Tuberculosis is a social disease, and presents problems that transcend the conventional medical approach.

Rene and Jean Dubos 1952
Why Behavioral Science?
- Recognition of the limitations of technology in improving health and eliminating disease (e.g., effective treatment for TB has been available for decades)
- Recognition of the role of human behavior in health outcomes
- Increasing research on influencers of behavior to health outcomes, including intrapersonal (i.e., individual, social and cultural, health systems, and public policy)

Why is Behavioral Science Important to TB?
- Due to the lengthy treatment regimen, the control of TB continues to be challenged by patient adherence to LTBI and TB medications.
- Acceptance and adherence to lengthy treatment for the asymptomatic condition of LTBI increases these challenges.

Why is Behavioral Science Important to TB?
- Social and economic factors such as poverty, homelessness, substance use, availability of and accessibility to appropriate care and services, and TB knowledge, attitudes and beliefs, have a significant impact on the personal TB experience.
- TB control efforts are also challenged by the disparities in communities affected by TB.

“Studies are needed to determine how basic behavioral theories can enhance understanding for the creation of tailored interventions for high risk populations”

—Institute of Medicine Report, Ending Neglect: The Elimination of Tuberculosis in the United States, 2000
IOM Call for Behavioral Science Research

- Explore impact of behavior change models on health seeking behavior and adherence to treatment
- Identify cultural barriers to prevention, treatment, and control—and the role of incentives and enablers
- Tailor adherence interventions to patients’ needs, lifestyles, social support systems, and beliefs about health
- Ensure translation of research into TB programs

What’s happened in the last 10 years….  

- DTBE’s behavioral and social science research has focused on
  - Treatment adherence,
  - Care-seeking behavior,
  - Patient-provider communication,
  - Perceptions of and ways to enhance the effectiveness of contact investigations,
  - Factors influencing acceptance of and adherence to LTBI treatment, and
  - Provider behaviors.
- Much of the research includes or targets pertinent high-risk populations, such as minorities, foreign-born, and disenfranchised populations.

TB Behavioral and Social Science Projects

- Developing culturally and linguistically appropriate patient TB education materials
- Assessing the knowledge, attitudes, and culture-specific beliefs about LTBI among several high risk groups
- Identifying barriers to the acceptance, implementation, and adherence to the LTBI guidelines and development of strategies to overcome barriers

TB Behavioral and Social Science Projects

- Assessing TB Knowledge, Attitudes, Beliefs, and Practices Among Private Providers Serving Foreign-born Populations
- Addressing TB Among African Americans in the Southeast: Identifying and Overcoming Barriers to Treatment Adherence for Latent TB Infection and TB Disease
- Determining the acceptability and usability of the iGRAs compared with the TST among patients and providers

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.
Using Behavioral Science Theories and Models in TB Research

- Using Knowledge and Attitude Variables as Predictors and Outcomes - Dr. Paul Colson
- Identifying Salient Messages to Address BCG Vaccine Misconceptions – Dr. Joan Mangan
- Both used behavioral theories and models to structure and guide the research
- Both used Health Belief Model that had its origin in TB

Thank you for your attendance and the upcoming expert speakers!

For more information please contact Centers for Disease Control and Prevention
1600 Clifton Road NE, Atlanta, GA 30333
Telephone: 1-800-CDC-INFO (232-4636)/TTY: 1-888-222-6248
E-mail: cdcinfo@cdc.gov Web: http://www.cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Background
- Working at Fort Washington Men’s Shelter as part of a Columbia Psychiatry project
- NYC had seen a dramatic upsurge in TB, particularly in congregate settings like shelters and prisons
- Also doing a postdoc at the HIV Center for Clinical and Behavioral Studies
- Was familiar with Knowledge and Attitudes (K&A) studies in HIV but could find few on TB K&A

Knowledge & Attitudes (K&A)
- Most TB K&A studies in the literature were conducted in developing countries
- US studies focused on high risk populations: drug users, immigrants, the homeless
- Most studies assessed TB knowledge but not attitudes
Instrument Development

1) Conducted focus groups with:
   - Homeless men in shelter
   - TB/LTBI patients at Harlem Hospital
2) Developed first draft of questionnaire
   - Tested for face validity with physicians, researchers, service providers
3) Piloted questionnaire with target respondents for comprehension, understanding, specific language choices

Knowledge Items

- True/false items testing respondents’ knowledge of:
  - transmission
  - testing
  - treatment
  - Items examined individually and also combined in a score measuring overall knowledge

Health Belief Model (Becker)

- Individual perceptions
- Behavioral beliefs
- Subjective norms
- Motivations to comply

Theory of Reasoned Action (Fishbein & Azjen)

- Behavioral beliefs
- Normative beliefs
- Behavioral intentions
- Behavior

Other Attitudinal Factors

- Self-efficacy (Bandura)
- Health Locus of Control
- Stigma
- Acknowledging Status
- Intentions

My K&A Studies

<table>
<thead>
<tr>
<th>SOURCE &amp; POPULATION</th>
<th>DESIGN</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV Center: Non-Patients</td>
<td>Cross-sectional</td>
<td>847</td>
</tr>
<tr>
<td>Pathways: LTBI Patients</td>
<td>Longitudinal</td>
<td>379</td>
</tr>
<tr>
<td>TB Patients</td>
<td>Longitudinal</td>
<td>199</td>
</tr>
<tr>
<td>TAPAS: LTBI Patients</td>
<td>Longitudinal</td>
<td>251</td>
</tr>
<tr>
<td>Fast Track: LTBI Patients</td>
<td>Longitudinal</td>
<td>153</td>
</tr>
<tr>
<td>Physicians at HHC &amp; CUMC</td>
<td>Cross-sectional</td>
<td>134</td>
</tr>
<tr>
<td>Task Order 13: LTBI Patients</td>
<td>Longitudinal</td>
<td>1,692</td>
</tr>
<tr>
<td>Task Order 9: Foreign-born TB Patients</td>
<td>Cross-sectional</td>
<td>1,475</td>
</tr>
<tr>
<td>Task Order 12: TB Providers</td>
<td>Cross-sectional</td>
<td>92</td>
</tr>
<tr>
<td>Task Order 23: African-American TB Patients</td>
<td>Cross-sectional</td>
<td>673</td>
</tr>
</tbody>
</table>
HIV Center Study

Participants:
- 848 participants in six HIV studies in New York City

Design:
- Common questionnaire used across studies
- Data collected through face-to-face interviews

Samples

<table>
<thead>
<tr>
<th>Sample</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mothers of delinquent boys</td>
<td>99</td>
</tr>
<tr>
<td>Mothers of depressed girls</td>
<td>71</td>
</tr>
<tr>
<td>Women in family planning clinics</td>
<td>331</td>
</tr>
<tr>
<td>Gay men in serodiscordant couples</td>
<td>149</td>
</tr>
<tr>
<td>Homeless men with mental illness</td>
<td>133</td>
</tr>
<tr>
<td>Gay men (vintage cohort)</td>
<td>65</td>
</tr>
</tbody>
</table>

Findings

- Misconceptions about:
  - Casual transmission
  - Confusion with HIV
  - Confusion about infection & disease
  - Association of age and knowledge
  - The homeless had more accurate information about testing & treatment

TB Adherence Partnership Alliance Study (TAPAS)

Participants:
- 251 patients receiving treatment for Latent TB Infection (LTBI)
- 66% were foreign-born (FB)
- All FB were from TB-endemic countries; no single country dominated
- Significance:
  - FB represent 62% of TB cases in the US
  - FB represent 73% of people under LTBI treatment

TAPAS

Design:
- Randomized controlled trial of a peer-based intervention to enhance adherence to LTBI treatment
- K&A examined at baseline
- The study’s main effect is reported in a paper under review
- This analysis compared K&A in US and foreign-born participants
Findings

Knowledge:
- Misconceptions re kissing & strangers
- No overall differences between FB & US-born

Attitudes:
- No difference on 10 of 17 items
- US-born more likely to acknowledge LTBI, be concerned about reaction of family/friends, worry about passing TB germs
- FB more likely to feel “protected”

Benefits & Barriers:
- No overall differences
- FB more likely to be concerned for family, worried about stigma, find pill-taking difficult

Task Order 13: Prospective Study of LTBI Treatment

Participants:
- 1,692 persons offered LTBI treatment in 30 clinics in the US and Canada

Design:
- Prospective study examining:
  - Demographics
  - Life Circumstances
  - Knowledge & Attitudes
  - Experiences with Health Care, including TB/LTBI
  - Clinic Characteristics

Task Order 9: TB Among the Foreign-born

Participants:
- 1,475 foreign-born persons diagnosed with TB in 22 sites in the US and Canada

Design:
- Cross-sectional study examining:
  - Demographics/socioeconomic status/health insurance
  - TB diagnosis and symptoms
  - Health-seeking behaviors
  - Knowledge and attitudes
  - Missed opportunities for detection and diagnosis of TB

Multivariable Predictors of LTBI Treatment Acceptance

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Reg. coeff.</th>
<th>SE</th>
<th>Adj. OR</th>
<th>95% CI</th>
<th>P-value</th>
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</thead>
<tbody>
<tr>
<td>Interception</td>
<td>-0.2035</td>
<td>0.7352</td>
<td>-</td>
<td>0.787</td>
<td>-</td>
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<tr>
<td>Participant believes</td>
<td>0.7018</td>
<td>0.2401</td>
<td>2.02</td>
<td>1.26</td>
<td>0.004</td>
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<tr>
<td>Higher TB knowledge</td>
<td>0.1184</td>
<td>0.0414</td>
<td>1.13</td>
<td>1.04</td>
<td>0.004</td>
</tr>
<tr>
<td>Inconvenience of clinic schedule</td>
<td>1.074</td>
<td>0.2731</td>
<td>2.93</td>
<td>1.71</td>
<td>&lt;0.001</td>
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<tr>
<td>Acculturation</td>
<td>1.1826</td>
<td>0.3393</td>
<td>3.26</td>
<td>1.68</td>
<td>&lt;0.001</td>
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<tr>
<td>Healthcare worker</td>
<td>-0.7473</td>
<td>0.3145</td>
<td>0.47</td>
<td>0.26</td>
<td>0.018</td>
</tr>
<tr>
<td>LTBI treatment</td>
<td>-1.2533</td>
<td>0.2401</td>
<td>0.29</td>
<td>0.18</td>
<td>0.001</td>
</tr>
<tr>
<td>Believe that taking</td>
<td>-2.8294</td>
<td>0.2398</td>
<td>0.06</td>
<td>0.04</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>
Analytic Plan

- Prior Studies:
  - Descriptive, comparing US and foreign-born
  - Predicted treatment outcomes using K&A and other variables
- This Study:
  - Used factor analysis to identify K&A factors
    - Knowledge and Perceived Risk / Stigma
  - Examined variables predicting Knowledge and Perceived Risk / Stigma used multivariable techniques

Significant Predictors of TB Knowledge

- Region of origin (esp. Mexicans, Latin Americans)
- Higher education
- Higher income
- Older
- Undocumented status
- BCG vaccinated
- Greater number of TB symptoms

Significant Predictors of Perceived Risk/Stigma

- Region of origin (esp. Mexicans)
- Middle-aged
- English fluency
- 2-3 years in the US/Canada
- Greater number of TB symptoms
- Living in crowded conditions

Next Steps

- Application of these analytic techniques to other populations, particularly US-born African-Americans compared to US-born whites (TBESC Task Order 23)
- Comparison of K&A across populations using common questionnaire items
- Longitudinal analysis: pre-treatment vs. post-treatment

Overview of Presentation

- Outline the impact TB myths and misconceptions have on TB control.
- Review misconceptions TB suspects and contacts commonly report related to the BCG vaccine, and TB testing and treatment.
- Discuss results from a project that aimed to identify effective messages addressing misperceptions surrounding the BCG vaccine.
The myths & misconceptions surrounding TB are among the most effective means for stigmatizing the patient, engendering secrecy, eroding self-esteem, altering peoples’ behavior, generating mistrust, creating social outcasts and impoverishment.

To achieve the elimination of tuberculosis, we must address the myths & misconceptions surrounding the disease, which impede prevention and control efforts.

Why Do We Care?
- When individuals are provided information that appears inconsistent with existing beliefs or behaviors, the resulting dissonance may lead some to:
  - Purposefully avoid or ignore new information
  - Downplay importance of the information
  - Add interpretations consistent with existing beliefs, behaviors, or personal characteristics
- These responses enable “biased optimism” — belief that a person will stay well, despite their risk

Misconceptions Surrounding Bacille Calmette–Guérin (BCG) (1)
- Currently, the only medically available TB vaccine
- Distributed since the 1920s
- More than 3 billion persons vaccinated worldwide

Misconceptions Surrounding BCG (2)
- A number of countries employ large-scale vaccination campaigns (including BCG) to control infectious diseases
  - Campaigns are supported by mass media promotions
  - Exalt the benefits of vaccination
  - Include appeals to parents to ensure their children’s health

Misconceptions Surrounding BCG (3)
- Whereas these campaigns ensure high vaccination rates, they may also contribute to three common misconceptions:
  1. The BCG vaccine protects a person from becoming sick with TB throughout their entire life.
  2. A “positive” TB screening test result is caused by having been vaccinated with BCG, not from TB infection.
  3. If BCG vaccinated, treatment for TB infection is not necessary.


Project Aim
Discern salient messages to mitigate the dissonance Hispanic persons may experience relative to having been vaccinated with BCG and subsequently being informed they should be tested and/or treated for TB infection.

This project is supported by a Social Behavioral Research Grant (SB-160793-N) from the American Lung Association and the American Lung Association of the Southeast.

Project Overview

PHASE 1:
- Collect Messages from Providers
- Organize Message Statements into Thematic Groups

PHASE 2:
- Validate Message Statements
- Select Statements for Further Testing

PHASE 3:
- Test Message Statements with Hispanic Persons
  - 2 Groups
  - Previously Diagnosed with TB/LTBI
  - Never Diagnosed

PHASE 4:
- Combine Statements to Create Comprehensive Educational Messages and Test w/ Target Audience of Never Diagnosed Persons

Phase 1
- Staff (n=60) from 5 TB programs
  - Reviewed 3 common BCG misperceptions
  - Transcribed messages they have used to persuade BCG vaccinated TB suspects and contacts to undergo TB testing and treatment
- Investigators
  - Conducted a systematic analysis of messages
    - Identified messages/themes repeated across the 3 misperceptions
    - Organized statements into 7 thematic message groups

Phase 2
- All staff message statements, in each thematic group, reviewed by TB experts
  - Deleted inaccurate messages
  - Edited to improve reading ease/comprehensibility
  - Established content validity
- Staff messages in each thematic group were then selected for:
  - Accuracy
  - Representativeness of all messages in the group
  - Strength from a theoretical perspective
    - Health Belief Model
    - Elaboration Likelihood Model
    - Framing of Actions

Phase 3
- To discern the most persuasive staff message statements:
  - Semi-structured interviews
    - 10 foreign-born Hispanic persons previously diagnosed with TB disease or latent TB infection
  - Four semi-structured focus group interviews
    - 43 Hispanic persons who worked with, or sought services from, a community organization assisting migrant workers
    - No prior diagnosis of TB disease or LTBI

7 Thematic Message Groups from Staff Messages
1. In general, why BCG is given
   - Where the vaccine is used
   - Why children are given the vaccine
   - Who is given the vaccine
2. BCG helps to decrease the risk of developing severe forms of TB
3. Why the vaccine is not completely effective/protection wanes
4. Evidence the vaccine’s protection wanes
   - Incidence of TB around the world
   - Testing outcomes
   - The “Clinical Picture” (signs and symptoms of illness)
5. Reasons for getting tested for TB
   - The vaccine’s limitations
   - What you gain from being tested
   - Know your test results
   - What you can lose from not being tested
6. The TB testing process and test results
7. Treatment
Results: Phase 3
The Focus of Selected Messages Statements

- Focus attention on obtaining a positive result
- Address perceived susceptibility
- Encourage a person to evaluate the issue by drawing upon prior experiences and knowledge

Considerations: Constructing Educational Messages from Preferred Statements

Why Consider Message Framing?
Framing can lead to different decisions and behaviors

- Get the best care available and stay healthy.
- Don’t get sick with a disease that can kill you.

Framing Health Information

- Prevention-oriented better promoted by positively-framed messages
  - LTBI Treatment
- Detection-oriented better promoted by negatively-framed messages
  - Testing for TB Infection


Long Comprehensive Message “A”
Statements earned most votes in each of the 5 thematic groups
Both Positively and Negatively Framed Statements

Short Message “B”
Primarily Negatively Framed

Short Message “C”
Primarily Positively Framed

Short Message “D”
Both Positively and Negatively Framed Statements
Phase 4 Respondents
Recruited through a community-based organization serving migrant workers

<table>
<thead>
<tr>
<th></th>
<th>(N=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No prior diagnosis of TB or LTBI</td>
<td>100%</td>
</tr>
<tr>
<td>Vaccinated with BCG as a Child</td>
<td>Yes: 75%</td>
</tr>
<tr>
<td>Gender</td>
<td>Male: 25%</td>
</tr>
<tr>
<td>Age Range</td>
<td>27-56 yrs</td>
</tr>
<tr>
<td>≤ 9th Grade Education</td>
<td>38% (n=3)</td>
</tr>
<tr>
<td>Resided in U.S. &gt; 5 yrs</td>
<td>75% (n=6)</td>
</tr>
<tr>
<td>Countries of Birth</td>
<td>Mexico 75%</td>
</tr>
</tbody>
</table>

The Feedback

**Long Comprehensive Message “A”**

- 13 Sentences
- Presented as 6 message statements
- Each statement read & discussed during interviews
- Investigators examined concepts reflected in participant responses

**Flesch-Kincaid Grade level:** 6.55

**Gunning Fog Index:** 7.66

**Flesch-Kincaid Reading Ease score:** 74.99

**“Fairly easy”**

**Fernandez-Huerta score:** 93 “Very Easy”

**Long Message “A”**

1. BCG is used in countries where many people are sick with tuberculosis (TB). Small children have an immature immune system. Because they may be exposed to persons with TB, the vaccine is given to babies and small children.

2. Many people think the BCG vaccine will protect them from TB for their entire life. However, the vaccine does not always prevent tuberculosis.

3. If a person breathes in TB germs, the vaccine helps lower the chance a person will develop severe forms of TB or die from TB. So, people who have had the BCG vaccine can still get sick with TB.

4. We have tested other people from your country who were given the vaccine; their tests were negative. This shows that a positive test is probably the result of contact with a person sick with TB disease, and not from the vaccine.

5. 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.

6. 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.

* 50% or more of participants reiterated the statements in bold, black font

When asked to report their thoughts as they listened to Message A...

- Half of the participants indicated they contemplated their own, or family member’s susceptibility to TB.
- Others discussed increased perceptions of disease severity.
- Some expressed the belief that when they immigrated to the US they had left the problem of TB behind in their country of birth.

What information needs to be clarified?
- What information should be added?

Define “immature immune system”

Explain whether a person with LTBI could infect others

Explain how TB germs get in the air

Explain who is at greater risk for becoming sick with TB disease

Explain the difference between the vaccine and the test ***
(1) The explanation that the vaccine lowers a person's chance of developing severe forms of TB if the germs are inhaled

(2) The advice that a person not take a chance with their health

(3) The encouragement to take treatment to protect loved ones

Each statement read & discussed during individual interviews.
Participants asked to select the message they liked best.
- 1 liked B
- 3 liked C
- 3 liked D
- 1 liked D, but reported they better understood C

Selected messages were discussed further.

**English Version**

**Message C:** Positive / Gain Framed

- 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 protected a person for life, tuberculosis would not be a problem in the world.
- “Knowledge is power,” and we can protect ourselves from disease.

**Gunning Fog index:** 6.95
**Years of formal education needed:** 5.86
**Flesch-Kincaid Grade Level:** 5.86
**U.S. grade level needed:** 5.86
**Flesch Reading Ease:** 77.52
**Fernandez-Huerta Reading Ease (Spanish):** 100

**“Take Home Lessons” (1)**

- Positive and gain framed messages
- Illustrate personal susceptibility
  - How people are infected (we all breathe)
  - Who is at higher risk for infection and disease
- Encourage evaluation based on prior knowledge
  - If the BCG vaccine worked perfectly – no one would have TB

**“Take Home Lessons” (2)**

- Check for cognitive dissonance
  - Ask patients to repeat information back in their own words
  - Invite patients to talk about what the provided information means to them

**“Take Home Lessons” (3)**

- Explain the differences between the BCG vaccine and the TST test
  - Placing a TST is not a treatment or re-vaccination
- Be mindful of the literacy demand
- Use the systematic process for health education
  - Needs assessment → Develop → Pilot test → Implement → Assess
Acknowledgements

- Co-Investigators: Dr. Sebastian Galindo and Dr. Tracy Irani, University of Florida, Gainesville, FL.
- The 61 individuals who participated in the interviews and graciously shared their time, attention, and thoughts.
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- Dr. Wanda Walton and Amara Khan, CDC, NCHSTP, Division of TB Elimination, Atlanta, GA.

Questions and Discussion

- Type your questions to host and panelists using the “Q&A” option at the top of your screen.
- You can type questions throughout the webinar.

Thank you for your participation!!