoms" mean to you? What does "germs" mean to you?
7. How many of you know what the word "latent" means? *[Moderator to spell out l-a-t-e-n-t.] [Show of hands.]*
    a. How many of you are unsure what the word "latent" means? *[Show of hands.]*
    b. Can someone please define the word "latent"?
        i. What other words come to mind when you hear the word "latent"?
8. Some people find the phrase "latent TB infection" unclear. What other words or phrases would you recommend to describe the condition explained in statement B? *[Probe for alternatives such as: latent tuberculosis infection, TB infection, sleeping TB, dormant TB, quiet TB, hibernating TB.]*
    a. In this statement, what does "inactive" mean to you?
    b. In your folder, there is a list of other words or phrases that describe this condition. Please circle the two phrases that you find the most clear. If you have another word or phrase not on this list, write it down besides the "Other" option. *[Moderator reads each term aloud.]*
9. How many of you knew that if you have latent TB infection you do not feel sick? *[Show of hands.]*

Statement Z (4): There are two kinds of tests that are used to detect TB germs in the body: the TB skin test and the TB blood test. A person with latent TB infection has a positive TB skin test or TB blood test.

10. Tell me in your own words what this statement is trying to tell you.
11. Is anything about this statement confusing to you?
    a. What does having "a positive" TB test mean to you?
12. Are there any words or phrases in this statement that you do not understand?

Statement U (5): People can have latent TB infection for years or decades before getting sick. Many people who have latent TB infection never develop TB disease.

13. Tell me in your own words what this statement is trying to tell you.
    a. What is the difference between "latent TB infection" and "TB disease"?
14. Does anything about this statement confuse you?
15. Are there any words or phrases in this statement that you do not understand?

Statement M (6): A person with latent TB infection cannot give TB to others.

16. Tell me in your own words what this statement is trying to tell you.
17. After reading this statement, how concerning does latent TB infection seem to you? *[If needed: On a scale of 1 to 10 where 1 is "Not at All Concerning" and 10 is "Extremely Concerning," how important does latent TB infection seem to you?]*
18. What could you add or change to this statement to make latent TB infection seem more important?

Statement F (7): Some people develop TB disease soon (within 2 years) after becoming infected, before their immune system can fight the TB germs. Other people may develop TB disease many years later when their immune system becomes weak for another reason.

19. In your own words, what is this statement saying?
20. Does anything about this statement confuse you?
    a. What does "immune system" mean to you? What does "germs" mean to you?
21. Are there any words or phrases in this statement that you do not understand?

Statement V (8): In the United States, up to 13 million people may have latent TB infection, according to estimates from the U.S. Centers for Disease Control and Prevention (CDC). Without treatment, they are at risk for developing TB disease.

22. After hearing that "up to 13 million people may have latent TB infection," how common does latent TB infection seem to you?
    a. How common do you think latent TB infection is in your community? *[If needed: more or less common than other communities in the United States?]*
23. After hearing that people without treatment "are at risk for developing TB disease," how concerned are you when thinking about people with latent TB infection who haven't been treated? *[If needed: On a scale of 1 to 10 where 1 is "Not at All Concerned" and 1 is "Extremely Concerned," how concerned does this information make you feel?]*
    a. Is there anything you would add to this statement to make it clearer to people that getting treatment for latent TB infection is very important? *[Listen for/Probe: Adding that a person with TB disease could die if they are not treated.]*

Statement X (9): One in four people worldwide may be infected with TB.

24. Of the two following statements, which one makes you think latent TB infection is big problem?
    a. "One in four people worldwide may be infected with TB." *(Write on flip chart.)*
    b. "25 percent of people in the world may be infected with TB." *(Write on flip chart.)*

Theme B: Risk factors for latent tuberculosis infection developing into tuberculosis disease

Statement Ca (10a): Without treatment, on average 1 in 10 people with latent TB infection will get sick with TB disease in the future. For some people, that risk is much higher.

25. Tell me in your own words what this statement is trying to tell you.
    a. What does "risk" mean to you?
26. How concerned does this statement make you feel about what can happen if you do not get treated for latent TB infection? *[If needed: On a scale of 1 to 10 where 1 is "Not at All Concerned" and 10 is "Extremely Concerned," how concerned does this information make you feel?]*
27. Which statement is clearer to you:
    - "Without treatment, on average 1 in 10 people with latent TB infection will get sick with TB disease in the future." *(Write on flip chart.)*
    - "Without treatment, on average 5 percent to 10 percent of people with latent TB infection will get sick with TB disease in the future." *(Write on flip chart.)*

28. Which of the above statements sounds more important?

Statement Cb (10b): For those with latent TB infection, the risk for getting sick with TB disease is higher for people with HIV, diabetes, other conditions that affect their immune system, or persons receiving immunosuppressive therapy.

29. Tell me in your own words what this statement is trying to tell you.
30. Are there any words or phrases in this statement that you do not understand?
    a. What does "risk" mean to you? What does "immune system" mean to you? What does "immunosuppressive therapy" mean to you?

31. If we put the following two statements together, is it clear to you what the statements are trying to say?
    a. Statement A: Without treatment, on average 1 in 10 people with latent TB infection will get sick with TB disease in the future. For some people, that risk is much higher. The risk is higher for people with HIV, diabetes, other conditions that affect their immune system, or persons receiving immunosuppressive therapy.

Statement J (11): Some people develop TB disease soon (within 2 years) after becoming infected, before their immune system can fight the TB germs. Other people may get sick years later, even more than 10 years after they were infected, when their immune system becomes weak for another reason. This is known as reactivation of latent TB infection.

32. In your own words, what is this statement saying?
33. Are there any words or phrases in this statement that you do not understand?
    a. What does "immune system" mean to you? What does "germs" mean to you?
    b. How many of you are familiar with the word "reactivation"?
        i. Can someone please tell me, in your own words, what the word "reactivation" means?
    c. Do you have suggestions for other words that could be used instead of "reactivation"? *[Probe for: revive, activate again, awaken, wake up, become active.]*

Statement P (12): Most TB disease in the United States is caused by reactivation of latent TB infection.

34. Tell me in your own words what this statement is trying to tell you.
35. Is anything about this statement confusing to you?
36. What information would help you better understand this statement?

Statement G (13): TB disease in the United States is most common among people born in countries where TB disease is more common.

37. Tell me in your own words what this statement is trying to tell you.
38. Is anything about this statement confusing or offensive to you?
39. What do you think of when you hear "countries where TB disease is more common"?

Statement R (14a): CDC estimates that 92% of TB cases among non-U.S.–born persons are caused by reactivation of latent TB infection that was acquired in their home country, years before arrival in the United States.

40. In your own words, what is this statement saying?
41. Is anything about this statement confusing or offensive to you?
42. Are there any words or phrases in this statement that you do not understand?
    a. What does "cases" mean to you?
43. Of the following two statements, which is clearer:

a. CDC estimates that 92% of TB cases among non-U.S.-born persons are caused by reactivation of latent TB infection that was acquired in their home country, years before arrival in the United States.
b. CDC estimates that approximately 9 in 10 TB cases among non-U.S.-born persons are caused by reactivation of latent TB infection that was acquired in their home country, years before arrival in the United States.

Statement YY (15a): CDC and the U.S. Preventive Services Task Force recommend testing populations that are at increased risk for latent TB infection, including people born in countries where TB disease is common, regardless of how long they have been in the United States.

44. Tell me in your own words what this statement is trying to tell you.
45. How does including "CDC" and "the U.S. Preventive Services Task Force" in the statement make you feel about the statement? *[Probe: Does this make the statement more believable/more important?]*
46. Does this statement motivate you to find out more about latent TB infection and who is at risk? Why/Why not?
    a. What would motivate you to find out more about who is at risk?

Moderator: Now, I am going to read a statement that "goes with" (accompanies) the statement we just read.

Statement YY (15b): People born in or who frequently travel to countries where TB disease is common include Mexico, the Philippines, Vietnam, India, China, Haiti, and Guatemala, or other countries with high rates of TB disease.

47. Does anything surprise you about this statement?
48. Before this focus group, how many of you knew that TB disease is common in the countries I listed, including [insert country of origin of participants]?
49. Are there any words or phrases in any of the statements that you do not understand?
50. Does this list motivate you to get tested for TB infection? Why/Why not?
51. Do these statements make you want to learn more about TB infection?
    a. What other information would you like to know about TB infection?

Theme C: Bacille Calmette-Guérin (BCG) vaccine

Statement H (16): Bacille Calmette-Guérin (BCG) is a vaccine for TB disease. This vaccine is not widely used in the United States, but it is often given to infants and small children in other countries where TB is common.

52. Tell me in your own words what this statement is trying to tell you.
53. Can someone tell me what a "vaccine" is?
54. How many of you have heard of the "Bacille Calmette-Guérin" vaccine?
    a. How about the "BCG" vaccine?
    b. *[If applicable]* Where did you learn about this vaccine?
    c. *[If applicable]* What do you know about this vaccine?
    d. How do you think the BCG vaccine affects the risks for tuberculosis?
55. If you were to read a brochure or fact sheet on this type of vaccine, what term would you be more likely to recognize:

a. "BCG" vaccine
b. "Bacille Calmette-Guérin" vaccine
c. Something else? Like "TB vaccine" or "vaccine for TB"?

<u>Statement O (17):</u> Many people born outside of the U.S. got the BCG vaccine to protect against severe forms of TB as a child. This protection becomes weak over time.

56. Tell me in your own words what this statement is trying to tell you.
57. Does anything surprise you about this statement?
58. How believable is this statement? *[If needed: On a scale of 1 to 10 where 1 is "Not at all Believable" and 10 is "Extremely Believable," how believable is this information—specifically that protection becomes weak over time?]*
    a. What else could be added to this statement to make it <u>more</u> believable?
59. Is anything about this statement confusing or offensive to you?

<u>Statement NN (18)</u>: People who were vaccinated with BCG can get infected with TB and become sick with TB.

60. Tell me in your own words what this statement is trying to tell you.
61. Does anything surprise you about this statement? What questions does this statement make you want to ask?
62. How believable is this statement? *[If needed: On a scale of 1 to 10 where 1 is "Not at All Believable" and 10 is "Extremely Believable," how believable is this information—specifically that even with the BCG vaccine, someone can still become sick with tuberculosis?]*
    a. What else could be added to this statement to make it <u>more</u> believable?
63. How motivated does this statement make you to find out more about the BCG vaccine?
    a. What else do you want to know about the BCG vaccine?

<u>Statement XX (19)</u>: There are two kinds of tests that are used to detect TB germs in the body: the TB skin test and TB blood tests. Sometimes the BCG vaccine can cause a positive reaction to a TB skin test, even if the person is not infected with TB germs.

64. Tell me in your own words what this statement is trying to tell you.
65. Is anything about this statement confusing to you?
    a. What does it mean that the BCG vaccine can cause a positive reaction … even if the person is not infected?
66. How does this statement make you feel? *[Listen for: concerned, confused, etc.]*
67. Does this statement motivate you to take any action? If so, what action?

<u>Statement AA (20)</u>: TB blood tests, unlike the TB skin test, are not affected by prior BCG vaccination. TB blood tests are the preferred method of TB testing for people who have received the BCG vaccine.

68. Tell me in your own words what this statement is trying to tell you.
69. How likely would you be to recommend a TB blood test to a loved one who had received the BCG vaccine?
    a. What else would you need to know about the TB blood test to make this recommendation?
70. Is anything about this statement confusing to you?
    a. What does "a positive test result" mean?

b. What does "prior BCG vaccination" mean to you?

71. Are there any words or terms in this statement that you do not understand?
72. How does this statement make you feel?

Topic D: Latent tuberculosis infection testing and diagnosis

Statement TT (21a): Anyone can get infected with TB germs. However, some people have a higher risk of getting infected with TB germs.

73. Tell me in your own words what this statement is trying to tell you.
    a. Can someone tell me in your own words what the phrase "higher risk" means in the above statement?

Moderator: Now, I am going to read four statements that "go with" (accompany) the statement we just read. Anyone can get infected with TB germs. However, some people have a higher risk of getting infected with TB germs. People who should be tested for TB infection include:

- **Statement La (21b): People born in or who frequently travel to countries where TB disease is common, including Mexico, the Philippines, Vietnam, India, China, Haiti, and Guatemala, or other countries with high rates of TB disease.**
- **Statement Lb (21c): People who currently, or used to, live in large group settings, such as homeless shelters or prisons and jails where TB disease is more common.**
- **Statement Lc (21d): Health care workers and others who work in places at high risk for TB transmission, such as hospitals, homeless shelters, correctional facilities, nursing homes, and residential homes for those with HIV.**
- **Statement Ld (21e): Someone who has spent time with a person who has infectious TB disease.**

74. Does anything surprise you about these statements?
75. Before this focus group, how many of you knew that TB disease is common in the countries I listed, including [insert country of origin of participants]?
76. Are there any words or phrases in any of statements that you do not understand?
77. Does this list motivate you to get tested for TB infection? Why/Why not?
78. Do these statements make you want to learn more about TB infection?
    a. What other information would you like to know about TB infection?

Statement ZZ (22): There are two kinds of tests that are used to detect TB germs in the body: the TB skin test and the TB blood test. The TB skin test requires two visits (one to perform the test and a second for it to be read). The TB blood test requires only a single visit to draw blood.

79. Tell me in your own words what this statement is trying to tell you.
80. Is anything about this statement confusing to you?
81. How likely would you be to go get tested for TB knowing that people born in [insert country of origin of participants] are at higher risk? [OR How likely would you be to encourage someone you love, who was also born in [country of origin], to get tested for TB?]
    a. For those of you unlikely to go get tested, what makes you not want to get tested? *[Listen for: distrust in doctors, cultural barriers, transportation difficulties, lack of child care, cannot take time out of work, fear of the test's results, no health insurance to cover costs, fear of immigration status being reported to authorities.]*
    b. For those of you likely to go get tested, what test would you prefer? Why?

Statement VV (23): A positive TB skin test or TB blood test only tells that a person has been infected with TB germs. It does not tell whether the person has latent TB infection or has progressed to TB disease. More tests, like a chest x-ray, are needed to rule out TB disease.

82. Tell me in your own words what this statement is trying to tell you.
83. Is there anything about this statement that you do not understand?
84. Now, how likely are you to get tested for TB knowing that if it is "positive" you will need more tests, like a chest x-ray, to rule out TB disease? [OR: How likely would you be to encourage someone you love to get tested for TB?]
    a. If unlikely, what would motivate you to get tested?
    b. What would incentivize or encourage you to get tested no matter how many follow-up appointments it may take?

Statement BB (24): A diagnosis of latent TB infection is made if a person has a positive TB skin test or TB blood test result and a medical exam does not indicate TB disease.

85. Tell me in your own words what this statement is trying to tell you.
86. Is there anything about this statement that you do not understand?
    a. What does "a positive TB skin test or TB blood test" mean to you? What does "a diagnosis of latent TB infection" mean to you?
87. What else does this statement make you want to know about the skin test or blood test?

Topic E: Treatment for latent tuberculosis infection

Statement MM (25): People with latent TB infection do not have symptoms, are not sick with TB, and they cannot spread TB germs to others. However, if latent TB germs become active in the body and multiply, the person will go from having latent TB infection to being sick with TB disease. The good news is there are medicines people can take to treat the latent TB infection that will prevent it from developing into TB disease. This is often referred to as treatment for latent TB infection.

88. Tell me in your own words what this statement is trying to tell you.
89. Are there any words in this statement that you do not understand?
    a. In this statement, what does "active" mean to you? What about "multiply"?
90. Can someone please tell me what the word "latent" means?
    a. How many of you find this word unclear? *[Ask participants to raise hands and count out loud for the audio-recording.]*
91. Some people find the phrase "latent TB infection" unclear. What other words or phrases would you recommend to describe the condition explained in statement MM? *[Probe for alternatives such as: latent tuberculosis infection, TB infection, sleeping TB, dormant TB, quiet TB, hibernating TB.]*
92. How important do you think it is to get treated for latent TB infection?
93. How likely are you to get tested and treated for a condition if you do not feel sick?
    a. What would motivate you to get tested if you don't feel sick?
    b. If you get tested, and find out that you test "positive" for TB germs, but still do not feel sick, how likely are you to seek treatment?
        i. What would motivate you to seek treatment?
        ii. Is there anything else you would need to know about treatment before you decided to seek treatment?
        iii. What would make you not want to get treated and why?

94. How much does the phrase "treatment for latent TB infection" motivate you to get treated? (What other words/phrases would you recommend to describe treatment for the TB condition where TB germs are latent, or inactive, in the body?)
    a. Do any of the following phrases make getting treatment sound more important than "treatment for latent TB infection" to you?
        i. "TB preventative therapy for latent tuberculosis infection"
        ii. "Treatment for TB infection"
        iii. "Chemoprophylaxis for latent tuberculosis infection"

95. Now I am going to ask you to compare two statements. Tell me which is the clearest in telling you that getting treated for latent TB infection is important, and why.
    - **Statement MM (26): People with latent TB infection do not have symptoms, and they cannot spread TB germs to others. However, if latent TB germs become active in the body and multiply, the person will go from having latent TB infection to being sick with TB disease. For this reason, people with latent TB infection should be treated to prevent them from developing TB disease.**
    - **Statement UU (27): If you have a positive TB skin test or TB blood test, but do not have any other signs and symptoms of TB disease, you may have latent TB infection. If you have TB infection, you may need medicine to prevent getting TB disease later. This is called treatment for latent TB infection.**

96. Now I am going to ask you to rank four statements in order of which would motivate you most to get treated for latent TB infection if you tested positive:

    - **Statement Da (28a): Treatment for latent TB infection is 90% effective in preventing the development of TB disease.**
    - **Statement Db (28b): Treatment will help you stay healthy and keep those you love safe from TB.**
    - **Statement Dc (28c): Taking your medications for latent TB infection can prevent you from developing TB disease in the future.**
    - **Statement Dd (28d): Taking TB medication is the only way to kill the TB germs in your body.**

97. Tell me why you ranked the statements (above) in the order you did.
98. Is there anything else that would motivate you to get treated?

Statement PP (29): Treatment for latent TB infection can take 3 to 9 months, depending on the regimen.

99. Tell me in your own words what this statement is trying to tell you.
100. Tell me in your own words how this statement makes you feel about treatment?
    a. What does the word "regimen" mean to you?
101. Does this statement make you unsure about getting treated? Why/Why not?
    a. If length of time to get treated (3 to 9 months) is a concern for you, what would make it less of a concern?

Statement JJ (30): Most people can take their TB medicine without any problems. However, people respond differently to medications. You could have side effects from the medicine.

102. Tell me in your own words what this statement is trying to tell you.

103. Tell me in your own words how this statement makes you feel about treatment?
    a. What does the term "side effects" mean to you? What do the terms "medication" and "medicine" mean to you?
104. Does this statement make you unsure about getting treated? Why/Why not?
105. What else would you want to know about side effects (or anything else) before deciding to get treated?

TRUSTED INFORMATION SOURCES/PREFERRED COMMUNICATION CHANNELS
[5-10 minutes]

1. Very briefly, when you need to seek health or medical care, where do you go? *[Probe: clinic, health center, health department, hospital emergency room, hospital outpatient department, doctor's office, etc.]*
    a. How often do you seek health or medical care?
    b. For what purposes do you seek health or medical care?
    c. With whom do you go to seek health or medical care?
    d. What makes you more likely or less likely to seek health care? *[Probe for barriers: insurance, public charge – may negatively affect immigration status]*

2. What are your <u>most trusted</u> sources for information about health?
    a. If you were looking for information about tuberculosis, what trusted source(s) would you turn to?
        i. What websites or organizations would you trust most for information about tuberculosis?

3. If you had a question about tuberculosis, how comfortable would you feel asking your health care provider (doctor, nurse, pharmacist, clinic, hospital)?
    a. How do you communicate with your health care provider outside of in-person visits?

4. What challenges, if any, have you had communicating with your health care provider because of your language or accent? What challenges, if any, have you had with your health care provider not understanding your culture? *[Probe for specifics: language/cultural barriers.]*

5. If the CDC wanted to let you, and people like you, know about latent tuberculosis infection, where should they put that information? *[Ask for detailed information source/communication channels: television (which stations?), radio, magazines (which ones?), newspapers, experts/providers, social media, in-person gatherings, through children's school, through faith-based organizations, through community-based locations like the community recreational center or public library or gym, at shopping centers, etc.][Moderator to probe for responses beyond "sending emails".]*

6. If you saw information on latent tuberculosis infection and you wanted your family members, friends, colleagues, and/or neighbors to see it too, how would you <u>share</u> this information?

7. What is your top preferred <u>format</u> for receiving information on latent tuberculosis infection? [*Probe: hard-copy/printed brochure/fact sheet/infographic/FAQ document; book; website; app; podcast; wallet card; blog; newsletter; website (which ones?).]*

8. How important is it to you that this information be in a language other than English?

CLOSE [<5 minutes]

What I'd like to do next is ask the observers if they have any additional questions or need clarification on any of the issues we've discussed. *[Ask any questions from observers.]*

ROTATION OF THEMES AND MESSAGE STATEMENT BY AUDIENCE			
Focus Group ID	**Audience (by Country of Birth)**	**Themes**	**Message Statement # for Testing**
1	China	Theme A: Basic information on latent tuberculosis infection (statement 1, 2 and 3 only) Theme B: Risk factors for latent tuberculosis infection developing into tuberculosis disease Theme C: Bacille Calmette-Guérin (BCG) vaccine Theme E: Treatment for latent tuberculosis infection	1–3 9–14 15–19 24–28
2	China	Theme A: Basic information on latent tuberculosis infection Theme D: Latent tuberculosis infection testing and diagnosis Theme E: Treatment for latent tuberculosis infection (exclude statement 25, similar to 3)	1–8 20–23 24; 26–28
3	Guatemala	Theme A: Basic information on latent tuberculosis infection (statement 1, 2 and 3 only) Theme B: Risk factors for latent tuberculosis infection developing into tuberculosis disease Theme C: Bacille Calmette-Guérin (BCG) vaccine Theme E: Treatment for latent tuberculosis infection	1–3 9–14 15–19 24–28
4	Guatemala	Theme A: Basic information on latent tuberculosis infection Theme D: Latent tuberculosis infection testing and diagnosis Theme E: Treatment for latent tuberculosis infection (exclude statement 25, similar to 3)	1–8 20–23 24; 26–28
5	India	Theme A: Basic information on latent tuberculosis infection (statement 1, 2 and 3 only) Theme B: Risk factors for latent tuberculosis infection developing into tuberculosis disease Theme C: Bacille Calmette-Guérin (BCG) vaccine Theme D: Latent tuberculosis infection testing and diagnosis (exclude statement 22, similar to statement 19)	1–3 9–14 15–19 20–21; 23
5	India	Theme A: Basic information on latent tuberculosis infection Theme B: Risk factors for latent tuberculosis infection developing into tuberculosis disease Theme E: Treatment for latent tuberculosis infection (exclude statement 25, similar to 3)	1–8 9–14 26–28
6	India	Theme A: Basic information on latent tuberculosis infection (exclude statement 4; similar to statement 19) Theme D: Latent tuberculosis infection testing and diagnosis Theme E: Treatment for latent tuberculosis infection	1–3; 4–8 20–23 25–28
8	Mexico	Theme A: Basic information on latent tuberculosis infection (statement 1, 2 and 3 only) Theme B: Risk factors for latent tuberculosis infection developing into tuberculosis disease Theme C: Bacille Calmette-Guérin (BCG) vaccine	1–3 9–14 15–19

		Theme D: Latent tuberculosis infection testing and diagnosis (exclude statement 22, similar to statement 19)	20–21; 23
9	Mexico	Theme A: Basic information on latent tuberculosis infection Theme B: Risk factors for latent tuberculosis infection developing into tuberculosis disease Theme E: Treatment for latent tuberculosis infection (exclude statement 25, similar to 3)	1–8 9–14 26–28
10	Mexico	Theme A: Basic information on latent tuberculosis infection (exclude statement 4; similar to statement 19) Theme D: Latent tuberculosis infection testing and diagnosis Theme E: Treatment for latent tuberculosis infection	1–3; 5–8 20–23 25–28
11	Philippines	Theme A: Basic information on latent tuberculosis infection (statement 1, 2 and 3 only) Theme B: Risk factors for latent tuberculosis infection developing into tuberculosis disease Theme C: Bacille Calmette-Guérin (BCG) vaccine Theme D: Latent tuberculosis infection testing and diagnosis (exclude statement 22, similar to statement 19)	1–3 9–14 15–19 20–21; 23
12	Philippines	Theme A: Basic information on latent tuberculosis infection Theme B: Risk factors for latent tuberculosis infection developing into tuberculosis disease Theme E: Treatment for latent tuberculosis infection (exclude statement 25, similar to 3)	1–8 9–14 26–28
13	Philippines	Theme A: Basic information on latent tuberculosis infection (exclude statement 4; similar to statement 19) Theme D: Latent tuberculosis infection testing and diagnosis Theme E: Treatment for latent tuberculosis infection	1–3; 5–8 20–23 25–28
14	Vietnam	Theme A: Basic information on latent tuberculosis infection (statement 1, 2 and 3 only) Theme B: Risk factors for latent tuberculosis infection developing into tuberculosis disease Theme C: Bacille Calmette-Guérin (BCG) vaccine Theme E: Treatment for latent tuberculosis infection	1–3 9–14 15–19 24–28
15	Vietnam	Theme A: Basic information on latent tuberculosis infection Theme D: Latent tuberculosis infection testing and diagnosis Theme E: Treatment for latent tuberculosis infection (exclude statement 25, similar to 3)	1–8 20–23 24; 26–28

List of messages tested

Topic A: Basic information on latent tuberculosis infection

1. Anyone can get TB. TB germs are spread through the air from one person to another.
2. People who are infected with TB but are not sick have a condition called latent TB infection.
3. People with latent TB infection do not feel sick, do not have symptoms, and cannot spread TB germs to others. This is because the TB germs are latent, or inactive, in their body. If their TB germs become active, they can develop TB disease.
4. There are two kinds of tests that are used to detect TB germs in the body: the TB skin test and the TB blood test. A person with latent TB infection has a positive TB skin test or TB blood test.
5. People can have latent TB infection for years or decades before getting sick. Many people who have latent TB infection never develop TB disease.
6. A person with latent TB infection cannot give TB to others.
7. Some people develop TB disease soon (within 2 years) after becoming infected, before their immune system can fight the TB germs. Other people may develop TB disease many years later when their immune system becomes weak for another reason.
8. In the United States, up to 13 million people may have latent TB infection, according to estimates from the U.S. Centers for Disease Control and Prevention (CDC). Without treatment, they are at risk for developing TB disease.
9. One in four people worldwide may be infected with TB.

Topic B: Risk factors for latent tuberculosis infection developing into tuberculosis disease

10. Without treatment, on average 1 in 10 people with latent TB infection will get sick with TB disease in the future. For some people, that risk is much higher.
11. For those with latent TB infection, the risk for getting sick with TB disease is higher for people with HIV, diabetes, other conditions that affect their immune system, or persons receiving immunosuppressive therapy.
12. Some people develop TB disease soon (within 2 years) after becoming infected, before their immune system can fight the TB germs. Other people may get sick years later, even more than 10 years after they were infected, when their immune system becomes weak for another reason. This is known as reactivation of latent TB infection.
13. Most TB disease in the United States is caused by reactivation of latent TB infection.
14. TB disease in the United States is most common among people born in countries where TB disease is more common.
15. CDC estimates that 92% of TB cases among non-U.S.–born persons are caused by reactivation of latent TB infection that was acquired in their home country, years before arrival in the United States.
16. CDC and the U.S. Preventive Services Task Force recommend testing populations that are at increased risk for latent TB infection, including people born in countries where TB disease is common, regardless of how long they have been in the United States.
17. People born in or who frequently travel to countries where TB disease is common include Mexico, the Philippines, Vietnam, India, China, Haiti, and Guatemala, or other countries with high rates of TB disease.

Topic C: Bacille Calmette-Guérin (BCG) vaccine

18. Bacille Calmette-Guérin (BCG) is a vaccine for TB disease. This vaccine is not widely used in the United States, but it is often given to infants and small children in other countries where TB is common.
19. Many people born outside of the U.S. got the BCG vaccine to protect against severe forms of TB as a child. This protection becomes weak over time.
20. People who were vaccinated with BCG can get infected with TB and become sick with TB.
21. There are two kinds of tests that are used to detect TB germs in the body: the TB skin test and TB blood tests. Sometimes the BCG vaccine can cause a positive reaction to a TB skin test, even if the person is not infected with TB germs.
22. TB blood tests, unlike the TB skin test, are not affected by prior BCG vaccination. TB blood tests are the preferred method of TB testing for people who have received the BCG vaccine.

Topic D: Latent tuberculosis infection testing and diagnosis

23. Anyone can get infected with TB germs. However, some people have a higher risk of getting infected with TB germs.
24. People born in or who frequently travel to countries where TB disease is common, including Mexico, the Philippines, Vietnam, India, China, Haiti, and Guatemala, or other countries with high rates of TB disease.
25. People who currently, or used to, live in large group settings, such as homeless shelters or prisons and jails where TB disease is more common.
26. Health care workers and others who work in places at high risk for TB transmission, such as hospitals, homeless shelters, correctional facilities, nursing homes, and residential homes for those with HIV.
27. Someone who has spent time with a person who has infectious TB disease.
28. There are two kinds of tests that are used to detect TB germs in the body: the TB skin test and the TB blood test. The TB skin test requires two visits (one to perform the test and a second for it to be read). The TB blood test requires only a single visit to draw blood.
29. A positive TB skin test or TB blood test only tells that a person has been infected with TB germs. It does not tell whether the person has latent TB infection or has progressed to TB disease. More tests, like a chest x-ray, are needed to rule out TB disease.
30. A diagnosis of latent TB infection is made if a person has a positive TB skin test or TB blood test result and a medical exam does not indicate TB disease.

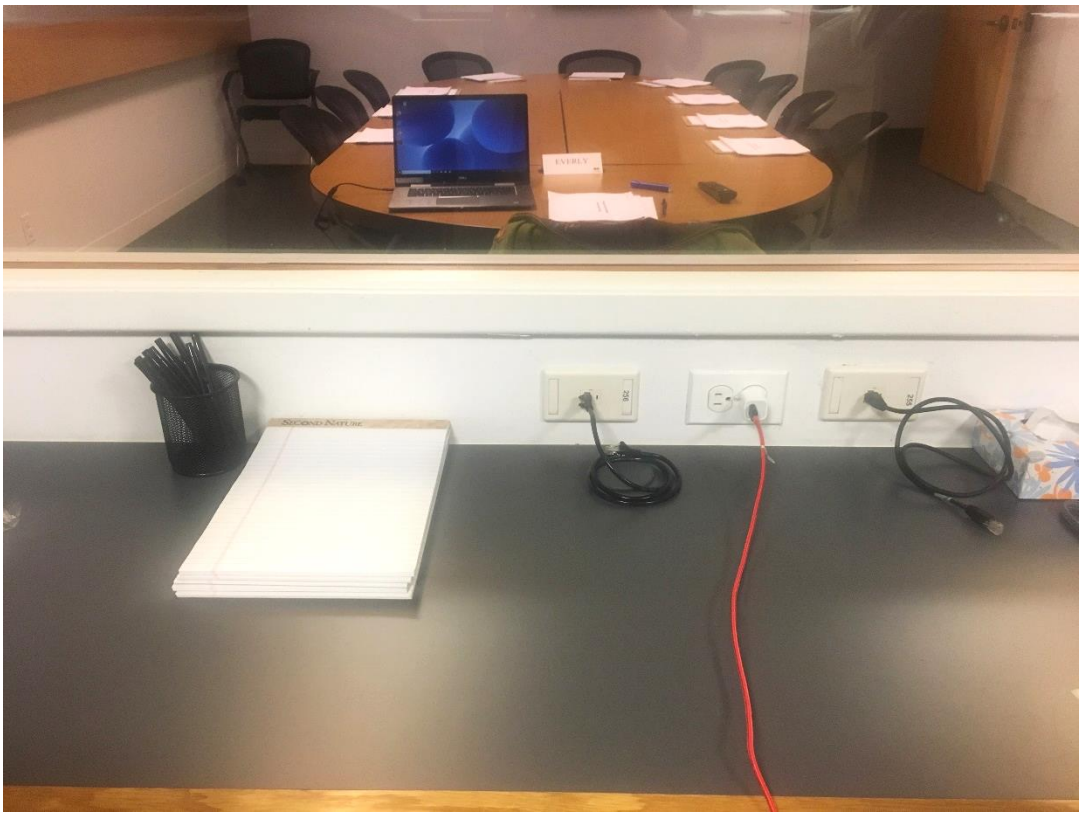
Topic E: Treatment for latent tuberculosis infection

31. People with latent TB infection do not have symptoms, are not sick with TB, and they cannot spread TB germs to others. However, if latent TB germs become active in the body and multiply, the person will go from having latent TB infection to being sick with TB disease. The good news is there are medicines people can take to treat the latent TB infection that will prevent it from developing into TB disease. This is often referred to as treatment for latent TB infection.
32. If you have a positive TB skin test or TB blood test, but do not have any other signs and symptoms of TB disease, you may have latent TB infection. If you have TB infection, you may need medicine to prevent getting TB disease later. This is called treatment for latent TB infection.

33. Treatment for latent TB infection is 90% effective in preventing the development of TB disease.
34. Treatment will help you stay healthy and keep those you love safe from TB.
35. Taking your medications for latent TB infection can prevent you from developing TB disease in the future.
36. Taking TB medication is the only way to kill the TB germs in your body.
37. Treatment for latent TB infection can take 3 to 9 months, depending on the regimen.
38. Most people can take their TB medicine without any problems. However, people respond differently to medications. You could have side effects from the medicine.

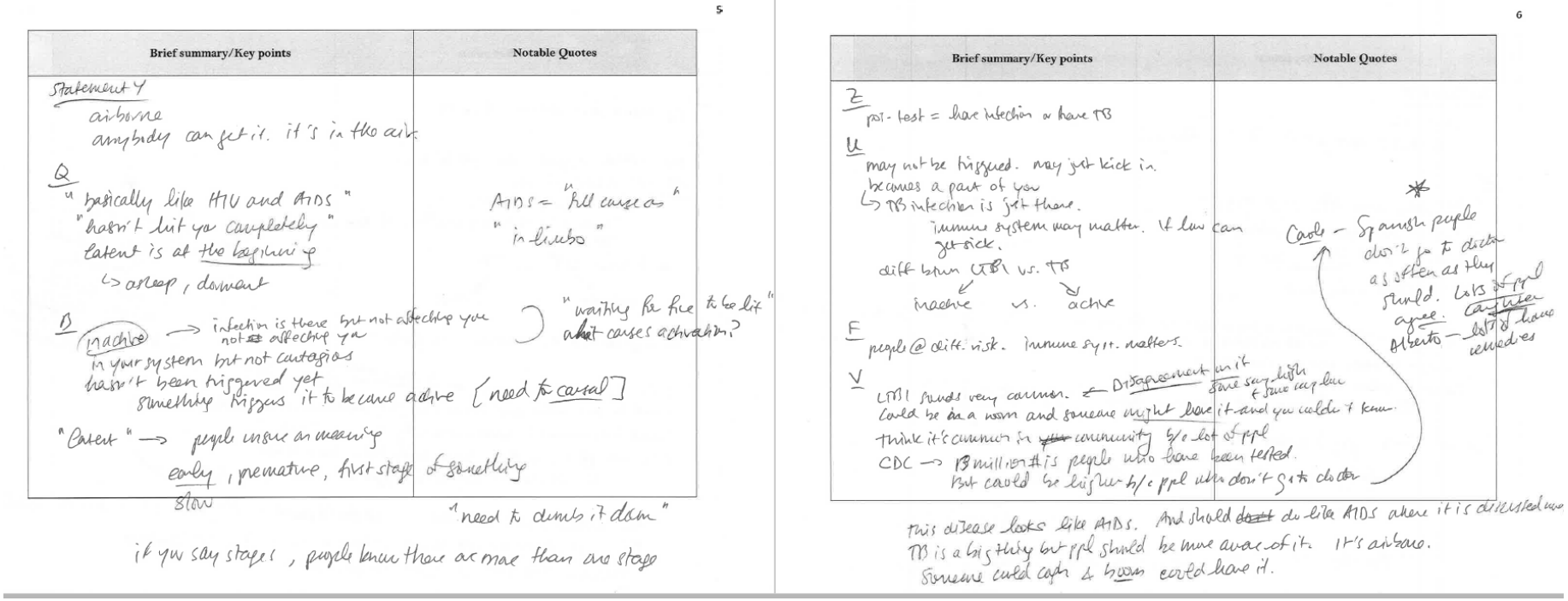
Photos of message testing facilities


Welcome!




TB preventative therapy
for LTBI
• Treatment for TB infection
• Chemoprophylaxis for LTBI

Example fieldnotes



5

Brief summary/Key points	Notable Quotes
Statement Y airborne anybody can get it. it's in the air. Q " basically like HIV and AIDS " " hasn't hit you completely " Latent is at the beginning ↳ asleep, dormant D inactive → infection is there but not affecting you in your system but not contagious hasn't been triggered yet something triggers it to become active [need to consult] "Latent" → people unsure on meaning early, premature, first stage of something slow	AIDS = "kill cause a" " in limbo " " waiting for fire to be lit " what causes activation?

"need to consult it down"

if you say stages, people know there are more than one stage

6

Brief summary/Key points	Notable Quotes
Z pos - test = have infection or have TB U may not be triggered. may just kick in. becomes a part of you ↳ TB infection is just there. immune system may matter. If low can get sick. diff btwn LTBI vs. TB inactive vs. active F people @ diff. risk. Immune syst. matters. V LTBI sounds very common. ← Disagreement on it Could be on a norm and someone might have it and you wouldn't know. think it's common in ~~your~~ community b/c lot of ppl CDC → 13 million # is people who have been tested. But could be higher b/c ppl who don't go to doctor	Carole – Spanish people don't go to doctor as often as they should. Lots of ppl agree. Can't afford Alberto – don't have remedies

this disease looks like AIDS. And should ~~don't~~ do like AIDS where it is discussed more
TB is a big thing but ppl should be more aware of it. It's airborne.
Someone could cough & boom could have it.

Message testing codebook

Name	Definition	Example
1. Believability/ facts	Definition: Apply whenever participants talk about how much they believe a statement or piece of information. This may include statements about "facts," "research," or the "legitimacy" of some source.	"...and it's based on a scientific fact that we are prevalent with TB." "It's better to hear like *who's* doing the study and where are these statistics coming from. Is it just a number that's being pulled or do you have backing as to what you're saying? So, that's -- I think that's important.
2. Carrier	Definition: Apply whenever participants use the language "carry" or "carrier" or a synonym such as "bring" to describe TB/LTBI or other health conditions.	"It's the people who carry the virus, they don't even know."
3. Cause for concern	Definition: Apply whenever participants explain why they are or are not concerned about some health condition. May overlap with severity and risk codes.	"So in a sense I don't worry about it because everybody got vaccinated so what's to worry about, but in another sense you can flip it to say, 'The reason why you have to get vaccinated is because it's actually a problem.'
4. Common - prevalence	Definition: Apply when participants discuss how common they think TB or other health conditions are. This usually came up in response to a specific question.	"I think um I'd say about four people has TB." "Um it's not common because how many people are in the United States? And it says here that it's only 13 million so it's not very common."
5. Contagious	Definition: Apply when participant describes a condition as contagious or not contagious. Whenever concept of contagion comes up (includes words like "spread" or "give").	"It's highly contagious, you can spread it. You have the virus and then develop in your body– but uh and give by will."
6. Country / culture/ government	Definition: Apply when participants name specific countries, talk about stereotypes of people in their country or cultural stereotypes (or larger region e.g., Latin Am) or mention gov entities (local, state, federal).	"I would love to know which countries. Like now I've heard that Philippines is on the list. OK, I didn't know that." "I remember I got tested in Mexico, I think they do it for every little kid. I think they give you like a card that I remember and then they check and they know." "I don't know about you guys, I only know with my family or my friends, but Guatemalans we are really stubborn. So, we -- most of us don't believe in medication because they think that the USA is trying to make money out of you."

Name	Definition	Example
7. Discrimination	Definition: Apply whenever someone explicitly mentions discrimination or says that something would involve negative differential treatment or targeting. This may include people saying something is "offensive" or "racist." Also apply when someone says something is not offensive or discriminatory.	"Birth country sounds a little racist, they can say, 'Well, what's your birth country?' And that can come out as a racist thing you know what I'm saying?"
8. Disease progression	Definition: Apply whenever participants discuss process around moving from LTBI to TB. This may include discussing "stages" or "progression" or "full blown." Exclusions: Do not apply if someone talks about odds about getting LTBI (i.e. just being exposed). The participant has to explicitly mention something about movement from one phase of the condition to the next.	"It's important to get tested to avoid getting a serious disease later on in the future." "*Even* if you have latent it still can develop to TB."
9. Etiology	Definition: Apply when participants describe the causes or causation of any health condition, including TB. Exclusions: Do not apply if participant talks about which countries or groups are at risk. For this apply, risk.	"Hypertension, just the fact of food – the type of food (GROUP LAUGHTER) that you eat. If you love salty food, so yeah." "No, there must be some *reason* for them to get it. I think it's malnutrition, you know, and uh… living conditions."
10. Finding out/ knowing	Definition: Apply whenever participants describe the process for detecting if they or someone else has a health condition. This may include questions about how to find out one's health status. Does not have to be about TB specifically. May overlap with several other codes such as "tests" and "symptoms."	"I would say latent TB infection is usually undetectable." "Maybe you carried it and you don't even know that you have it. You might not have any signs of it."
11. Health comparisons	Definition: Apply whenever someone uses an analogy, metaphor, simile, or makes any type of comparison to make sense of a health condition or process. It can be applied in cases where someone makes a positive or negative comparison (i.e, X is like Y or X is NOT like Y).	"LTBI is like a ticking time bomb" "I feel like even if you go untreated and you have latent, sleeping TB, one in ten is still pretty good odds. Like I feel like I'll get cancer before I get TB."
12. Health requirements	Definition: Apply whenever participants describe health requirements or mandates. This includes discussions of	"When I apply for immigration here, it's a mandatory screening and in China it's a mandatory vaccination and mandatory booster shot."

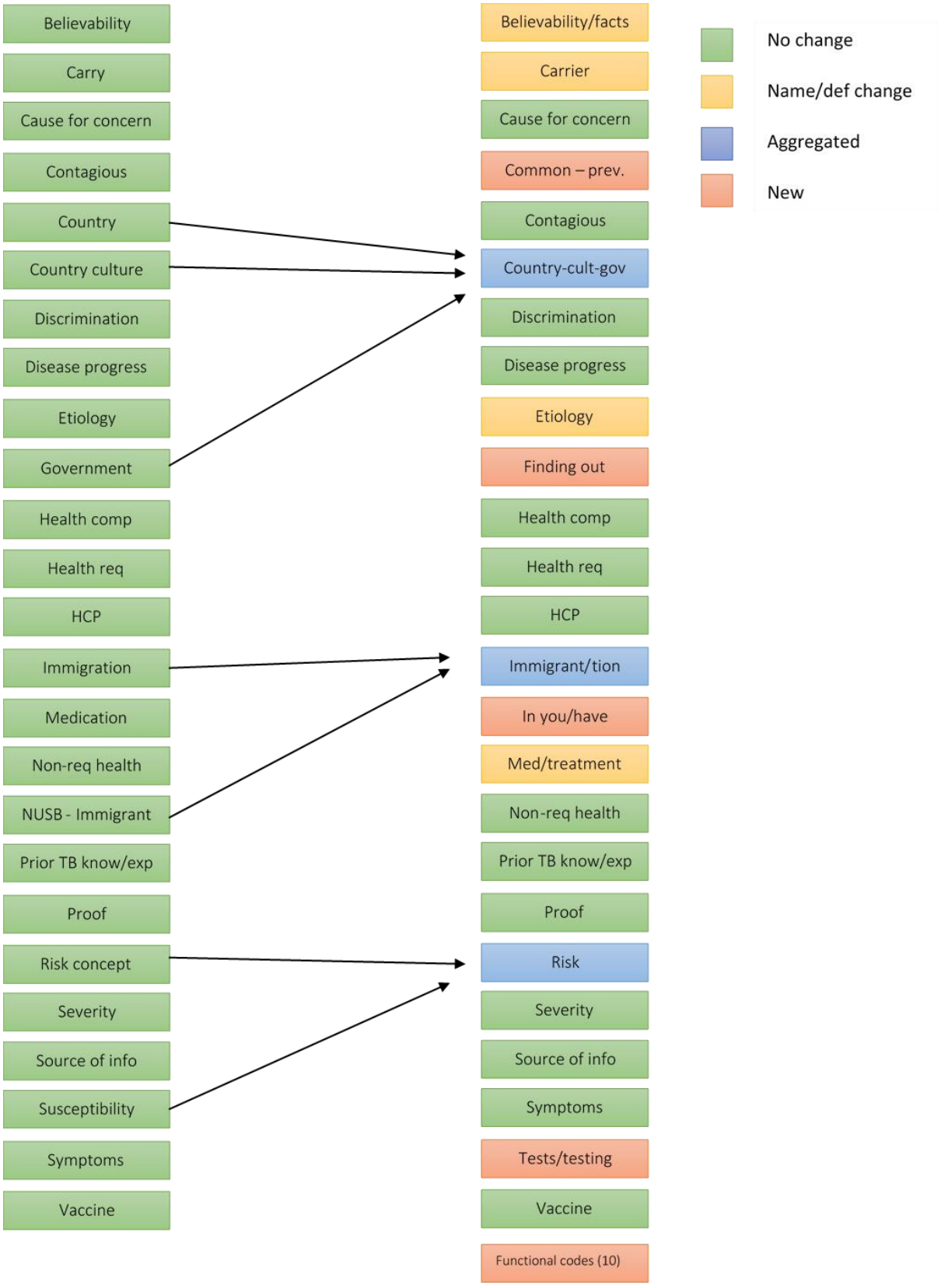
Name	Definition	Example
	required testing and vaccinations for work, school, or immigration.	
13. Healthcare provider	Definition: Apply whenever participants discuss healthcare providers such as doctors, nurses, pharmacists, etc. Can be specific, general, or hypothetical.	"And so I tested positive, and I was asked to go get um – get a test from my doctor for – so then – so I needed clearances from my lungs or something so that I wouldn't transmit it to some – to other people."
14. Immigrant/ Immigration	Definition: Apply whenever participants discuss "immigrants" or "non-USB" or when they describe process of immigration or immigration forms and paperwork.	"There's a lot of things coming out. I don't know if it's from immigrants. They like to blame everything on immigrants." "And now I'm applying for a green card and it's again, you have to get this laundry list of vaccines and TB is one of them. So it just comes up a lot in immigration process."
15. In you/ have/ infected	Definition: Apply when participants talk about the issue of "having" or being "infected" with germs, disease, condition. This often occurs with the verb "to have" but also with language like "in you." Idea of "getting it" or it being "inside of you." Often occurs with "finding out-knowing" code because people are asking questions about whether they "have it."	"Something that doesn't show up but it's in there in your system. That's how I understand it." "You can have TB but you won't necessarily show the symptoms."
16. Medication/ treatment	Definition: Apply whenever participant mentions medication or treatment. Also apply when discussing side effects. May occasionally overlap with "symptoms" and "healthcare provider."	"Yes. Side effects sometimes could be like when it's too much. Just like my mom. She get dizziness so instead of taking it for six months they lower her medication but uh the -- it become 12 months."
17. Non-required health seeking	Definition: Apply whenever participants discuss health seeking behavior (past, current, hypothetical) that is NOT mandated by some entity. Can be preventive or for sick visits. Exclusions: Do not apply if participant discusses required vaccines or medical tests.	"Even though you was vaccinated before as a child, you're supposed to check yourself." "Everyone and anyone can -- should get tested for this disease, not only people born here. They recommend everyone to get tested."
18. Prior TB knowledge & experience	Definition: Apply whenever participants recount prior knowledge or experience of TB (or LTBI). This can include stories, general memories about TB, and factual	"When I was still living in the Philippines. So I heard about it. I learned about it. People talk about it... The first time I heard about it and I can remember, they were saying 'TB.' "

Name	Definition	Example
	information. Also include if someone discusses lack of prior knowledge. Exclusions: Do not apply to generic interpretations of the message.	"He was normally used to a cough all the time. He was sitting isolated in the room separately because our understanding at that time was that it can spread very easily and sometimes he was in a hospital for a long time actually."
19. Proof	Definition: Apply whenever a participant describes having or needing "proof" of health status or TB status specifically.	"Why don't you get a vaccine in China so he can prove to the customs the US custom. Is he can prove that way?" "But on the other side, it says that if you have positive TB skin test, that means, yes, it is proven by whatever test something is there."
20. Risk	Definition: Apply whenever participant discusses susceptibility of getting any disease (not necessarily TB). Can be describing personal risk or risk groups, or questioning risk criteria.	"I mean if you're not .. one of the, if you're not from these countries listed um or have never been there I wouldn't bother … because um… I don't know I don't think it applies to me." "I will probably say older people and younger kids, because their immune systems are not fully functionable and they cannot combat infection. So, that's why they're susceptible."
21. Severity	Definition: Apply when participants discuss the seriousness of a condition (or lack thereof). Exclusion: Do not apply if participant only discusses likelihood of getting condition. For this, apply susceptibility.	Moderator: Does that make you less likely to get treatment because you think it's just too long? Participant.: Heck no. I would take it. It's a disease.
22. Source of health info	Definition: Apply whenever participant talks about where they have or would (not) get health information. Could be describing a specific experience or speaking in the abstract. Applies to the recency of a source (e.g., date of statistics). Will likely overlap with the code "believability" and "healthcare provider."	"The easy one is Google, but then you have to go to the doctor, obviously."
23. Symptoms	Definition: Apply whenever someone talks about symptoms or the lack thereof in relation to any health condition or even in abstract terms. Note that someone does NOT have to mention the word symptoms (although	"I thought you usually cough blood when you have this disease so I was surprised that part was left out."

Name	Definition	Example
	they can), they just need to talk about things that qualify as symptoms.	
24. Tests / testing	Definition: Apply whenever participants discuss medical tests or testing. This does not have to be specific to TB and can even include generic idea of medical testing (e.g., doing blood tests).	"So we were tested for TB you know when we were going to school. So everything was negative, you know?" "I know I --or I remember that, because I had to go-to go in-to go to school, I needed to get an X-ray on my lungs, and then they gave me a shot."
25. Vaccine	Definition: Apply when participant discusses any vaccine, including TB vaccine. Can be about experiences, beliefs, knowledge, etc.	"So when we got it, they just – they probably our family wasn't in-depth of what it detailed, and basically saying they just thought it was some kind of vaccine and we're gonna be OK. And you know our families are, we're kind of naive to a lot of things that are going on, we're not more updated, and we just get the OK, your kids do it and it's safe for them."
Functional codes	*Parent code for organizing nodes that are "functional" such as "good quotes" or codes to find specific sections of the FGD (e.g., question 1, moderator leaves room).*	
26. Closing comments	Definition: Apply to the section after the moderator comes back from the room and asks follow-up questions and/or gives additional information to participants.	
27. Communication preferences	Definition: Apply when participants talk about terminology or formatting preferences (e.g., video, fact sheet).	"I think I use what I said before, dormant TB because I think that brevity is important. I think when these get to be too wordy, I think that people get lost in something they don't understand." "I was also going to say a video but more like a concise three minutes video. There's that information videos, but if there was a fact sheet that's being thrown at me, I'm not reading it."
28. Good quotes		
29. Introductions	Definition: Apply when participants go around the room and say their name and favorite food.	
30. Medical definitions	Definition: Apply when participants give definitions for various medical terms such as latent, risk, vaccination, immune system, symptoms, bacteria, germs, etc.	Moderator: And what does germs mean, anybody? Who wants to define germs quickly? Participant: Bacteria. They're bacteria on your body and they are always there, but they don't react until certain conditions happen.

Name	Definition	Example
31. Moderator leaves room	Definition: Apply to section where moderator is out of the room.	
32. PowerPoint	Definition: Apply to section where moderator goes through PowerPoint slides on TB and LTBI.	
33. Question 1 Health concern	Definition: Apply to the responses to the first substantive question in the FGD, regarding health condition that concerns you and why.	
34. Question 2 Health concern COO	Definition: Apply to the responses to the second substantive question in the FGD, regarding health condition common in home country.	
35. Ranking	Definition: Apply whenever there are ranking questions and responses.	

Visualization of message testing codebook modification



Example message testing structured search and analytical memo

☒ Code "symptoms" across focus groups

- Knowledge of TB centers around the description of the symptoms. People describe the actual symptoms. Just describing coughing, spitting up blood.
    - The way of KNOWING or DEFINING a health condition is through symptoms. That is stripped away in the case of a latent condition. Reduces avenues for detection and comprehension. Becomes less detectable and knowable. Eludes us. Humans against nature. Unable to control if you cannot find/detect.

ADDITIONAL SEARCH TO DO: Do a search on how people described TB at the beginning of the focus group. Is it primarily through description of symptoms? Area afflicted (e.g., lungs).

- Way of distinguishing TB and LTBI
    - Having versus not having symptoms
    - LTBI is "hidden" (therefore unknowable), "unexpressed"
    - Some confusion about whether you have symptoms with LTBI
    - In defining latent, participants tend to emphasize the lack of symptoms. One nice example where they emphasize the issue of appearance, but set this up as DECEPTIVE (almost like a false negative):

> *P1: Latent TB is you don't have any symptom. You feel you are a normal person. But the TB disease, you feel you are sick.*
> ***Moderator: OK Thanks. And Chen, what would you say?***
> *P2: Yeah latent isn't that like uh-- like you're healthy. Looks good.*
> *P3: Looks healthy.*
> *P2: Yeah, looks healthy, yeah. (LAUGHS). But if you have the real TB disease, you get – you get sick. So that's different.*

- Defining symptoms (in abstract)
    - Affects the body
    - Feel it (different from simply affecting the body – something about being cognizant of it).
    - Consequences of a condition (we expect that the condition will make itself known to us!).
    - "Physical manifestation" of the condition (MANIFEST versus HIDDEN).
    - "Medical condition that you have based on the particular disease." Example of a cold, "if you have a runny nose and a cough, then you have a cold." LOGIC OF DEDUCTION.
    - Symptoms separated from the illness (treatment can alleviate symptoms or eliminate the problem itself)
    - "Clues that you have the disease"
    - "Signs that you have something"
    - "Appearance"
    - Issue about EXTERNAL INDICATORS of our INTERNAL STATE. We care about the internal bodily state. Everything else is a proxy. People focused on assumption that a single state exists (ontology) and want to find out best method for discovering this state (epistemology) or wonder whether the state is even knowable. With LTBI we have

limited ways of assessing condition. Symptoms are meant to be external expressions of the internal state. When they fail, tests can help. But tests are also flawed.

- Symptoms as motivation to seek medical care
  - Without symptoms no way to know that there is an issue, or to have a cue to seek medical help.
  - No incentive to get help. Might disincentivize if anything
  - Having symptoms, or seriousness of symptoms, motivation to seek care

- Side effects described as "symptoms" in several groups

- Contrast/juxtaposition between not having symptoms but still having the condition. This is set up as a tension by a lot of the participants.
  - "You don't show the symptoms, **but** you still have it."
  - "You might not have any signs of it, **but** you have it on your system."
  - "Something that doesn't show up, **but** it's *in* there in your system."
  - "You can have TB, **but** you won't necessarily show the symptoms."
  - "Maybe you have the TB, **but** there's no symptoms."

ADDITIONAL SEARCH TO DO: Figure out a way to search for these types of linguistic uses. Maybe do a word search on "but" or "even" as linguistic signals of tension or contrasts. Comes up when people try to define the word "latent.

Example message testing structured searches of linguistic phrases

Infected but no symptoms					
Clause 1	Connector	Clause 2	Group	ID	After which statement
That you're infected	but	you get the **symptoms at a later date** maybe?	GU (1)	Dig	Pre-statement/ what is LTBI
Just dormant or something that's there	but	**doesn't come to the surface** until something happens.	GU (2)	Mar	Post statement B/ define latent
It just means that you get it	but	it's in the **latent** stage. You **don't have the symptoms** for it.	VI (SF)	Ch	Statement Q
If you're latent, you just kind of have this bomb	but	it's **not blowing up** so you're not hurting anybody.	CH (CH)	An	Post-statement P/ discussion
Maybe you have the TB	but	there's **no symptoms**.	CH (NY)	Rh	Pre-statement/ what is LTBI
I think that they're saying that you can have the infection	but	it's not like -- kind of what she said -- it's **not making you sick**.	ME (H 1)	Dia	Statement Q
Latent means you have tested positive	but	you're **not necessarily showing** the symptoms.	IN (NY 1)	Sa	Post-statement U/ diff between LTBI and TB
There can be people who are infected with the virus	but	they **don't show any signs.**	IN (NY 2)	Su	Statement Q
You have it	but	it's **laying dormant** like a volcano.	FI (SF 1)	Mal	Pre-statement/ what is LTBI
It's just kind of somewhat contradicting to me when you say infected	but	then **not sick**. So what does that mean?	FI (SF 1)	Rol	Statement Q
P1: I didn't know you had TB. You had TB? P2: Yeah. Yeah	but	it was **dormant**.	FI (SF 2)	Ce	End of FGD
So, you … (laughs) so you *have* TB	but	it's **not active**.	FI (NY)	Kr	Statement Q
You **don't show signs** that you are a sick	but	then you have the infection.	CH (CH)	Ci	Statement Q
You **don't show** the symptoms	but	you still have it.	FI (SF 1)	Ro	Preferred latent term
You might not have **any signs** of it	but	you have it on your system.	ME (CH)	May	Pre-statement/ how common TB
Something that **doesn't show** up	but	it's *in* there in your system.	IN (NY 1)	Ch	Pre-statement/ what is LTBI
It says that even though your TB don't have any symptoms	but	it could be there, that's what it's trying to say.	IN (CH)	Ni	Statement Q
So you're not sick	but	you have a TB infection. Is it the same thing?	ME (H 2)	Unf	Statement Q

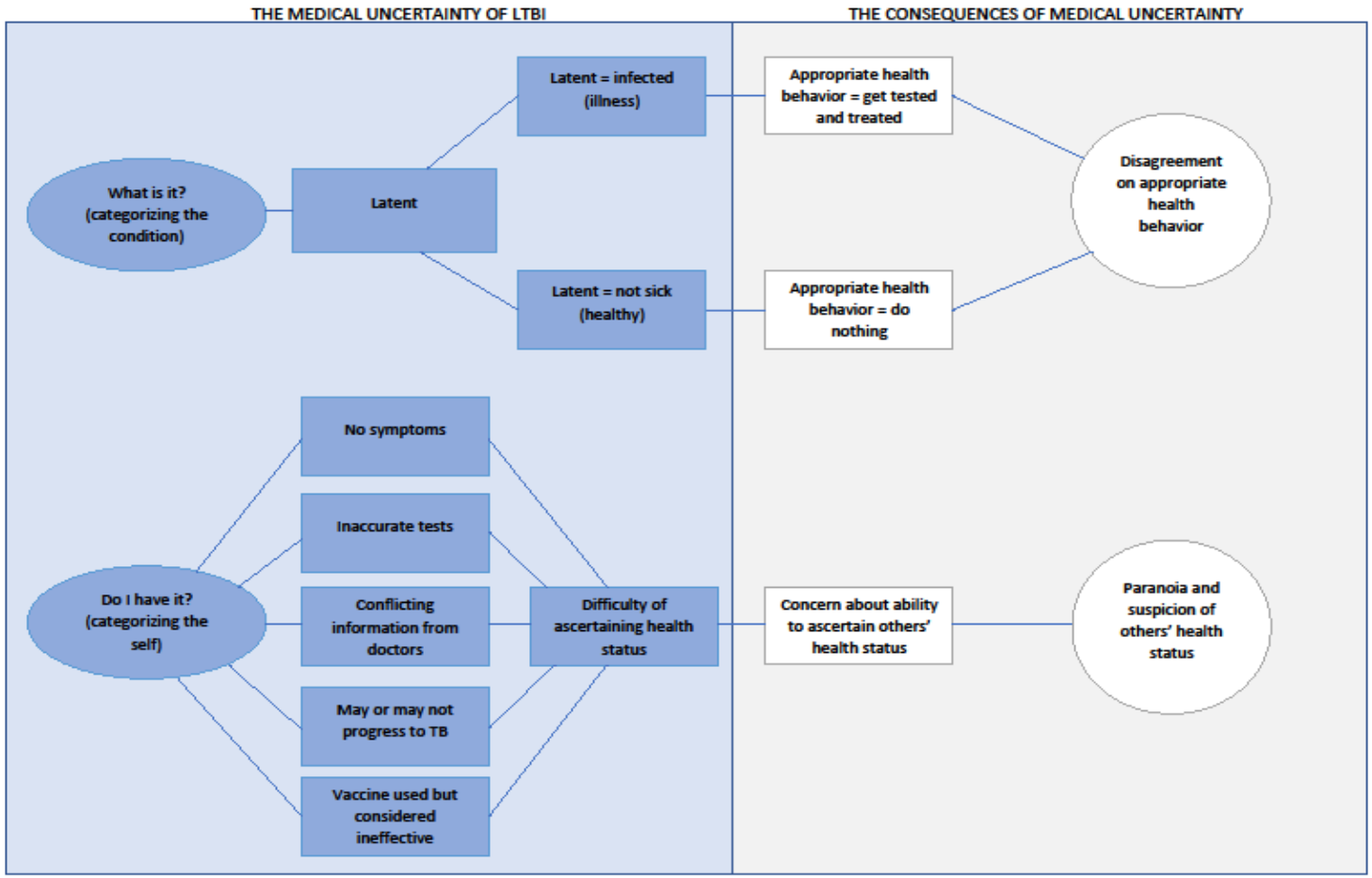
Not the real thing						
Clause 1	Connector	Clause 2	Group		ID	After which statement
Not **actually** have it	but	to be exposed to it	GU (1)		Vi	Pre-statements/ define latent
Somebody develops the **actual** disease	when	it becomes active	GU (2)		Ka	Statement F
So it kind of becomes confusing between having **normal TB**	and	latent TB infection.	IN (CH)		Ne	Post statement J/ discussion of "reactivation"
Just being positive means you're just exposed to it,	but	it **doesn't mean you have it**	VI (SF)		Ch	Pre-statements/ TB knowledge
It's more like exposed to it,	but	it's **not serious**.	VI (SF)		Lu	Pre-statements/ TB knowledge
You have the virus	but	you **don't actually have** the TB	GU (1)		De	Statement Q
Are you asking about the term latent	or	just the **actual** disease?	FI (SF 2)		Br	Post statement V/ how common in your community
They're inactive and only if they get activated	then	you **actually** get the disease	IN (CH)		Ab	Statement B
Because it's latent, it makes it sound	like	it's **not the real** infection	ME (H 1)		Dia	Pre-statements/ define latent
Maybe it [LTBI] is not as strong	as	the **regular** one?	ME (H 2)		Unm	Statement U
Can activate it to make it a disease or	until	it develops to an **actual** TB stage.	ME (H 2)		Cam	Statement B
Latent isn't that like -- like you're healthy. Looks good.	but	if you have the **real** TB disease, you get sick.	CH (NY)		Chn	Post-statement U/ diff between LTBI and TB
It hasn't hit you completely until it's -- I guess TB	then	that's when it's **actually** the infection.	ME (H 1)		Car	Statement Q
Latent looks like it's there -- a condition which can eventually trigger something on the TB	but	it's **actually** not that one.	IN (NY 1)		Pr	Post-statement B/ preferred LTBI terminology
It's a pre-condition. Like **pre**-stages	not	the **late** stage.	IN (NY 2)		Mau	Statement Q
It's not active. That mean you're fine.	Even	if you have **it**, you're okay.	VI (H)		Tw	Post-statement B/define latent

Example message testing analytical matrix

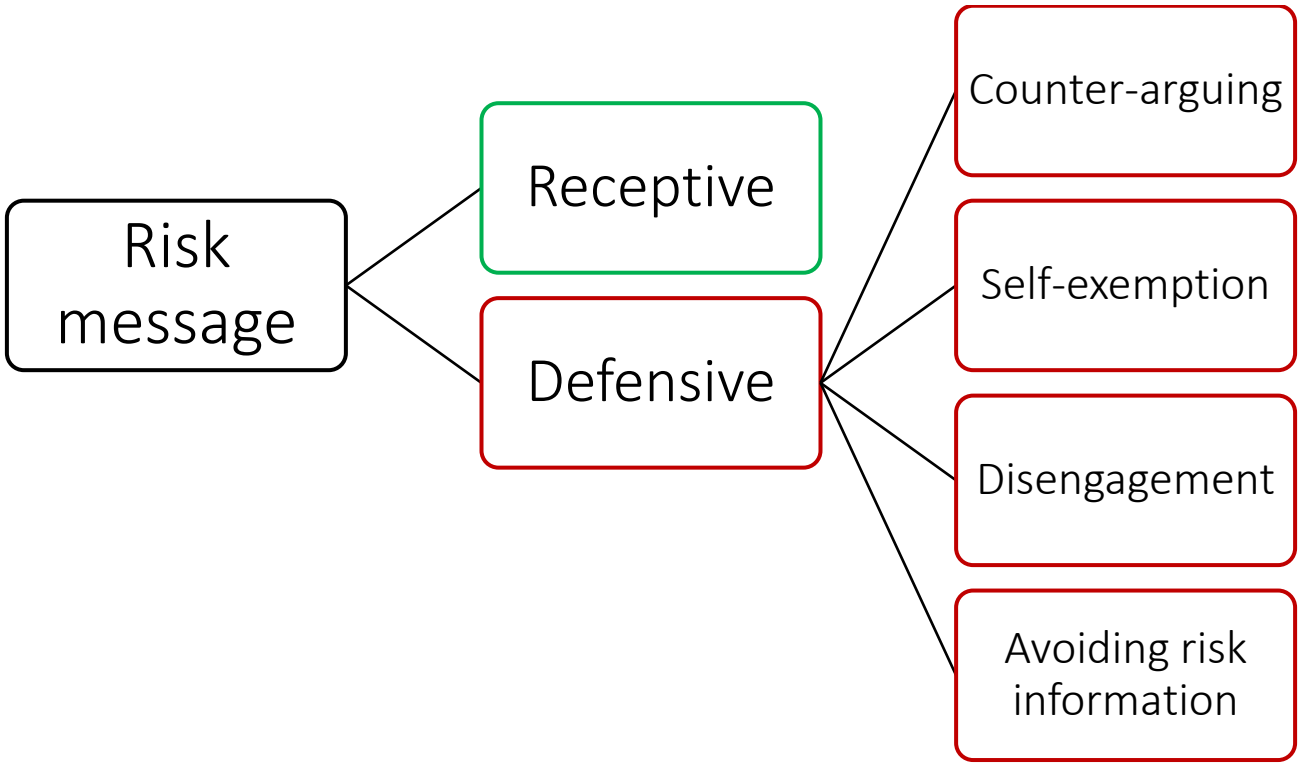
Country as health category Summary: In 9/15 groups, at least one participant asked for clarification on country or made a comment about country in their response to health conditions they were personally concerned about. In 9/15 groups, at least one participant asked for clarification on country or made a comment about country in their response to how common TB is. Detailed quotes are included in the two subsequent boxes.		
	Opening health question – country comment or clarification	*How common is TB – country comment or clarification*
1. Guatemala (1)	(1), One person mentions tapeworm in first question and says it is common in Guatemala. But doesn't ask for clarification on country.	(2) Two people say they don't think it is common in U.S. (don't ask for clarification but volunteer a distinction between countries)
2. Guatemala (2)	(0), No reference to country in opening question.	(0), No one asks for clarification on question or makes any reference to country in their response.
3. Vietnamese (SF)	(2), Two people naturally made comments about conditions that are common in Vietnam or among the "Vietnamese community" – both seemed to be referring to conditions that are common due to cultural traditions (food and food storage). Note – one person did ask for a clarification on the question but it was related to "current or historic."	(3), The entire discussion revolves around country. One person asks for clarification, others give their answer with the specific context of the country.
4. Filipino (SF 1)	(3), First comment out of the gate is about TB being common in the Philippines and Filipinos being more likely to be "exposed" to it. 2 other people make comments about health conditions related to the Philippines – hypertension and mental illness but both sound like they are cultural, former is due to diet and latter is due to not talking about it.	(1), First person to answer says it depends on where you do the survey.
5. Filipino (SF 2)	(2), First comment out of the gate is about TB being common in the Philippines. A second person lists high blood pressure, diabetes, and cancer and then says "those are the three biggest for Filipinos."	(0), No one asks for clarification on question or makes any reference to country in their response.
6. Indian (CH)	(1), First person (Aban) asks for clarification of "in this country or?" Told to focus on U.S.	(1), First person (Nilima) asks for clarification of whether here or in India.
7. Mexican (CH)	(0), No reference to country in opening question.	(0), No one asks for clarification on question or makes any reference to country in their response.

8. Chinese (CH)	(2), Two people (Yang and Ben) mention conditions that are common among Chinese (Lupus and Hep)	(1), One person asks "in the states or in China." Note: Someone else asks for clarification "in their lifetime."
9. Mexican (H 1)	(0), No reference to country in opening question.	(1), Karina makes a comment just before this question about how she is not concerned about TB because it is not common "over here." When moderator asks common question, no one asks for country clarification. However, Karina makes comment that people travel so number could be higher.
10. Mexican (H 2)	(1), One person says they are concerned about diabetes because it is common in the Hispanic community.	(0), No one asks for clarification on question or makes any reference to country in their response.
11. Vietnamese (H)	(0), No reference to country in opening question.	NOTE: Moderator specifies in the question that she is asking about how common TB is in "this country, in the United States." (1), One person still makes a distinction and says her estimate is 70% but she is specifically not talking about "native American people, I mean people like us, immigrants from different country."
12. Indian (NYC 1)	(0), No reference to country in opening question.	(2), One person says Indians have high rate of TB and another asks for clarification if the question is referring to India or US (and then afterwards if it is referring to Indians or Americans, because Indians in American would have higher rates).
13. Indian (NYC 2)	(2), Two people mentioned conditions that are common in India and one of them was TB.	(2), Two people specifically ask whether question is about here or in India. Discussion ensues about TB prevalence in US versus India.
14. Chinese (NYC)	(0), No reference to country in opening question.	(0), However note that moderator asked how many out of 100 in the United States. So there was no need to ask for clarification.
15. Filipino (NYC)	(1), One person says diabetes because Filipinos like rice (cultural as opposed to the country).	(0), No one asks for clarification on question or makes any reference to country in their response.

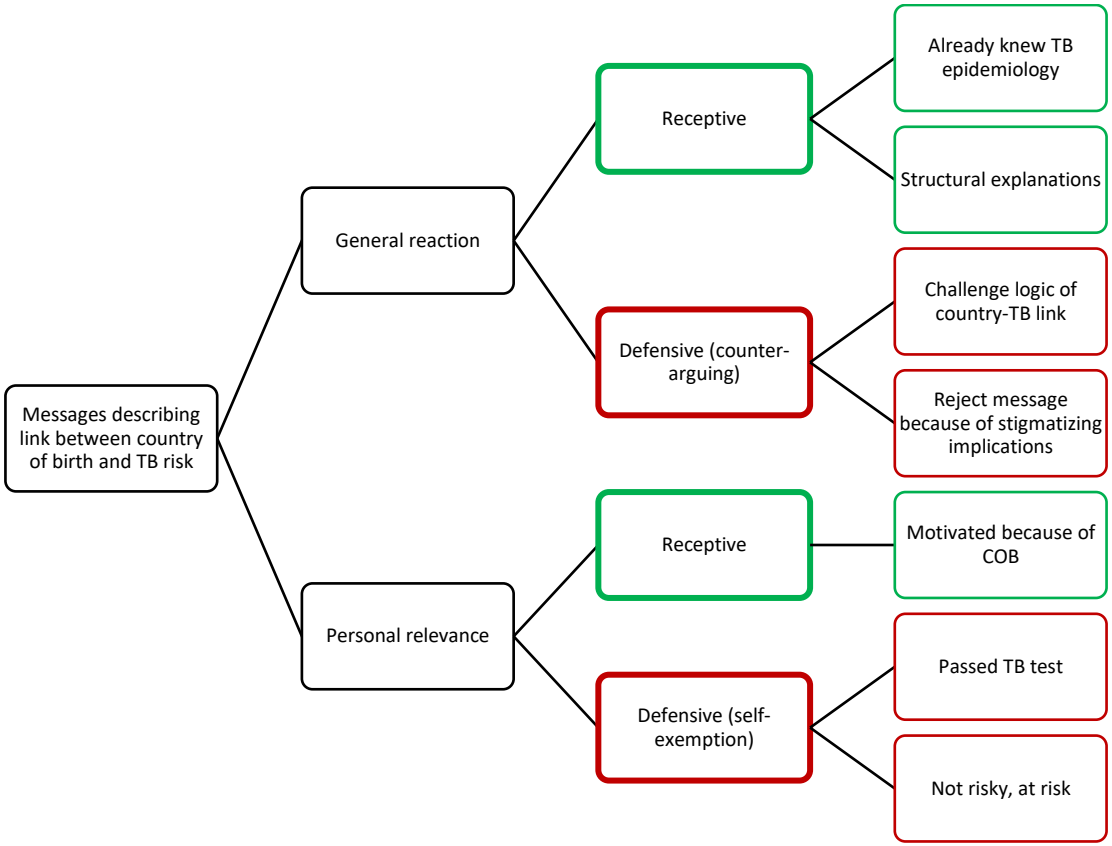
Medical uncertainty theoretical diagram



Defensive processing framework



Defensive processing theoretical diagram



Community health clinic staff interview guide (providers)

DIRECTIONS TO INTERVIEWER:

- ***Directions to interviewer, including scripts to read verbatim, are marked by gray boxes.***
- ***Sections of the guide are marked by black boxes. Each section is given a time estimate.***
- ***Questions are numbered. Some questions include sub-questions. These are marked by letters.***
- ***Probes are listed as "probes" under the questions. They are listed as additional points to bring up if participant gets off track or does not provide a detailed response.***
- ***Words that are italicized are not to be read aloud. All other text should be read aloud.***
- ***TOTAL INTERVIEW TIME IS APPROXIMATELY 30 MINUTES***

INTRODUCTION | 5 MINUTES

Thank you for agreeing to talk with me. Is this still a good time for you? My name is [name of interviewer]. Before we get started with the interview, I would like to go through a brief description of the research project, how the interview will unfold, and how we will use the information that you provide here today.

I've been asked to conduct this interview as part of a larger effort to better understand how community health clinics operate and how they make decisions around testing and treatment of infectious diseases. This study has been commissioned by TBESC, the TB Epidemiological Studies Consortium, which is funded by the Centers for Disease Control and Prevention (CDC). TBESC is particularly interested in latent tuberculosis infection, or LTBI. I will ask you some questions about LTBI and clinic practices. It may have been a while since you last thought about or considered LTBI so don't worry if you're not familiar with the subject.

We are talking to community health providers because you are the best experts on how your clinic operates and you have a deep understanding of what works and doesn't work in your clinic. I am involved in this project because I have expertise in conducting these kinds of interviews. I am not an expert on TB or LTBI, I'm just here to gather your honest opinions and suggestions. I have a series of questions that I would like to ask you, but please feel free to bring up other topics that you think are relevant. I want to emphasize that there are no right or wrong answers. We are simply interested in hearing your honest opinions. If you feel uncomfortable answering a question, you do not have to respond. Your participation in this interview is completely voluntary and you may opt out of participating at any time. That being said, your input is valuable to this research project, and we hope you will share your views with us. The full interview should last about 30 minutes with the option of extending beyond that time if you have additional information you would like to share.

I will be tape-recording the discussion. This is to make sure that the research team does not miss anything that you say here today. The recording will be securely stored and only the research team will have access to its contents. The recordings will be destroyed within 18 months. We will not use your name in conjunction with your statements and it will not appear in any reports. In addition, anything you

say today will not be shared with your supervisor or colleagues. Results shared back with your clinic will be in summary form and detailed statements will not be shared with your clinic. I am going to ask to record our discussion and then ask you to verbally consent to participate. Do you give me permission to begin recording?

BEGIN RECORDING

Now that I have covered the purpose of this interview, how the interview will unfold, and how we will protect your confidentiality, could you please state again for the record whether you are willing to participate in the interview?

WAIT FOR VERBAL CONSENT FROM PARTICIPANT

Thank you. Do you have any questions about the information provided so far?

WAIT FOR RESPONSE FROM PARTICIPANT

OK. Let's get started.

WARM-UP QUESTIONS | 5 MINUTES

READ ALOUD:
There are several sections to this interview. We'll start with a few background questions about you and your clinic. You can be relatively brief in this first section.

1. Let's start by discussing your role at this clinic. What are your primary responsibilities?
2. Now I want to talk about your clinic. Tell me a little about patient demographics and common health problems at your clinic.
   Probe: What would I see if I shadowed you for a week? Ages, socio-economic background, countries of birth, languages
3. Finally, tell me about your last interaction with the health department while working at this clinic.
   a. What might prompt you to collaborate or have contact with the health department?

KEY QUESTIONS | 20 MINUTES

LATENT TUBERCULOSIS INFECTION (LTBI) TESTING & TREATMENT

READ ALOUD:
Now we are going to discuss latent tuberculosis infection or LTBI. As a reminder, we're interested in latent tuberculosis infection, not TB disease.

4. Let's start by discussing you and your experience.
   a. What words or ideas come to mind when you think of latent tuberculosis infection, or LTBI?
   b. Tell me about your experience with LTBI and patients you might think are at high risk for LTBI.
5. When was the last time you tested a patient for LTBI? Tell me about the circumstances.
   Probe: Type of test used or available (i.e. skin test or blood test)
   a. When you have a positive test, how do you respond?
   b. Is there a certain patient scenario in which you would normally test for LTBI?
6. Now I want you to imagine that you have a medical student shadowing you.
   a. What types of recommendations would you give them in terms of testing for LTBI?
   b. What sources would you refer them to for more information?
   c. ***ONLY IF NO MENTION OF CDC***: When was the last time you visited the CDC website for information?

FACT SHEET-READ ALOUD: **I want to turn now to questions around the administrative impact of increasing testing and treatment of latent tuberculosis infection or LTBI at this clinic. First, let me share the definition of LTBI and 3 facts with you, which you may find helpful for our discussion.**

1. ***Fact #1: DEFINITION OF LTBI***
    a. TB bacteria can live in the body without making you sick. This is called latent tuberculosis infection or LTBI.
2. ***Fact #2: NO SYMPTOMS***
    a. People who have LTBI do not feel sick and do not have symptoms. The only sign of LTBI is a positive reaction to a TB skin test (TST) or a TB blood test (IGRA).
3. ***Fact #3: RISK OF TB DISEASE***
    a. Overall, about 5 to 10% of infected persons who do not receive treatment for LTBI will develop TB disease at some point in their lives.
4. ***Fact #4: RISK GROUPS***
    a. In 2017, non-U.S.--born persons were 15 times more likely to have TB than U.S.--born persons.

7. CDC and the U.S. Preventive Services Task Force recommends targeted LTBI testing for certain high-risk groups, in particular non-U.S. born patients.
    a. What are your thoughts on this recommendation?
    b. What would this recommendation mean for your clinic?

BARRIERS & SOLUTIONS

READ ALOUD:
For this next section, we are going to discuss barriers and potential solutions to increasing LTBI testing and treatment at your clinic.

8. I want you to imagine that it's your responsibility to increase LTBI testing at your clinic. Your goal is to test 100% of your high-risk patients.
    a. What would you need to do to accomplish this goal?
    b. What would you worry about getting in the way of accomplishing that goal?
    Probe: Clinic-related barriers? (e.g., time, training, supplies). Patient-related barriers? (e.g., communication, culture, cost).
    c. What are some solutions you think might resolve these issues?

9. Now, imagine that you're doing more testing for LTBI, which means you have several more patients with positive diagnoses.
    a. What would you need to do in order to make it viable for your clinic to treat these patients for LTBI?
    Probe: Clinic-related barriers? (e.g., time, training, supplies). Patient-related barriers? (e.g., communication, culture, cost).
    b. What are some solutions you think might resolve these issues?

CHANGES IN PRACTICE

READ ALOUD:
This last section deals with how changes are implemented at your clinic. We're interested in changes in practice, which could include policies, procedures, or initiatives.

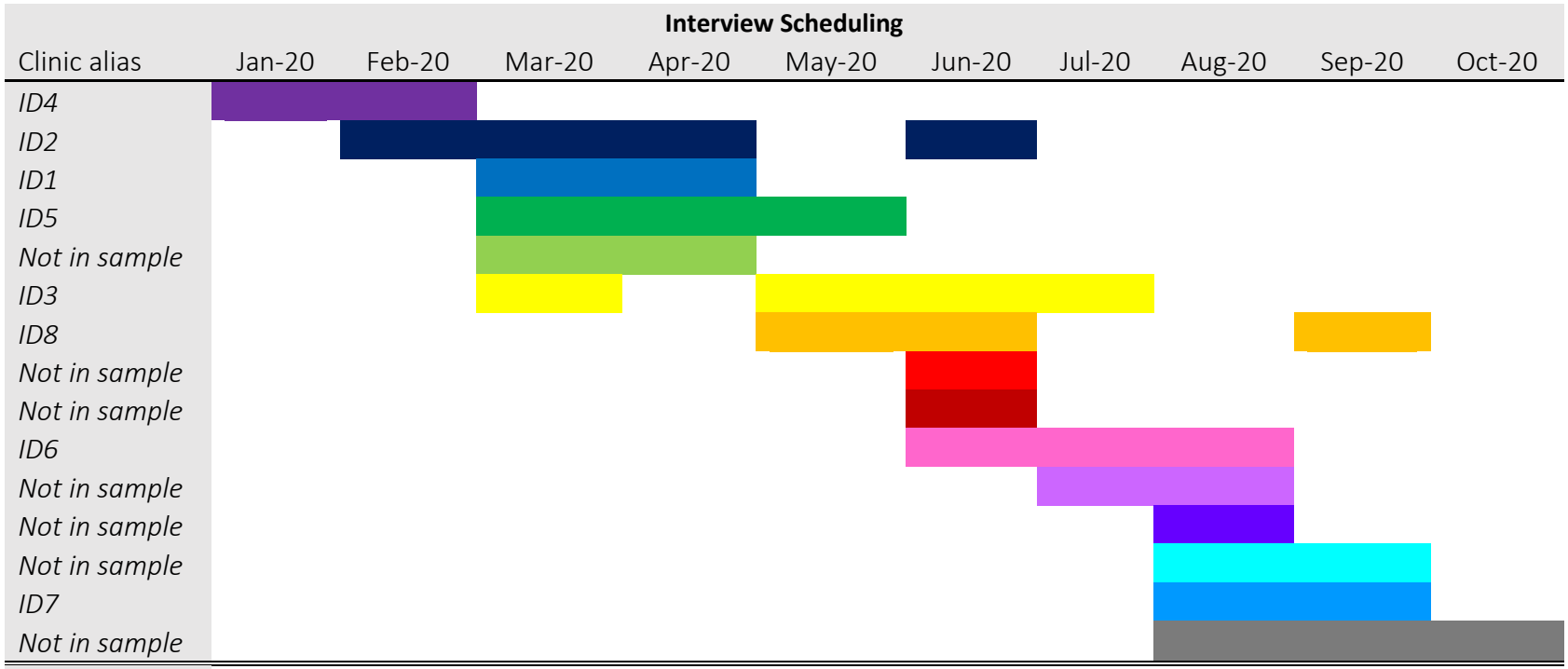
10. Take a moment to think about an example of a change in practice that was successfully implemented at your clinic. It does not have to be about LTBI. In fact, we'd like to hear about a change in practice unrelated to LTBI.
   a. Walk me through what happened.
   b. What caused the change?
   c. What about an unsuccessful change?

CLOSING QUESTION | 1 MINUTE

11. We are at the end of the interview. Is there anything else that you would like to add or anything that you think that we missed?

Thank you!

Visualization of interview schedule



Clinic alias	Jan-20	Feb-20	Mar-20	Apr-20	May-20	Jun-20	Jul-20	Aug-20	Sep-20	Oct-20
Monthly total	4	11	18	9	5	18	5	21	18	5
Total	4	15	33	42	47	65	70	91	109	114

Health department codebook

Name	Definition & Exclusions	Example
	Health department codes	
1. Directly	Definition: Apply when participants use the word "direct" or "directly" to talk about their interactions with the health department. Statements can be made EITHER in the affirmative (e.g., I have worked directly) or the negative (e.g., I have not interacted directly). Exclusions: Do not apply to uses of the word "directly" or "direct" outside of the health department context.	"I do not have much direct interaction with the health department at all." (ID80)
2. They take over	Definition: Apply when participants use language such as "take over" or "hand over" to talk about their interactions with the health department. This is usually said in the context of referring patients to the health department. Statements can be made EITHER in the affirmative (e.g., they take over) or the negative (e.g., they don't take over). Exclusions: Do not apply to uses of these phrases outside of the health department context.	"So, if we can connect the patient to the health department, they kind of take it from there." (ID64)
3. Communication/ feedback from HD	Definition: Apply when participants discuss communication or feedback from the health department. This can be regarding a desire for better communication/feedback or a statement about already having good communication/feedback. Exclusions: Do not apply for statements made outside the context of the health department.	"So even if they go to the Health Department, I wish we would have better communication, better feedback from them." (ID94)
4. Record sharing	Definition: Apply when participants mention sharing of records between the clinic and the health department. This includes records of treatment progress and patient records or files. Sharing can go both ways (HD to clinic or clinic to HD). Exclusions: Do not apply if participant discuss sending a patient to the HD (code: HD referral) or reporting a case (code: HD reporting).	"We contact them to make sure we are connected with the health department and the health department, they send us a report, like x-ray results, the plan of care and the treatment plan." (ID39).

Name	Definition & Exclusions	Example
5. Phone call	Definition: Apply when participants discuss calling the Health Department. This can include references to a phone number, specific calls, generally the idea of calling. This also includes EITHER affirmative (e.g., we call) or negative (e.g., we don't call) statements. Exclusions: Do not apply if participant discusses a phone call outside of HD context.	"We generally call our health department to get more information." (ID44)
6. Fax	Definition: Apply when participants discuss faxing the Health Department. This can include references to specific faxes, or generally the idea of faxing. This also includes EITHER affirmative (e.g., we fax) or negative (e.g., we don't fax) statements. Exclusions: Do not apply if participant discusses faxing outside of HD context.	"There is a designated nurse in our clinic that does all of our reporting to the health department, so basically as a provider I say 'Hey, Mr. Jones, his PPD was 16 millimeters could you please fax over the report to the health department.'" (ID37)
7. HD reporting	Definition: Apply when participants discuss reporting notifiable diseases to the health department. This includes specific references and mentions of the general practice of reporting cases to the HD. It does not have to specifically be about TB. Exclusions: Do not apply if participant talks about reports of information that are not notifiable diseases (e.g., reports on treatment plan). For this apply code "record sharing."	"But we interact with them pretty frequently either for consults for different things or reporting different infectious diseases." (ID23)
8. HD referral	Definition: Apply when participants discuss referring patients to the Health Department for testing or treatment. This includes both for LTBI and TB as well as other conditions if it comes up in context of HD. Apply to general statements as well as specific cases. Exclusions: Do not apply when participants talk about "referring" a medical student to the Health Department for additional information. Referrals must be patient referrals with the idea that the patient would physically go to the HD premise to get tested or treated.	"Okay. So, as it stands, currently we don't treat them here at our clinic. We refer them to the health department." (ID17)
9. Specific HD staff	Definition: Apply when participants mention specific staff working at the Health Department. This can include a reference to an "ID doc," "TB nurse," or a specific name. It can also be implied in the context of someone recalling a specific interaction with a HD staff member. Exclusions: None	"I've had conversations with our Public Health Department, Dr. [name] is a big TB expert here in Seattle at the Public Health Department so I've talked to him about particular cases before." (ID4)

Name	Definition & Exclusions	Example
	Other codes	
10. Keeping care at medical home	Definition: Apply when participants talk about keeping patients in a single medical location. This can include references to the difficulty of referring patients elsewhere (e.g., health department, pharmacy, external lab) or references to the benefits of keeping patients in one location, or with their primary care provider. This code may overlap with follow-up. Exclusions: None	"Or, if they do come back and get it read, and then it's like, "Okay, now you need to go here," it's always, "Okay, I'll get there as soon as I can," as… You know, and it might be… Transportation may be an issue. You know, our patients tend to like a one-shop-stop type thing." (ID102)
11. COVID	Definition: Apply when participants discuss COVID. This can include direct references (COVID, coronavirus) or general statements about the current pandemic or even implied statements (e.g., obviously now we can't see people in person because of what's going on). Exclusions: None.	"So, I mean, so for me, personally, I'm thinking latent TB it's just not that scary. I mean, it's nothing like HIV or even the one that we are having right now for the site, the new novel coronavirus." (ID9)
12. Protocol	Definition: Apply when participants talk about having a protocol. This can be about LTBI, other health conditions, or about protocols in general. Statements can be made EITHER in the affirmative (e.g., we have a protocol) or the negative (e.g., we do not have a protocol). Participants do not have to use the word protocol per se, but could imply it via other synonyms such as "process" or "procedure." Exclusions: None.	"If there is, like a said, a way to have a protocol in place that all patients get this and an order will be placed." (ID52)
13. EMR alert	Definition: Apply when participants talk about having an EMR alert. This can be about LTBI, other health conditions, or about EMR alerts in general. Statements can be made EITHER in the affirmative (e.g., we have an alert) or the negative (e.g., we do not have an alert). Participants do not have to use the word EMR or alert per se, but could imply it via other synonyms such as "EHR" "way to flag," or via brand names of EMR systems (e.g., EPIC). Exclusions: None.	"So I guess if it was up to me, I would, I mean the best thing would be if the EMR would signal it needed to be done." (ID22)
14. Transportation	Definition: Apply when participants talk about patient transportation. Statements can be made EITHER in the affirmative (e.g., they have good transportation) or the negative (e.g., they do not have good transportation). Also apply if participants talk about solutions to transportation barriers. Exclusions: None.	"Because the newly arrived refugees don't have transportation so we have to call a case worker through a third-party agency and try to schedule it with them." (ID45)

Name	Definition & Exclusions	Example
15. Follow-up	Definition: Apply when participants talk about patient follow-up to appointments or no-shows. Statements can be made EITHER in the affirmative (e.g., follow-up is great) or the negative (e.g., patients do not follow-up). Also apply if participants talk about solutions to follow-up barriers. Participants do not have to use the word "follow-up." References to issues with patients not coming to appointments, not responding to calls should be coded with this code. Exclusions: None.	"For our patients, again, the barrier is follow up. A lot of times they don't even follow up for their own doctor's appointments." (ID81)
16. Language and interpretation	Definition: Apply when participants talk about language and interpretation with patients including mentions of translators, patients speaking different languages, or a multi-lingual staff. Statements can be made EITHER in the affirmative (e.g., our staff speak many languages) or the negative (e.g., we face a lot of language barriers with our patients). Also apply if participants talk about solutions to language barriers. Exclusions: Do not apply to discussions of health literacy or not understanding certain medical terms like "latent."	"Oh, because you're trying to get your message across to the interpreter, and they're taking time to kind of figure out how to translate that into the specific language. And then they deliver that to the patient. And sometimes the patient gets confused still, and it's just a constant back and forth at that point." (ID44)
17. Cost	Definition: Apply when participants talk about cost or money, including patient costs or clinic costs. Statements can be made EITHER in the affirmative (e.g., we can cover these costs) or the negative (e.g., cost is a barrier). Also apply if participants talk about solutions to cost barriers. Exclusions: None.	"We're fortunate here that the lab work we do we pay for. The patient doesn't pay for it so I think that's a huge thing that people don't have to pay for the testing." (ID18)
18. Provider/staff education	Definition: Apply when participants talk about provider or other staff education on LTBI/TB. Statements can be made EITHER in the affirmative (e.g., we need education) or the negative (e.g., we don't need education). Exclusions: Do not apply to provider/staff education discussions on non-TB issues.	"I think, I guess for us here, and it's just my belief that as long as we are educated and we know what to do and how to go about it, that would always make the situation easier." (ID102)
19. Competing priorities/limited time	Definition: Apply when participants talk about competing priorities or limited time among providers or other clinic staff. This type of statement is usually made in reference to how addressing LTBI will be difficult given the many other demands on staff time. References to being "busy" or having to address other things first would be coded with this code. Exclusions: None.	"I think one of them is just time. Because sometimes we have so many other things to address with patients that we put the preventative health off to the next visit just to try to address as many of their current concerns as we can. So, I really do think it's just time." (ID54)

Name	Definition & Exclusions	Example
20. Patient education on LTBI	Definition: Apply when participants make explicit references to educational materials or approaches for patients regarding LTBI. Also apply if participant generally discusses how to talk to patient about LTBI, e.g., convincing to take treatment, explaining the test, explaining their risk. Exclusions: Do not apply if participant exclusively discusses patient education related to other health conditions.	"I think patient information, too, how we can encourage patients to get tested and that's very important, so that they won't spread in the community." (ID46)
Functional codes		
21. Question – Last interaction with HD	Definition: Apply systematically to the response to the standard guide question "what was the last interaction you had with the health department as part of your role at this clinic?" Do not apply to the guide question, only the response. Exclusions: Do not apply to any information provided later in the conversation after the guide question. If someone brings up additional information on their interactions, use the appropriate substantive code to capture.	"An interaction? Well I don't know what defines an interaction. We refer patients all the time for screening tests that are offered free through the Health Department. I don't know if that's considered an interaction. And they give us information back about the results of those tests. And besides the people running this study about the TB that's about it." (ID20)
22. Question – LTBI association	Definition: Apply systematically to the response to the standard guide question "what words or ideas come to mind when you heard the word latent tuberculosis infection or LTBI?" Do not apply to the guide question, only the response. Exclusions: Do not apply to any information provided later in the conversation after the guide question. If someone brings up additional information on words or ideas, use the appropriate substantive code to capture.	"Yeah. I think one of the first things that comes to mind for me is that it is likely something that is underdiagnosed, especially in the community that we care for here." (ID16)
23. Question – Hypothetical testing needs	Definition: Apply systematically to the response to the standard guide question "what would you need to increase testing to 100% of your high-risk patients." Do not apply to the guide question, only the response. Exclusions: Do not apply to any information provided later in the conversation after the guide question. If someone brings up additional information, use appropriate substantive codes to capture.	Responses are exceedingly long, no example given.
24. Question – Hypothetical treatment needs	Definition: Apply systematically to the response to the standard guide question "what would you need to increase treatment to 100% of your high-risk patients." Do not apply to the guide question, only the response.	Responses are exceedingly long, no example given.

Name	Definition & Exclusions	Example
	Exclusions: Do not apply to any information provided later in the conversation after the guide question. If someone brings up additional information, use appropriate substantive codes to capture.	
25. Question – change in practice	Definition: Apply systematically to the response to the standard guide question "what is an example of a change in practice that was successfully implemented at your clinic." Do not apply to the guide question, only the response. If the interviewer also has time and asks for a change that was unsuccessful, code that portion as well. Exclusions: Do not apply to any information provided later in the conversation after the guide question. If someone brings up additional information related to changes, use appropriate substantive codes to capture.	Responses are exceedingly long, no example given.
26. Good quotes	Definition: Functional code. Apply to segments that illustrate a point nicely and that might be used in later presentations or manuscripts. Exclusions: None.	N/A

Example health department analytical matrix

Clinic	Leadership (n=18)	Provider (n=34)	Patient services (n=25)
EXAMPLE CLINIC	What's needed for testing scale-up (HD in red): • CEO would need to be on board • Would need a coach • Would need dashboard for tracking • Additional dedicated staff for this work What's needed for treatment scale-up (HD in red): • Approach LTBI treatment as part of a public health problem, go after at-risk groups, would need a community health nurse for this work • Dedicated staff member working on LTBI (and possibly also COVID – thinks these two could be combined) HD quotes: "So, having in each community clinic that focus on certain populations and actually go after them for both vaccination and then screening and advise regarding isolation for patients who turn up positive for COVID-19, that sort of thing is very closely related to taking the results and communicating with patients on what LTBI is, indeed for treatment and even helping deliver the medicines and coach them through completing the treatment course. So, to me, they're way, way in the public health sector and a good nurse or community health nurse would be ideal for this." (ID36)	What's needed for testing scale-up (HD in red): • Access to cheaper tests, ideally QFT was cheaper (x2) • Better follow-up if they continue PPDs • Buy-in from providers • Patient education – reduce fear of knowing a result, fear of TB, educating on difference between LTBI and TB (x2) • System or registry in place to verify who has and has not been tested • More staffing support to implement (x2) • Incorporating screening into nursing intake as part of routine process What's needed for treatment scale-up (HD in red): • Need access to free meds from HD • HD possibly delivering meds to patients at home • Good collaboration with HD, ability to transfer difficult cases • Provider education on best LTBI regimens (x2) – one says from HD • Creating a satellite clinic located closer to patient population • Access to low-cost or free meds HD quotes: "I think that we would need to have a good collaboration with the TB clinic and our health department since, again, they have been the experts and they know how to do this well. That if we have a case that we are concerned about or don't understand or maybe have to change a medication regimen because of side effects then we can consult with them easily. So, I think having experts to consult with or even to potentially transfer cases to." (ID37)	What's needed for testing scale-up (HD in red): • Identify high-risk persons • Additional funding (x2) • Test at more convenient location to patients • More staffing • More supplies • Only do QFT not TST • Patient education on reason for test, available in different languages (x3) • Need protocol, nurse-led What's needed for treatment scale-up (HD in red): • More cooperation, resources from HD • Someone from HD comes to clinic weekly • Resolve communication/ transportation issues with sending patients to HD • Do treatment on site rather than refer out b/c patients more comfortable at clinic • More provider education, maybe HD could provide education • More staffing (x3) • Location where patients could pick up meds closer to home • Time for patient education on RX • Low cost meds HD quotes: "Probably more information because so much of it is deferred to the health department. Our providers probably haven't prescribed anybody a TB treatment regimen since maybe when they were working in India 10 years ago or when they were working in other countries. Because here it is handled by the health department, so meeting with the nurse practitioner at the health department to review the treatment recommendations and guidelines." (ID45)