New Jersey Medical School Global Tuberculosis Institute
May 16, 2013
1:00 pm EST

Slide 1

Rajita Bhavaraju: Good afternoon and welcome to our series of web based seminars on Best
Practices and TB control. Today's seminar will focus on Behavioral and
Social Science: Implications for TB Control. My name is Rajita Bhavaraju
and I'm a Training and Consultation Specialist at the New Jersey Medical
School global Tuberculosis Institute.

Slide 2 Our faculty today are myself, and Dr. Wanda Walton…

Slide 3   As well as Dr. Paul Colson and Dr. Joan Mangan.

Slide 4 Our first speaker is Dr. Wanda Walton. Dr. Walton is the Chief of the
Communications, Education and Behavioral Studies Branch in the Division of
Tuberculosis Elimination at the Centers for Disease Control and Prevention in
Atlanta, Georgia. I'll now turn the program over to her. Wanda …

Wanda Walton: Thanks Rajita. Today I'll be providing an overview of behavioral science and
its role in TB control efforts.

Slide 5 All of us who work in TB can agree with the statement from Rene and Jean
Dubos in 1952, "Tuberculosis is a social disease that presents problems that
transcend the conventional medical approach."

Slide 6 Behavioral science actually had its origin in TB. One of the earliest models
developed to explain health behavior, The Health Belief Model, was
developed in the 1950's to examine motivators to participation in free TB
screening programs, as compared to the factors that lead others not to
participate in these screening programs.

Slide 7 Many factors influence individual behavior including knowledge, attitudes,
self-image, perceived risk, norms, self-efficacy, emotions, social influence
and personal advocacy. Some of these factors have more influence than
others.

1

Slide 8   Generally why should we focus our efforts on behavioral science? We've recognized the limitations of medical technology and improving health in eliminating disease. For example, effective treatment for TB has been available for decades, but we have yet to eliminate this disease. We've also recognized the role of human behavior and health outcomes, with much of the current research focusing on influencers of behavior such as social and cultural connections as well as health systems and public policy.

Slide 9   When trying to understand and create a positive influence on health behavior, behavioral science provides a way to place interaction of health and behavior in a framework, better understand health behaviors, identify potential points for intervention, and influence behavior in a direction that promotes health. Interventions based on health behavior's theories and models are not guaranteed to succeed, but they are more likely to produce desired outcomes.

Slide 10   So why is behavioral science important to TB? Individual behavior, both patient and provider, is a key factor in both preventing and screening TB. Adherence to the lengthy treatment regimens for latent TB infection and disease presents a major challenge for both patients and their healthcare providers, especially acceptance and adherence to lengthy treatment for the asymptomatic condition of latent TB infection increases these challenges.

Slide 11   On an individual basis, social and economic factors such as poverty, homelessness, substance abuse, availability of and accessibility to appropriate care and services and TB knowledge, attitudes and beliefs have a significant impact on the personal TB experience. In addition, TB control efforts are often challenged by the disparities in the communities affected by TB.

Slide 12   The 2000 Institute of Medicine Report on the Elimination of TB in the United States stated, "Studies are needed to determine how basic behavioral theories can enhance understanding for the creation of tailored interventions for high risk populations."

Slide 13   The report called for behavioral science research to explore the impact of behavior change models on health seeking behavior and treatment adherence, identify cultural barriers to prevention, treatment and control as well as the

role of incentives and enablers, tailor adherence intervention to patients' needs, lifestyles, and social support systems and beliefs about health. And ensure translation of research into TB programs.

Slide 14   In follow-up, CDC's Division of Tuberculosis Elimination convened a TB and Social Science Research Forum in December 2003, with over 60 partners and behavioral scientists to identify and prioritize TB behavioral and social science research gaps, guide TB behavioral and social science activities, build and establish partnerships among behavioral and social science researchers focusing on TB and establish ongoing communication among researchers.

Slide 15   So what's happened in the last 10 years? The Division of Tuberculosis Elimination's behavioral and social science research focuses largely on the major behavioral components influencing effective TB prevention and control. Issues including, but not limited to, treatment adherence, care seeking behavior, patient provider communication, perceptions of and ways to enhance effectiveness of contact investigations, factors influencing acceptance of and adherence to latent TB infection treatment and provider behaviors. Much of the research includes or targets pertinent high risk populations such as minorities, foreign-born persons and disenfranchised populations.

Slide 16   Some specific behavioral and social science projects have included developing culturally and linguistically appropriate patient TB education materials, assessing the knowledge, attitudes and culture-specific beliefs about latent TB infection among several high risk groups and identifying barriers to the acceptance, implementation, and adherence to the latent TB infection guidelines and development of strategies to overcome barriers.

Slide 17   It's also included assessing TB knowledge, attitudes, beliefs and practices among private providers serving foreign-born populations, addressing TB among African Americans in the southeast who identify and overcome barriers to treatment adherence for latent TB infection and TB disease and determine the acceptability and usability of interferon gamma release assays as compared with a tuberculosis skin test among patients and providers.

Slide 18	So I go back to my original question of why is behavioral science important to TB. Behavioral and social science research in TB has helped us better understand the behavior of TB patients and contacts, as well as that of providers. Ongoing research is needed to understand the behaviors of both patients and providers, and the impact of their actions on TB-related care seeking, diagnosis, treatment success and prevention.
Slide 19	Today you're going to hear from two researchers who have used behavioral science theories and models to structure and guide TB research. Dr. Paul Colson on using knowledge and attitude variables as predictors and outcomes and Dr. Joan Mangan on identifying salient messages to address BCG vaccine misconceptions. And I'd like to point out both of them use the health belief model that had its origin in TB.
Slide 20	So I thank you for you attendance today and let's hear from our upcoming speakers.
Rajita Bhavaraju:	Thank you so much, Wanda, for that very useful overview of behavioral and social sciences and some of the practical outcomes and projects that have been occurring recently, and as well as the origins of the social and behavioral sciences.
Slide 21	I'd now like to turn the program over to Dr. Paul Colson. Dr. Colson is the Program Director at the Charles P. Felton National Tuberculosis Center, ICAP at the Mailman School of Public Health at Columbia University. Paul, I'll turn the program over to you.
Paul Colson:	Thanks very much, Rajita. I'd like to talk today about some investigations of TB knowledge and attitudes, or K&A, which we've undertaken. The purpose of this inquiry was to better understand what TB and LTBI patients were thinking about TB and its treatment; what they knew, with the goal of improving treatment, adherence and completion.
Slide 22	This is a picture of a shelter I was working in the early '90's, the Fort Washington Men's Shelter in New York City. It's a little out of focus. This picture's gone through several generations, unfortunately, but you get an idea

of what sort of environment this is. This shelter at that time held 1200 men in a single large room. And it's probably pretty clear to this audience what the risks of TB transmission might be in such an environment.

Slide 23   So I became involved while working in the psychiatry program in the shelter. And like many places in the U.S., New York City had seen a growing number of TB cases over the late '80's, and early '90's, with a large concern about TB, with the New York Post famously doing a cover story about catching TB while riding the subway. I was doing a post-doctoral fellowship and I was reading a lot of K&A studies about HIV, but I couldn't find equivalent studies, or many equivalent studies in tuberculosis.

Slide 24   Most of the studies I was able to identify had been conducted in developing countries, often published in the International Journal of TB and Lung Disease. And these studies while interesting, had limited applicability to the United States. They're largely descriptive studies. There were a few domestic K&A studies that were conducted with specific populations. You see on the slide here – drug users, immigrants, homeless. Most of these studies assessed TB knowledge, but did not give attention to attitudes. And probably, more importantly, they tended not to be guided by any sort of theoretical model.

Slide 25   This left me with the situation of having to develop a questionnaire, and the way I did that was through several steps. I initially conducted focus groups with homeless men in that shelter that I showed a pictured of, and also TB and LTBI patients at Harlem Hospital. I developed a first draft of a questionnaire, I tested for face validity with physicians, other researchers and service providers. And then I piloted the questionnaire with target respondents regarding their comprehension of the items, their understanding looking at specific language choices.

Slide 26   So I developed a number of knowledge items, and this is one area actually where I could draw on somewhat from some previous studies, particularly a study of the homeless by Jacqueline Tulsky in San Francisco and a study of injecting drug users by Hannah Wolf here in New York.

Basically I developed true/false items that tested their knowledge of three topics – transmission of TB, how we test and what the testing means for TB, and how it's treated. And you could take you to these items individually to examine it or you could also total up the correct responses to make an overall knowledge score.

Slide 27   Wanda had referred to the Health Belief Model. And I just want to briefly talk about a couple of these theoretical models because, as I said, I think it's important to consider attitudes, and not just knowledge.

Knowledge is just something that obviously we can try kind of improve through health education. What's known about attitudes is a little more murky and what the role of specific attitudes are is still something we need to explore more. But looking at the Health Belief Model. Obviously, here's knowledge under a modifying factor.

The Health Belief Model suggests that something called perceived threat or sometimes also called perceived risk, which is made up of a person's beliefs about their susceptibility to the disease, and how severe the disease is. So obviously one might say well, I could get cold at any time but, you know, colds are a pain but they're not so serious. And so you might feel sort of relatively low perceived risk about colds.

Tuberculosis, HIV obviously, will be a different constellation of the severity of the disease, certainly is more serious disease than a cold. Susceptibility, you may feel as an individual that you're not very susceptible. You're not likely to get TB. So these all go into a person's perceived risk, and also what people weigh in considering health actions is their perceived benefits and what they perceive as barriers.

So these are sort of the intra-psychic factors we're looking at. The Health Belief Model also talked about the cues to action that you see at the bottom box here, which are external factors that induce people to act on their health beliefs. It might be a physician reminding a patient to consistently take the medication. It could be a patient themselves figuring out a strategy – say

6

having their medicines next to the tooth brush so they'll remember to take their medicine at night before going to bed.

Slide 28   Another theory that I tried to use in developing the items was the Theory of Reasoned Action. And this looks a bit more at intra-psychic factors compared to the Health Belief Model. And generally, it suggests that one not only acknowledges how other people view a certain issue but whether you're motivated to follow that norm or to act differently.

So to give a non -TB example: your teenager may realize that you and your immediate family frown upon premarital sex, but he or she goes ahead and does it anyway. Right – they know what the norm is – premarital sex is not good. But for a variety of reasons, they go ahead and do it.

All right, think about LTBI for a minute. Your family's belief system may be that when a doctor prescribes something, you take that medicine. But it might be that you don't see the point. You think it's a hassle of taking a pill everyday and you don't feel sick, so you don't take it. So that's somewhere here in the chart – recognizing what the normative of beliefs are and then what is your motivation to comply, and that leaves to a subjective norm.

In a similar way, you might be a homeless person living in a shelter. And your belief is if you take care of yourself, eat right, get enough sleep, you'll be healthy. But as you look around you, there's other guys in the shelter who are doing the same thing, but they're getting sick with TB. That would have an impact on your behavior, your attitude toward that behavior.

Slide 29   I also looked at a number of other theoretical models. I don't want to suggest that my research has been guided by a single theoretical model. I don't think in TB knowledge and attitudes, we're at that level of understanding about these issues yet. So what I was doing was looking at a variety of theoretical models that might be useful, including the idea of self-efficacy that Albert Bandura put forward.

Self-efficacy is essentially one's belief that you can accomplish a certain thing, and it's due to be an important in HIV but also in tuberculosis. In HIV,

the way it's often expressed is that if you believe you can consistently use condoms, despite having different types of partners, having different kinds of social pressure, perhaps being intoxicated. So – and – or even facing a resistant partner, do you believe you could go ahead and do what you believe is the right thing? That's self-efficacy.

Health locus of control is an interesting concept. It hasn't often played out very well in research studies. That relates to the idea that whether you believe health outcomes are due to your own behavior, your own efforts, in which case you have an internal locus of control, or whether your health outcomes are due to external factors such as your physician or God, or fate. That would be a person that has a strong belief with external locus of control beliefs.

Stigma certainly is a factor that needs to be explored in an infectious disease like tuberculosis. You're probably all aware that tuberculosis is very stigmatized around the world. Acknowledging status is not a very fancy term but I have found in my research that people who simply don't believe that they're infected with TB, you know, that winds up being a major factor, whether they're adherent or whether they can start treatment. And finally, intentions. People have intentions of varying strengths. Some feel say well I'll go ahead and take the medicine as long as, you know, it's easy but when they run into barriers, it goes out the window.

Slide 30   This is a number of studies that my colleagues and I have conducted around tuberculosis knowledge and attitudes. The ones in red are the one's I'll be discussing today.

Slide 31   The first study I'd like to talk about is the initial one I did, when I told you about the formative work in terms of interviewing homeless men. At the HIV Center of Clinical Behavioral Studies in New York where I was doing my post-doc, there were six HIV studies being conducted, and I was able to implement a common questionnaire about tuberculosis knowledge and attitudes across these 848 participants. And in all these cases, data was collected in the same manner, through face-to-face interviews.

Slide 32   People in these studies were all at varying levels of risk of tuberculosis and nobody in this study was being treated for TB or LTBI. Certainly a number of people in these different samples came from poor neighborhoods, came from other countries, live in crowded conditions, particularly a shelter. So as I said, they have varying levels of risk for TB and varying levels of knowledge.

Slide 33   I just wanted to point out some of the major findings. I found significant misconceptions about the casual transmission of TB; people thinking that they could get it on the subway, they could get it from passing a stranger who's coughing. There was a fair amount of confusion with HIV. Many people thought that TB was not curable, as HIV is not curable. Many people thought it could be transmitted through sexual activity, which tuberculosis is not.

And the general confusion about infection versus disease. I know from a variety of other studies that's very common and even among health care professionals, there's often not clarity about the distinction between infection and disease. I did see an association between age and knowledge that the older people have more accurate knowledge about TB, perhaps from being alive longer, perhaps from having known relatives or distant family members who had been treated for TB in the '40's or '50's. Homeless people had more accurate information about testing and treatment something that I attribute to the fact that living in congregate settings like shelters and jails, they were probably approached about getting LTBI treatment.

Slide 34   So now I'd like to talk about another study. And the study I just talked about, the HIV centered study, offered only descriptive findings about the participants' knowledge and attitudes. In this study, I was able to take those descriptive findings from another sample and prepare two groups. And this was a randomized clinical trial that was funded by the National Heart and Lung and Blood Institute, and what you see here is the title and the cite et cetera for where you can find that article. Search it and read it.

Slide 35   The larger study was called the Tuberculosis Adherence Partnership Alliance Study, briefly said TAPAS. 251 patients were receiving treatment for LTBI, two-thirds of which were foreign-born. And all the people who were foreign-born were from TB endemic countries, generally Central and South America,

and a number of people also from Africa. And the reason this is important to look at the foreign-born, is because the foreign born represents 62% of the TB cases in the United States and 73% of people under LTBI treatment in the United States.

Slide 36   So the design of TAPAS was a randomized clinical trial that was testing a peer-based intervention to enhance adherence to LTBI treatment. We looked at knowledge and attitudes at baseline, and the main effect of this study is reported in a separate paper that's under review right now. But what I did was just took the knowledge and attitudes data and compared the U.S. and foreign-born participants.

Slide 37   Briefly, the findings were that like the previous study there were misconceptions particularly around transmitting TB through kissing, and that strangers would be more likely to give TB to you than a family member, which we all know is not true. And that there were not overall differences between the foreign-born and the U.S. born in terms of levels of knowledge.

In terms of attitudes, there were no difference on 10 out of 17 items. The U.S. born participants more likely to acknowledge LTBI, be concerned about the reaction of family and friends, to worry about passing TB germs. Foreign-born were more likely to feel protected, most likely because many of them had received BCG vaccination.

 In terms of their assessment of benefits and barriers, there were not, again overall, larger overall differences. The foreign-born were more likely to be concerned for their family, worried about stigma and defined pill taking difficulties.

Slide 38   I'd like to move to another study. In 2001, the CDC formed the Tuberculosis Epidemiologic Studies Consortium (TBESC). The Consortium had the express purpose of conducting epidemiologic, behavioral, economic and programmatic research in TB and LTBI in the U.S. and Canada. In the Consortium's first 10 year cycle, a number of studies on behavioral focus were conducted and Wanda mentioned several of them in one of her final

slides. I'd like to focus on two TBESC studies in which I was involved, Task Orders 13 and 9. As with the other studies, we examined individual knowledge and attitude items and ran cross tabulations to explore differences across groups.

Slide 39   First to talk about Task Order 13. This included 1,692 people who were offered LTBI treatment in 30 clinics in the U.S. and Canada. When I say offered LTBI treatment, it's important because most LTBI studies simply take a group of patients who have been prescribed, who started LTBI treatment, and then followed them. This study started at the point where people offered treatment and many people refused treatment. And that allowed us to examine that, because people who refused treatment were also interviewed at baseline. So we conducted this study which the slide shows you, examined demographics, life circumstances, knowledge and attitudes, experience with healthcare and clinical characteristics.

Slide 40   What this study allowed us to do, unlike the previous studies, is to use multivariable techniques to look at knowledge and attitudes and other factors against an overall outcome, which in this case is treatment acceptance. And I know this table is maybe a little difficult to read, but let me point out some of the main things.

Again, I'm sure that many people understand the distinction here of being able to run a multivariable equation because that tells you it takes a number of factors which may all be related to each other in various ways and identify the independent contribution of each of these factors to the outcome.

So some of these items here are knowledge and attitudes, and some of them are more circumstantial things, so even healthcare workers, essentially the factors listed up at the top were factors if you look at the adjusted odds ratio column, when it's above one, these are factors that encourage treatment acceptance or are associated with treatment acceptance. Odds ratios below one generally suggest that these are factors that discourage treatment acceptance or led to declining treatment.

11

So people who are healthcare workers would more likely to decline LTBI treatment and non- healthcare workers, if you'd been recommended for treatment in the past, you're more likely to decline again. If you thought that taking medicines would be a problem, you're likely to decline.

Speaking of attitudes, persons who believes they can personally spread TB germs is more likely to accept treatment. That's sort of interesting because we all know that a person with LTBI cannot spread germs, but if you have that false belief, you're more likely to accept treatment.

People with better knowledge, for the most part, are more likely to accept treatment. People who thought that the clinic schedule would not be inconvenient are more likely to accept treatment. And finally in terms acculturation, people with low acculturation, that is people who are more recently arrived in the U.S., who don't speak English as well, were more likely to accept and people who had high acculturation were more likely to decline treatment.

I should just say too this sort of analysis about what's predicting treatment acceptance has been paired also – we have a separate paper using the same techniques to look at treatment completion, that also uses those circumstantial factors and knowledge and attitudes variables.

Slide 41	Finally, I'd like to talk about the paper that we've published from Task Order 9, which was a study of foreign-born TB cases.
Slide 42	1,475 foreign born persons diagnosed with TB in 22 sites. Again, it examines similar factors as you saw in the slide about Task Order 13 with a bit more attention on how people came into care which is a very important issue for the foreign-born both because of the immigration process, and then also what sort of efforts and messages they're given once they're in the United States. Again, there's a particular interest in missed opportunities in that process of considering someone's in the United States and actually come in.
Slide 43	What's a little different about this, I started out with talking about a descriptive study, the HIV Center Study and then the TAPAS study which

compared U.S. and foreign-born, and then Task Order 13 where we predicted treatment outcomes using knowledge, attitudes and other variables. Task Order 9 is different in that it sort of turns it on its head. Instead of trying to use knowledge and attitudes to look at an outcome, we tried to figure out what is predicting knowledge and attitudes.

We did factor analysis of people's responses to knowledge and attitudes items, all some 30 or so items and came up with two factors. One was a knowledge factor and one was a perceived risk for stigma factor. So then we use multivariable techniques to examine what was predicting separately, knowledge and perceived risk for stigma.

Slide 44   Again, one can look at the article to see the elaborate tables, and this is sort of a brief summary of what those tables would tell you. The higher levels of knowledge came from what region of the world one came from, but Mexicans and Latin Americans seem to score higher. People with higher education and higher income also scored higher on TB knowledge Again, these are multivariable techniques so these are independent contributions. You might say people with higher education probably have higher income also. Okay, but in this case we're using multivariable techniques which shows that despite what your income is, if you have higher education, you're more likely to have higher knowledge. Or despite what your education was, if you're at a higher income, you had higher knowledge. Older people had better knowledge. People who are undocumented interestingly enough had better knowledge about TB. People who are BCG vaccinated and people who have more symptoms of TB tend to have better knowledge.

Slide 45   Then the other factor that came out in the factor analysis was this feeling of perceived risk of stigma. Again region of the world was important and Mexicans seems to score the highest on these feelings of perceived risk for stigma. People who are middle aged felt more perceived risk for stigma. People who are more fluent in English, people who had been in the U.S. and Canada for two to three years; where it's kind of interesting – it wasn't the new arrivals who felt more perceived risk for stigma, or the people who have been in here for a long time. It was the people who have been here for a

couple of years. It's kind of hard to understand what that means. Again people with greater number of symptoms, which create more risks. It's understandable. People living in crowded conditions.

Slide 46   I just want to say where we're going with these analyses. There's one more Task Order, 23 from the original ten year cycle that we have data. And that study looked at U.S. born African Americans compared to U.S. born whites with TB. So we're just analyzing that data now Having used sort of a common tool of questionnaire items across these studies that allow me to try to do a comparison across populations, I've seen how people responded to the same item. And a final thing I plan to do is for some of these studies, we measured knowledge and attitudes both at baseline and at ending of treatment, and that would also be another analysis I'd like to undertake is to examine changes in knowledge and attitudes over time. Thank you very much for your attention. I'll turn it over now to Dr. Mangan.

Rajita Bhavaraju: Thank you so much Paul for your wonderful overview of some of the behavioral science theories that you used, as well as your findings and your different studies looking at the knowledge and attitudes about tuberculosis.

Slide 47   I'd like to now turn the program over to our last speaker, Dr. Joan Mangan. Dr. Mangan is a behavioral scientist at the Centers for Disease Control Prevention and Division of Tuberculosis Elimination. Joan, I'll turn it over to you.

Joan Mangan: I'll echo the other speakers and say thank you so much for joining us today. There have been a number of excellent studies that have explored people's knowledge, attitudes and beliefs about tuberculosis, and this has been quite informative for tuberculosis control and I think Dr. Colson's talk really illustrates this for us.

Today I'm going to be sharing the results of a project that my colleagues and I took some findings from other researchers who had looked at KAP and we tried to take it a step further, very much focusing on misconceptions surrounding the BCG vaccine.

14

Slide 48	So for the next twenty minutes, I'm going to outline the impact myths and misconceptions have on TB controls, I'll review some of the misconceptions TB suspects commonly report related to the vaccine and then TB treatment. I'd also like to discuss results from some of these projects where we start to identify effective messages.
Slide 49	The myth and misconceptions surrounding TB are amongst the most effective means for stigmatizing patients, engendering controversy, eroding self-esteem, altering people's behavior, generating mistrust, and creating social outcasts and impoverishment.
Slide 50	If the elimination of tuberculosis is going to be a reality, we must address the myths and misconceptions surrounding TB. A lot of people will talk about, you know, providing this actual information to patients, but why do we care about these myths and misconceptions?
Slide 51	Research had demonstrated that when individuals are provided information that appears inconsistent with existing beliefs or behaviors, there's a dissonance or a conflict that may lead some individuals to either purposely avoid or ignore new information. Some people might downplay the importance of the information, and others might add interpretations that are consistent with existing beliefs, behaviors or personal characteristics. So in essence, they're trying to reconcile some of the old information with new information they're being provided. All of these types of responses can enable biased optimism, or the belief that the person is going to stay well despite their risks.
Slide 52	Let's talk about the misconceptions specifically surrounding the BCG vaccine. Currently, it is the only medically available TB vaccine that has been distributed since the 1920's. And more than three billion individuals have been vaccinated worldwide.
Slide 53	A number of countries employ large scale vaccination campaigns that include the BCG to control infectious diseases. And these campaigns are often supported by mass media promotions that extol the benefits of vaccination and include appeals to parents to ensure their children's health. Whereas these

15

campaigns ensure high vaccination rates, they can also contribute to three common misconceptions.

Slide 54   The BCG vaccine protects a person from becoming sick with TB throughout their entire life. That a positive TB screening test is caused by having been vaccinated with BCG, and not from infection. And if BCG vaccinated, treatment for TB infection is not necessary.

Slide 55   Prior to coming to CDC, colleagues and I wrote a grant and we submitted it. It was funded by the American Lung Association. This grant that my colleagues and I wrote while I was still, before I came to CDC, really the aim of it was to identify the salient messages that were going to help to mitigate some of that dissonance or some of the conflict Hispanic persons may experience relative to having been vaccinated with BCG, and subsequently being informed that they should be tested and/or treated for TB infection.

Slide 56   And we really thought to do this in a very systematic way, and this slide just kind of provides the project to you in a bit of a nutshell. But we did do it in four phases and I'm going to go into these in a little bit more detail. So first we started off by approach providers, and asking them to provide messages to us. My colleagues and I organized these message statements into thematic groups. Then we sought to validate the statements that we had collected, select those that we were going to take forward and test with members of the target audience and then we did two phases of testing.

In the first, we went out and started it off with individuals who had a previous diagnosis of either TB or LTBI. And then we went out with a larger group of Hispanic individuals who had never been diagnosed with TB or LTBI. And then finally, we took our statements and we brought them back together to provide more comprehensive or robust messages and we took these out as well to members of the target audience to solicit their input on these messages. So let me go into a little bit more detail and show you some of the results.

Slide 57   So in that Phase 1, the staff members that we went out and collected messages from – there were a total of 60 staff members. They came from five TB programs including Virginia, Florida, Alabama, South Carolina and Illinois.

And we provided them the three common BCG misperceptions that I had provided earlier, and we asked them to go ahead and write out the messages that they had used to persuade BCG vaccinated TB suspects and contacts to undergo TB testing and treatments. Then my colleagues and I sat down and we did a very systematic analysis of the messages that everyone had provided. And we saw that even though there were three misperceptions, there were a lot of common messages and themes repeated across that the staff had provided to us.

Slide 58   So we turned around and we organized these statements into what we were calling seven thematic groups. And here they are.

The first group we compiled in general why is BCG given, and we saw that some of the messages focused on where the vaccine was used, who is given the vaccine, and why children are given the vaccine. The second set of messages really focused on why BCG helps to decrease the risk of developing severe forms of TB. The third group of messages is why the vaccine is not completely effective and that the protection wanes. The fourth group were message statements that tried to provide evidence of the vaccine's protection waning, and this included discussing things like incidence of TB around the world, testing outcome and the "Clinical Picture," or the signs and symptoms, of illness of people who had been vaccinated. The fifth group focusing on reasons for getting tested for TB, and these message statements talked about the vaccine's limitations, why it was important to know your test results, what a person would gain from being tested and what a person would lose from not being tested. And then finally the last two groups included the testing process itself and test results and treatment. So my colleagues and I when we were going to go forward and start testing the messages, we opted to focus on the first five groups. We did not include the message statements from groups six and seven and this reason was two-fold. First, when we looked at all the message statements we had in the first five groups, there was quite a few of them. And we realized that we were going to go out and do focus groups, it would be a lot of asking people, "What do you think? "Why do you like this? Why don't you like this?" And if you keep doing that over a period of time, people get a little fatigued and we didn't want to get perfunctory responses.

Secondly when we were talking about the testing process, test results and the treatment, that tends to be a little bit more factual, so we opted to focus instead on the first five groups.

Slide 59   In Phase 2, we took these message statements in the first five groups and then we had them reviewed by TB experts. And we went through and we were deleting some messages that could be inaccurate in different contexts. We tried to edit some of the statements to improve their reading ease or their comprehensibility, and a lot of this was taking out some of the very scientific terms and trying to bring in more lay language and then of course establishing the validity of the content of the messages.

At that point then we sat there and we said okay, we've got these messages. Now we need to select which ones are going to go into the testing phase. Then again we were focusing on very accurate statements. We wanted statements that would be representative of other messages in the group and we were using health theories and models to try and help us discern which messages we were going to use. And we focused on three. The Health Belief Model which Dr. Walton and Dr. Colson have already discussed, so I won't go into detail. The Elaboration Likelihood Method, and in this method there's two routes by which you would persuade somebody to take action. The first is the central route, and this is where you're providing information but would kind of cue an individual to use some of their existing knowledge or their existing experiences to evaluate what it is that you're suggesting to them, and then also evaluate the feasibility and the desirability of what you're suggesting. The other is the peripheral route and this is where you really try and cue a person to kind of have a bit of an attitudinal or an emotional response to what is being said. So you might look to cue them to be very excited about something, or very nervous or anxious in order to get them to take action. But the impact of this type of messaging, you typically see to be very short term. It won't take you through a longer period of time.

And then finally we were looking at framing of action. And I'm going to go into a little bit more detail on framing of action because we spent a lot of time really looking at this piece of the messaging. But you can frame things in a

very positive way or a very negative way. You could frame things in a way that you show people what they're going to gain or what they're going to lose. And I'll go into more detail.

Slide 60   Once we had these messages, and we did make our selections, then we wanted to identify which ones were the most persuasive. So as I stated before, we did do some semi-structured interviews. We brought together ten foreign born Hispanic persons who had been diagnosed with either TB disease or latent TB infection. These individuals, most of them when we did interview them, were undergoing therapy at the time.

Out of the 10, 70% were male. They ranged in age from 19 to 71 years and their average age was about 40. Their countries of birth included Cuba, Mexico, Guatemala, Peru and Uruguay. About 30% have resided in the U.S. for more than five years.

We got their feedback. We made a few little tweaks. And then we turned around and we conducted four semi-structured focus group interviews with 43 Hispanic persons who worked with or sought services from a community organization that aimed to assist migrant workers. None of the individuals that we interviewed had a prior diagnosis of TB disease or LTBI from a physician.

And out of these 43 individuals, 75% were female. They ranged in age between 18 and 67 years. Again, the average age was 37.9 years. 60.5% of them had a sixth-grade education or less. And their countries of birth included Mexico, Argentina, Honduras, Puerto Rico, and we did have five individuals who were actually U.S. born, but they had lived and worked in the migrant community their entire lives.

Slide 61   When we got their feedback on which message statements they liked the most, it was very interesting because we were seeing that there was a bit of a pattern. They did prefer messages that were focusing their attention on obtaining a positive result which is coming from the positive action framing. They preferred messages that addressed perceived susceptibility from the Health Belief Model. And they were also preferring messages that were

encouraging them to evaluate the issues by drawing upon their prior experiences and knowledge, which again which is that central route from the Elaboration Likelihood Model.

Slide 62 So once we had their feedback on all of these statements, then we were aiming to turn around and build more comprehensive messages from all these statements together. And there were a number of considerations that went into this.

Slide 63 First off we were looking at the readability. We were really aiming to have message statements that were going to require grade levels between six and seven, and we wanted a Flesch Reading Ease score or 70% or higher meaning approximately 70% of the population would be able to read it pretty easily. We had a lot of debate on using either a long message or short messages, and part of this is based on their experiences going into these focus groups. A lot of the participants really liked seeing all the message statements. They liked that it was very descriptive. They felt it was very informative and they appreciate seeing all the information in context.

But we also appreciate that if we went out with very long messages, this could get a little overwhelming and some people might find them too complex. Less is more. You know, going with the shorter message could be very helpful, but you'll recall at the very beginning I talked about that biased optimism, where people will sometimes try and reconcile old information with new, so if we had too short of a message would people remain unconvinced and still think that they were protected.

We did spend a lot of time again looking at positive and negative frames, gain frames and loss frames and again positive frames and negative frames using either positive words, terms or phrases versus negative words, terms or phrases. And the gain frame verses loss frame, this is where you talk really about the advantages of adhering with whatever the recommendation is versus the disadvantages or the consequences of not following what was being recommended. And this caused us a lot of back and forth conversation amongst the investigators, because why really look at this message framing?

20

Slide 64   It's been long held that framing can lead to different decisions and different behaviors. And here's an example of statements for just taking the LTBI treatments. You know, to sit there and say this is positively framed or gain framed, you say "Get the best cure available and stay healthy. Take the LTBI treatment." Versus the more negatively framed statement which would be something more along the lines of, "Don't get sick with a disease that can kill you. Take the LTBI treatment."

Slide 65   And the other reason that we were really going back and forth, back and forth on this positive versus negative framing was there's been a number of papers looking at this issue and Rothman and Salovey in 1997 did a review of a number of studies, and they came forward with recommendations after reviewing other people's work that said, if whatever you're advocating is prevention- oriented such as LTBI treatment, you're better served by a positively framed message, whereas if you are doing something that's detection oriented such as testing for TB infection, again this is better promoted by a negatively framed message. So we're trying to convince people to do both when you're going out and doing those contact investigations.

Slide 66   After much deliberation, my colleagues and I decided that we were going to go forward and we were going to test four messages total. We were going to use a long comprehensive message to appeal to the people who like the information in context, and to create this message we were using those statements that earned the most votes in each of the five thematic groups, and that we were really aiming to get both positively and negatively frame statements represented.

And then in the short messages and we call these "B", "C" and "D." Message B was primarily negatively framed. Message C was primarily positively framed and Message D was a combination of both positively and negatively framed statements.

Slide 67   I'd like to share a little of the feedback that when we went back out and we tested these messages with you.

Slide 68   We had a total of eight individuals where we sat down and we did one-on-one in-depth interviews. These individuals were recruited during a community-based organization again that served migrant workers. None of them have been diagnosed with TB or LTBI prior to the interview. Most had been vaccinated with BCG as a child. 75% were able to say yes they were. One person was unsure and one person reported that they had not been vaccinated, and actually they had been born in the United States.

The gender of the group, it was 25% male versus 75% female. Age range again was 27 to 56 with an average of 35.9. 38% of the group has a sixth-grade education or less. The majority had resided in the U.S. for more than five years, and again the countries of birth represented were Mexico, Honduras and the one individual who had been born in the U.S. and had been back and forth.

Slide 69   So let's talk a little bit about that long message. This was composed of 13 sentences, which could be a very, very long message so we envisioned, you know, perhaps this could be something that would be put into a brochure. It could form some scripts for some video or some public service announcement or it could kind of provide a script for somebody who's going to go in and have a conversation with patients. When we did the readability calculation, the English version of it was coming in with a grade level between 6 and 7 and the English version again, if we did the Flesch-Kincaid reading score, it came in as fairly easy. It scored a 74.9, so again, approximately 75% of the population should be able to read this.

When we took the Spanish version of the message in through the readability calculations, the Fernandez-Huerta score is very similar to the Flesch-Kincaid. This scored a 93, so it was considered very easy. These 13 sentences that made up the long message, we sat down with the interviewee, presented them as six message statements, and had a lot of discussion on what do you like about it, what don't you like about it and asked them to sit there after going through each of the statements and discussing them going through the entire message and asking people, you know, go ahead and tell me the message back in your own terms.

Slide 70   So this is long Message A and again, like I said, this would serve more as a script. BCG is used countries where many people are sick with tuberculosis. Small children have an immature immune system. Because they may be exposed to persons to TB, the vaccine is given to babies and small children. Many people think the BCG vaccine will protect them from TB for their entire life, however the vaccine does not always prevent tuberculosis.

If a person breathes in TB germs, the vaccine helps to lower the chance that the person will develop severe forms of TB or die from TB. The people who have had the BCG vaccine can still get sick from tuberculosis. We have tested other people in your country who are given the vaccine and their tests were negative. This shows that your positive test is probably the result of contact with a person who is sick with TB disease and not from the vaccine. Do not take a chance with your health. If the tests show the TB germs are in your body, take the treatment because TB can kill you. With no treatment, you can get sick and spread TB germs to your family and friends. Get treated, stay healthy and keep those you love safe from TB.

And you see in this slide that some of the text is in blue and some of it is in bolded black font. The text that's in bolded black font, when we read the entire message to the participants and we said, you know, tell us in your own words this statement – what you're getting from this. 50% or more of the participants reiterated the concepts in these statements back to us. So again these are part of the most salient pieces of this message that immediately people were able to reiterate for us.

Slide 71   When we asked the participants to report their thoughts as they listened to Message A, half of the participants indicated that they had contemplated their own or family members' susceptibility to TB, again going back to that Health Belief Model. Others discussed an increase in perception of the disease's severity. Again, this is Health Belief Model. Some had expressed the belief that when they immigrated to the U.S., they had left the problem of TB behind in their country of birth and this is going to the Elaboration Likelihood Model where you use that central route. You get people to kind of reflect back on their own knowledge and experiences.

23

Slide 72   When we asked the participants what information needed to be clarified in this message, or what information should be added, it was interesting. One of the individuals came back and asked us if we could define an immature immune system, and my colleagues and I, we really had a lot of debate whether we should even keep that sentence in the long message, but when we had gone through the focus group with 53 individuals, this is the message that had risen to the top and had elicited a lot of votes, so we did. And out of this group, we did have someone who asked us to define that.

One person asked us to explain whether a person with LTBI could infect others. Two of the participants wanted there to be an explanation of how TB germs get into the air. One participant asked us to explain who's at that greater risk for becoming sick with TB disease and then we also had a participant who had asked us to explain the difference between the vaccine and the test. And it was interesting to see this come back out to us in this round of focus groups because we had heard this before when we were initially testing the initial message statements, because it was repeated to us on a number of occasions. People perceive the TST test to either be a treatment in of itself or to be a booster vaccination.

Slide 73   When we asked participants to state what they liked best about the messages, there were three things that came out of this conversation. First, the participants like the explanation that the vaccine lowers the person's chance of developing severe forms of TB if the germs are inhaled. They appreciated the advice that a person not take a chance with their health and they also appreciated the encouragement to take treatment to protect a loved one.

Slide 74   After having these conversations regarding the long message, then we sat there and we started to review the short messages with the participants. And again you see the types of messaging that we used. Each of the statements, each in the short statements, were read and discussed and then the participants were asked to select the messages that they liked best. And out of the group, one participant liked B the best, the negatively framed, three liked C, which was the positively framed, three liked D, which included both positive and negatively framed and one person reported that they liked D but that they

24

better understood C. Then after they told us which one they liked, we took that selected message and we discussed it further.

Slide 75   And because of time constraints I'm not going to go into a lot of information in here, but I am going to share at least Message C with you and you can see the readability scores on this again. And this message was, "We still have a lot of TB disease in the world. Most of the TB is found in countries that use the BCG vaccine. If the vaccine protects a person for life, tuberculosis would not be a problem in the world. Knowledge is power and we can protect ourselves from disease. Knowing the protection from the vaccine wears off, it is important to be tested for TB. Find out if the TB germs are in your body and if you need medicine. If your tests show germs are in your body, you need to be treated. Treatment will help you to stay healthy and keep those you love safe from tuberculosis."

You can see the first two statements there. Again, looking at that Elaboration Likelihood Model, where it's the central route where you ask people think about, you know, you already have knowledge. You already have experience and those first two statements are tapping into that to get the person to really evaluate the situation.

Slide 76   I am going to share with you some of the take home lessons that we took out of this project. The positive and gain frame messages certainly worked a little bit better, and this is consistent with some of the other literature that's out there that says if you use the negative, again, you get a short term effect. You might get people to do something immediately, but it doesn't always carry through. You know, that fear, that anxiety, it doesn't carry through something like nine months of INH treatment. People appreciated statements that were illustrating their personal susceptibility such as how people are affected and who is at higher risk for infectious disease. People appreciated statements that were going to encourage them, again, to evaluate based on their prior knowledge.

Slide 77   Also, it was important to check for some cognitive dissonance. This is where you would, as a provider in a clinic, ask patients to repeat information back in

their own words, or invite them to talk about what the provided information means to them. We saw this come out quite frequently as we were doing our interviews where people still even after they have been exposed to all of these message statements, we still got a couple in the crowd that would go back and try and reconcile from the old information in with the new. We'd strongly encourage you to always, always check for that cognitive dissonance.

Slide 78   Finally, explain the difference between the BCG vaccine and the TST Test. As I said before we were hearing, quite frequently, that people thought that this was a treatment or a revaccination. Always be mindful of the literacy demand. And then that systematic process for health education. Whatever you're going to do is so important. It helps us and we recognize even with these messages we were so systematic, that they could probably do with a little bit more refinement.

Slide 79   This project was quite labor intensive and there are so many people to thank. I've got them listed here, but I just want to acknowledge my co- investigators, Dr. Galindo, Dr. Irani at the University of Florida; and certainly Dr. Wanda Walton and Amera Kahn because once I came here to CDC, they were very supportive of this work.

Slide 80   Thank you very much.

Rajita Bhavaraju: Thank you so much Joan for that great overview of how you use the behavioral sciences as well as the theories that we've already discussed to develop your message points and sort of retest them.

Slide 81   We now have some time for discussion with all of the presenters. I'm going to start with the first question, and the question actually can go out to all three of you. It was a good question about whether, you know of , studies or the work being done on looking at the differences in gender and attitudes related to women and men getting TB and any studies that have been done or any work's that's been called out to do that. And I'll send that out to any of the presenters.

Wanda Walton: Rajita, this is Wanda. I know, we haven't had so much in the United States of this, but I know there are a number of other countries that have done this. And that's, the one of it is that's based on the fact that in other countries based on the country, it's who is getting the disease. I was a reviewer on a paper regarding a study that was done in Pakistan, and I believe in that country the majority of the people with TB were women. And so they were looking at those aspects and focusing on that population. I don't know of any really in the United States. Paul, do you know of any?

Paul Colson: I'm not sure with anybody looking at differences in those attitudes across gender. Certainly the epidemiology, you're right, Wanda. In different countries like in South Africa TB is mostly in men and then often in miners and people working in sort of congregate settings like mines. But I'm not aware of studies that have looked at differences in gender.

Rajita Bhavaraju: Thank you. I know that there have been some as Wanda mentioned internationally. Paul, well you've mentioned that to actually disaggregate some of the data and actually look at those gender differences with data that already exists. So I think there's been a lot of work done in calling to, to actually look at some of those differences. And so, I think you're right. I think research has been done in that area. Joan, a question came through about the use of interpreters for your focus groups in your interviews and perhaps how that might have affected responses that came through in terms of your discussion with them?

Joan Mangan: There were no interpreters used because the investigators were actually bilingual. We recorded all of the interviews, and we did have an individual who was a native Spanish speaker who transcribed all of the interviews and then they were translated into English and the translation was checked by one of the other investigators so that Tracy Irani and I who are not as fluent in Spanish were able to sit there and look at the data. So no we do not require interpreters. All interviews were conducted in Spanish.

Rajita Bhavaraju: Thank you for that clarification. I'm wondering from a practical standpoint looking at the National TB Indicator's project, there's a number of variables and benchmarks which are being used to evaluate programs. And I'm

wondering how some of the work you talked about in the behavioral health sciences can be used, how programs can use them, to evaluate some of the outcomes and things that they're trying to increase their quality and so for things like completion of therapy or getting contacts examined. What are some of the things that perhaps can be done, or perhaps have been done and I know Wanda, you did mention some examples of some studies that are being already done.

Wanda Walton: The main focus of any of this research is to inform interventions. So those interventions could be change in practice. It could be change in guidelines. It could be change or development of educational materials or training courses. So, we, behavioral science, you know, we have people who, their primary focus is behavioral science but we also have many health educators who are working in TB who utilize both behavioral science in their research following the systematic process as well as the development of those interventions or education materials. Materials that are coming out of CDC Division of Tuberculosis Elimination, all of our materials that we have, educational materials, have utilized behavioral research that has been going on. And I know the Regional Training and Medical Consultation Centers are doing the same thing. Whenever they do the systematic process they're actually looking at the needs for the target audience, and then testing the materials and interventions with patients and provider groups. All of these things work together and on many of us sit on the groups that work to develop new guidelines and new interventions. All of us have well integrated ourselves into how we can influence the practice and help people in their day-to-day activities in TB control programs.

Rajita Bhavaraju: Thank you, Wanda, for that explanation in terms of how the research is being used on a more practical level.

Paul Colson: Can I just add one thing? And this is not directly responsive to what Wanda is saying. I think her Branch is doing some great stuff. I guess one thing as a take home message I'd like to say to people, is think of health education as a conversation, not a lecture. I mean too often I see health educators who just talk at patients and there's a lot of important information to share certainly

28

but, you know, given some of the factors we've talked about, the feelings of perceived susceptibility and what people know from their home countries, you really have to be a give and take back and forth, and you have to explore with people what is hard about this. Or what don't you understand or what do you think will be difficult about doing the treatments? It's more sort of moving to counseling than lecturing.

Rajita Bhavaraju: That's a great point and actually another question actually just came in about how to deal with persons who are taking treatment for latent TB infection who may not want to take that treatment because they would rather use alcohol to excess – and I think your point is well taken that it should be more of a counseling approach as opposed to a lecturing approach. I think that answers that question actually quite nicely.

There was a question related to whether studies have been done related to access to TB treatment and care comparing foreign-born persons versus a refugee population or a newly arrived immigrant population. And if there haven't been studies done, how might a program maybe perhaps look at differences in access to treatment or how people are accessing treatment?

Wanda Walton: Yes there is, and actually one of the Task Orders and I think it may be Task Order 23 for the TB Epi Studies Consortium. And they were looking at the differences with foreign-born populations and trying to look at their access to care, what are the barriers to care and what are some things that will enhance peoples' health seeing behavior.

Paul Colson: I could just join in there. You're technically right. That was Task Order 9. Task Order 23 uses a very similar questionnaire though so for both of those studies there is a fair amount of attention given to how people access care and what is their health-seeking process. Because I know anecdotally we did a study in Harlem where we did qualitative interviews with people about what happens from the time they didn't feel well until they were finally diagnosed with TB and, you know, you get stories about people going to pharmacists and pharmacists giving them Nyquil and Robitussin and things like that. And even doctors often misdiagnose TB, so it's an interesting process.

And those two studies look carefully at whether people went to a doctor or whether they went to a pharmacist or whether they went to a healer in their community, you know someone who represents the traditions of medicine in different ethnic groups, or whether they went to a clergy person. That is something we still have to take a close look at and make those results available.

Rajita Bhavaraju: Thank you so much. Joan, a question for you regarding the readability tests. You extensively talked a bit about how you looked at readability in terms of getting your messages across to the individuals in your target audience. And so let's say somebody does develop a material. How might again a local program who's developing a material who's gone through some of the processes that you talked about go about testing the readability of a material that they're developing?

Joan Mangan: There's a couple of tools that actually are online that they could use and you can copy and paste your text directly from a Word document into it and it will sit there and it will do the different calculations. You specify which ones you want on some of the tools, and on others it will just give you the whole lot they're able to do. There's also a number of books that are out there that will provide guidance on doing things like the SMOG test and the FOG Test, where you actually have worksheets and you can sit there and you could do all the calculations yourself.

Wanda Walton: On the Find TB Resources webpage, there are some materials there specifically on the page looking at adapting materials, and I think we include some of those materials, and it was a good reminder to us to make sure that we do have those things included so we'll be looking at that as well.

Rajita Bhavaraju: Great. And I think that also hits home the point I think that Paul brought up quite early in his presentation as well that you don't have to reinvent the wheel. He actually did look at some of the previous literature that was done and so again, if you're looking to undertake a small project in your program and want to look at some of the attitudes and knowledge of persons that you're working with, you can certainly go through the literature and look at

what's already been done as well as materials which Wanda alluded to as well.

That's all the time today we have allotted for the seminar. I'd like to thank our faculty very much for sharing their knowledge and experience with all of us, and thank all of our participants for some really good questions and input.

Slide 82   And finally, the New Jersey Medical School Global Tuberculosis Institute provides medical consultation services to the Northeast region. You can call 1-800-4TB-DOCS with any questions regarding medical consultation, again in our region.

Slide 83   This concludes the conference. Thank you very much for your participation.

END