



# Racial Disparity in Tuberculosis (TB) in the Southeast United States

## Phase 1 Preliminary Results from Small Town, Montgomery County, North Carolina

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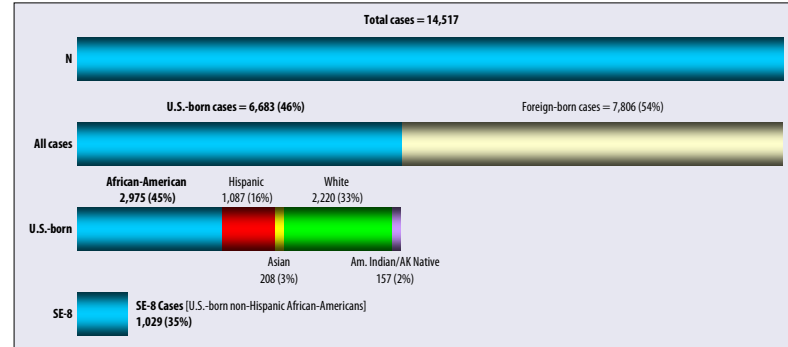
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### 1. Background

- In 2004 African Americans comprised the largest group (45%) of U.S.-born cases of TB and a substantial proportion of all U.S. cases (28%).
- Of the 2975 cases in U.S.-born African Americans, over a third (35%) resided in 8 Southeastern states (SE-8)

#### TB in U.S.-Born African-Americans, 2004



#### Project Mission: Reduce TB Disparity in African-Americans

##### Project Goals

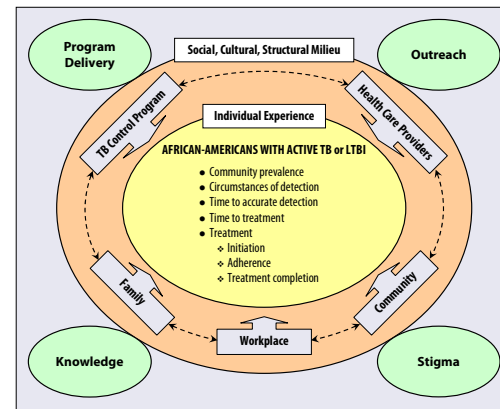
##### Phase 1

- Identification and understanding of socio-cultural racial, and health system barriers for African-Americans with or at risk for TB
- Investigate TB knowledge, attitudes, beliefs, and practices with respect to
  - Health seeking behavior
  - TB testing and diagnosis
  - Treatment adherence
  - Contact investigations
- Relationship to TB control programs
- Investigate TB knowledge, attitudes, beliefs, and practices held by providers and community leaders who serve African-Americans with TB or at risk for TB

##### Phase 2

- Devise and evaluate intervention(s) that will address the identified barriers to eliminate disparities in TB case rates among African Americans

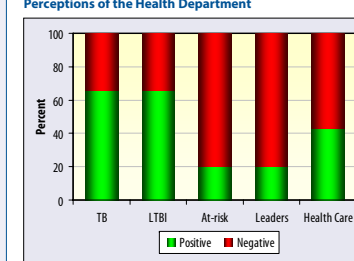
#### Conceptual Model for TB Disparity



### 3. Results

#### Program Delivery

##### Perceptions of the Health Department



Majority of staff and community providers thought patients felt a stigma associated with getting care at the health department

"She [a TB patient] said that everyone knows that if they see you in that [Health Department] lobby you have a STD."  
— HD staff

##### Contact Investigations

- Health Dept staff stated that a major problem for contact investigations was the use of multiple nicknames to identify potentially exposed individuals
- Staffing limitations
- Trust was the biggest factor cited by interviewees to facilitate and improve the contact investigation process

"He [TB patient] told me, 'Honey I don't know how to tell you this, but you are white.' He said, 'Well, it's just that they are not going to trust you, white people are the tax collectors or law enforcement, they might talk to you, but they are not going to tell you the truth.'"

"He had a good point. It takes several visits, for them to realize I don't care if somebody sneaks out the back door when I come in the front, or if they have someone extra living in government housing. I can tell when they open up but it takes awhile for them to get to that point. It thinks it's a basic trust issue because they don't know me so why should they trust me."  
— HD staff

#### Outreach

##### Preferences for Receiving Health Information

- Low literacy an issue
- Preference for
  - Face-to-Face
  - Patient stories

"Have somebody come around and talk to them. So they can ask questions and understand it better. Somebody with experience in it [TB] and they know enough to talk about it and try to explain it to them."  
— TB patient

- Pamphlets/brochures
- Ways to relay information
- Community Presentations
- Door-to-Door
- Via Mail

##### Community Leaders

People named different types of people/groups as community leaders (in order of frequency):

- Ministers/pastors/churches
- Doctors/nurses
- Political Leaders
- Educators
- Barbers
- Representative of social organizations (Eastern Stars and Masons)
- Funeral Directors
- Patient Representatives
- Community Watch participants

### 4. Conclusions

- Lack of TB knowledge a significant barrier
  - Fear and its companion stigma
  - Misinformation
- Improving TB services is hindered by lack of resources to consistently build trust and communicate
  - Contact investigations incomplete
  - Disconnect between patients and leaders/providers
- Reaching African-Americans
  - Thirst for TB information is there
  - Oral mode of information sharing is key

#### Next Steps

- Complete formative research at the additional sites
- Design the intervention based on the formative findings
- Implement and assess intervention
- Communicate research results

"You know it would be good if people were educated in diseases such as AIDS, TB, and other diseases because people are afraid and don't know how you contract these diseases. If people knew they wouldn't be afraid to get tested."  
— Community Leader focus group

### 2. Methods

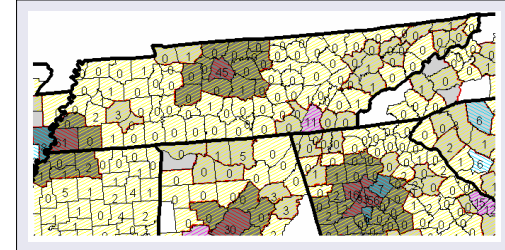
#### Which African American Communities?

How to find rural and urban counties with a high burden of TB in the African-American Community?

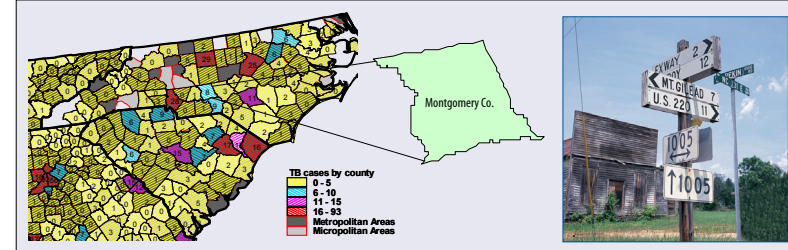
- Mapping of cases
- Quantify the TB burden
  - TB Disparity Score — the product of
    - Number of cases in African-Americans
    - Rate of cases per 100,000 population
    - Ratio of rate in African-Americans compared to whites

#### The Rural-Urban Continuum and Burden of TB in African Americans

##### Urban Cases — Tennessee, Georgia, Alabama, Mississippi (2002)



##### Rural Cases — The Carolinas (2002)



#### TB Disparity Score in Eight Southeastern States

	African American			
	TB Disparity Score	TB Cases	TB Rate	Rate Ratio Compared to Whites
Georgia	33,153	322	13.2	7.8
North Carolina	23,920	226	12.6	8.4
South Carolina	13,141	169	14.4	5.4
Tennessee	9,137	135	14.1	4.8
Louisiana	4,587	137	9.3	3.6
Alabama	3,641	119	10.2	3.0
Arkansas	2,934	53	12.3	4.5
Mississippi	2,411	96	9.3	2.7

Mississippi 2000 data; South Carolina 2003 data; all others 2002 data. Cases and rates are reported for US-born, non-Hispanic African Americans and Whites. Rates per 100,000 population based on estimates by race and county from 2002 U.S. Census Bureau.

#### 2002 Demographic Data — Small Town, North Carolina

	Montgomery County	Small Town
Total Population	26,822	1,389
Median age	36.7 yrs	38.3 yrs
Median household income	\$32,903	\$31,250
Female	49.4%	55.3%
African-American	21.8%	50%
Poverty level	15.4%	18.3%
High school	78.1%	74.2%
Bachelor's degree	10.0%	14.8%
TB in African-Americans		
2002 cases	8	8
TB rate per 100,000	141	1,151
Rank of TB Disparity Score	3rd of 688 counties in the SE-8	

#### Sought Multifaceted Perspectives on TB Disparity

##### Data Collection

- Semi-structured interviews
- Focus groups

##### Study Participants

- African-Americans
  - Active tuberculosis — 9 interviews
  - LTBI — 9 interviews
  - At Risk — 1 focus group
- Frontline TB Control Program staff — 4 interviews
- Health care providers for this community — 4 interviews
- Community leaders — 1 focus group

#### Analysis

- Transcribed interviews and focus groups
- Developed codebook
- QSR NVivo qualitative software
  - Coded data
  - Pulled out emergent themes
- Entered data from sociodemographic profile
- Tabulated data using Stata, Inc

#### Knowledge

##### Misconceptions

- TB skin test is a vaccination for TB

"We [husband and wife] try to take a TB shot every year because we don't want to catch it."  
— At-Risk focus group

"A lot of people think there is an immunization. A lot people come in and want their TB shot. I have to explain to them there is a TB skin test and we could see if you have got it or been exposed to it, but we can't give you an immunization."  
— Community provider

- Latent TB and Active TB are the same
- That TB is
  - Not curable
  - A virus
- You get TB from
  - Smoking
  - "Drinking behind others"
  - Pollution

##### TB Knowledge

- Lack of knowledge about TB was widespread
- Only 28% of active TB and LTBI people responded that they knew what TB was when asked

"I tell you I really don't know [what TB is]. In my knowledge I hear some say TB ain't nothing but cancer and bronchitis and stuff like that. With my knowledge I really don't know what it is."  
— TB patient

- At-risk community members had strong, firmly established beliefs about TB transmission

R1: I have some pamphlets at home that says you can't get it from drinking or smoking after anyone. They say you can't catch it from kissing either. I got that book from the lady at the health department.

R2: I thought you could get it from drinking and smoking after a person. They need to rewrite that.  
— At-Risk focus group

#### Stigma

##### Fear

- All interviewees cited instances of community members fears about TB

"Yes, they are afraid of it. Don't even mention it around them that somebody died from it."

"I think even the police in this community are afraid of it. They wear gloves and masks when they arrest somebody. They are afraid now."  
— Community Leader focus group exchange

- Many community members across groups expressed fear of being exposed to infectious individuals who were either unaware of their infectiousness or were purposely concealing it
- Some at risk and leaders thought that the practice of sending infected persons to sanitariums should be reinstated in order to protect community members

"I wish that the State would do people like they used to do like quarantine them and treat them until they become noninfectious but we are not doing that now. ... that is how we got that TB under control and in order to get that under control you have to take whatever means necessary."  
— Community Leader focus group

"If you know he got it why not take him on now and get this thing over with. If he has got something that is contagious people should be getting him off the street and put him somewhere that they can cure him. Why do you want him to be out here in the public?"  
— At Risk focus group

##### Stigma

- In general, TB and LTBI cases did not want to tell others about their TB diagnosis because of the very real fear of being stigmatized by the community

- People with TB or LTBI cite several instances where they were shunned or knew of others who were shunned because of TB

"Sometimes I wish I hadn't told nobody that I had the virus. I went in there and told my supervisor. I went in there and she had a mask on. Sometimes I wish I hadn't told. They couldn't really understand that I just had the virus I didn't really have TB. That part was hard you know. Everybody said you got TB and I said I got the virus."  
— LTBI Patient

"I had to put it within myself that it won't nothing that I done to get this. That helped me overcome it and to know that ain't no need to be ashamed about it because it is airborne"  
— TB Patient

#### Acknowledgements

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