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## Socio-Cultural and Structural Factors and their Impact on Tuberculosis Prevention and Control for Rural African American Women in SE USA

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# Mycobacterium Tuberculosis





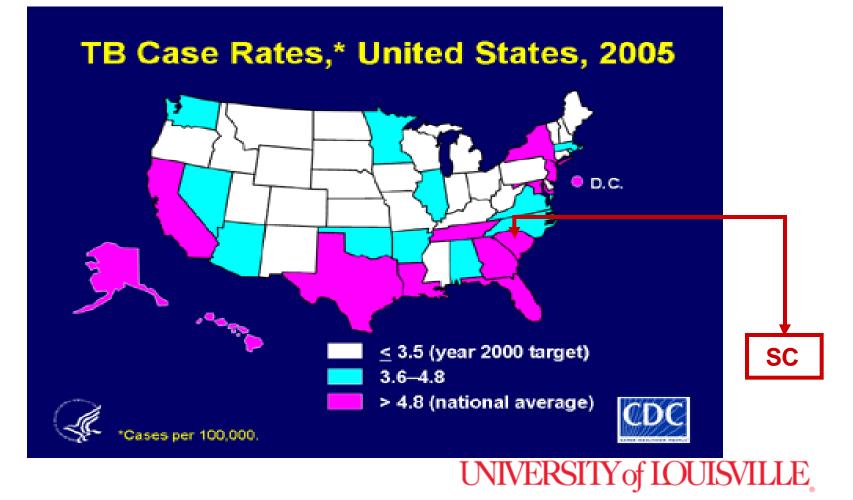
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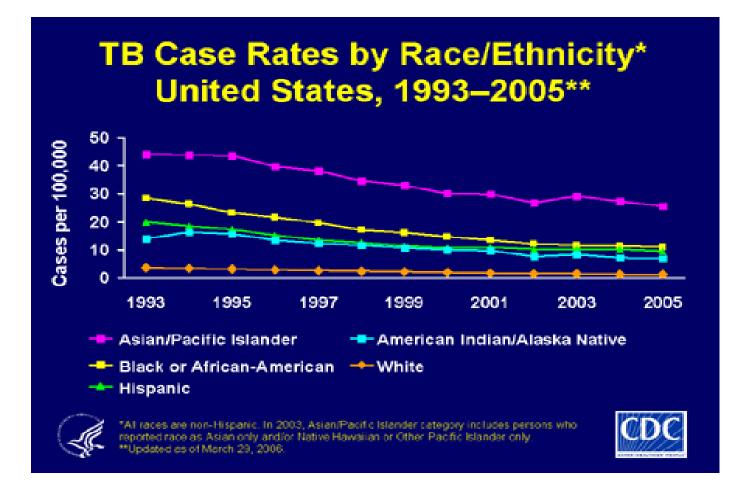
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# "...from what I grew up knowing about my father [having TB] and the way he was treated. To me that very day [being diagnosed] was like the worst thing in the world that could have happened."



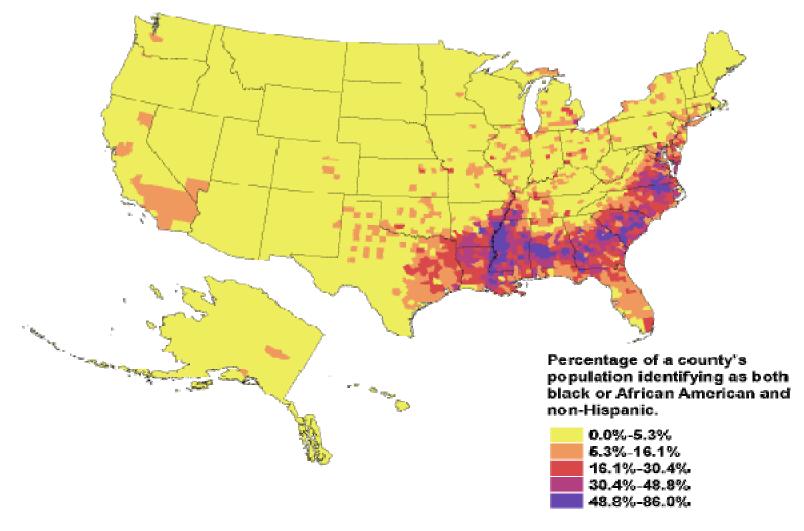
|    | 1999 | 2000 | 2001 | 2002               | 2003 | 2004 | 2005 |  |
|----|------|------|------|--------------------|------|------|------|--|
| SC | 8.1  | 7.1  | 6.5  | 6.2                | 6.1  | 5.6  | 6.1  |  |
| US | 6.4  | 5.8  | 5.6  | 2002<br>6.2<br>5.2 | 5.1  | 4.9  | 4.8  |  |



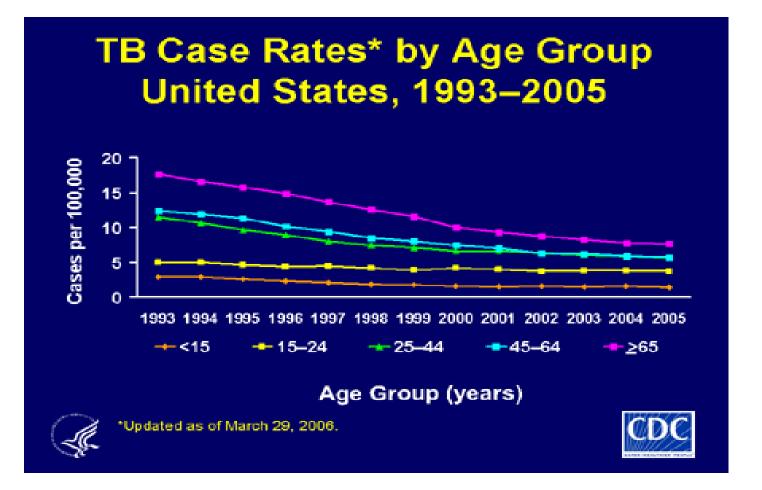


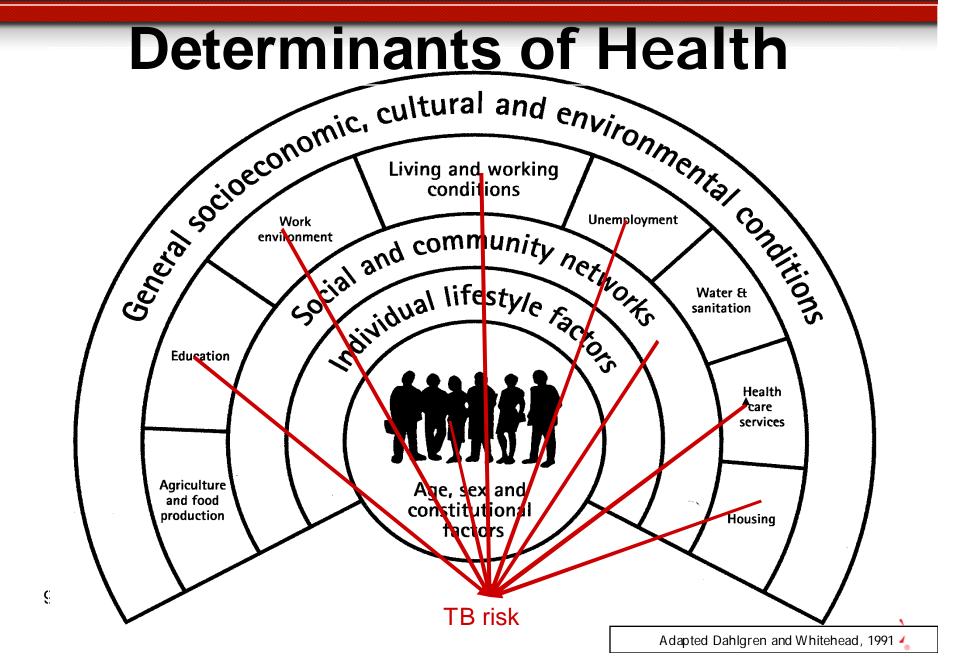
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# **Research Study**



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## **Research Questions**

- How are TB incidence and prevalence rates influenced by socio-cultural factors?
- What are the structural factors that influence tuberculosis incidence and prevalence?



# Study Design



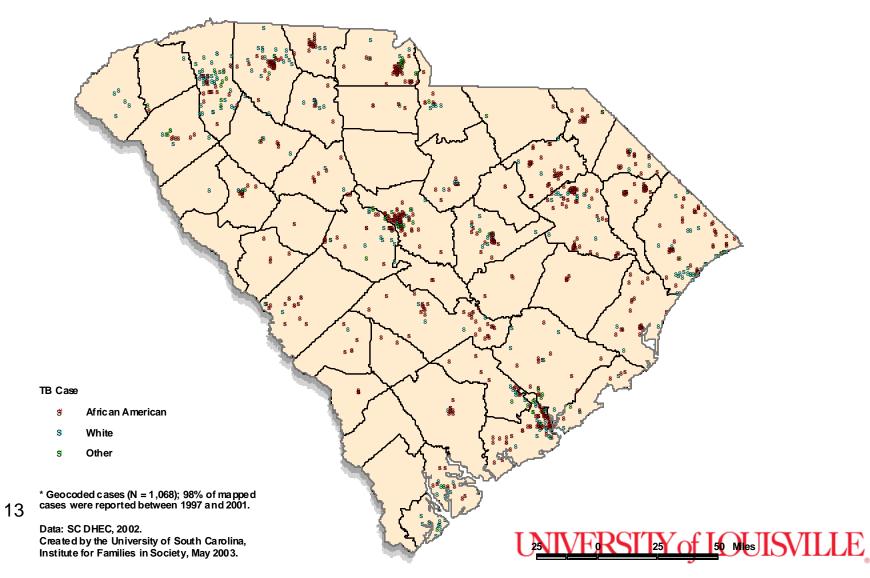
- 102 Face-to-Face semi-structured Interviews
- 28 Clinical Record Reviews
- 20 Key Informant Interviews

#### &

 – GIS Mapping and Spatial Analysis of 1,068 cases of TB



Reported Tuberculosis Cases, 1996 - 2002 \*



# Sample Description

- Sample Description
  - Persons with previous active TB
    - Most had pulmonary TB
  - Active TB 1997-2004
  - 5/13 health districts statewide
- Key informants
  - Service providers at the local level



# **Study Population**

- 84% African American
- 30% female
- Average age 50 years
- 83% had a single diagnosis of TB
- 26% reported having latent TB previously
  - 30% reported completing medication



# **Presentation Focus**

#### Sample subset

- Twenty-eight African Americans
- Female
- Age
  - 25-44 (43%)
  - 45-64 (29%)
  - >65 (25%)
- 85% had a single diagnosis of TB
- 15% reported having latent TB prior to the most recent diagnosis



# Methodology

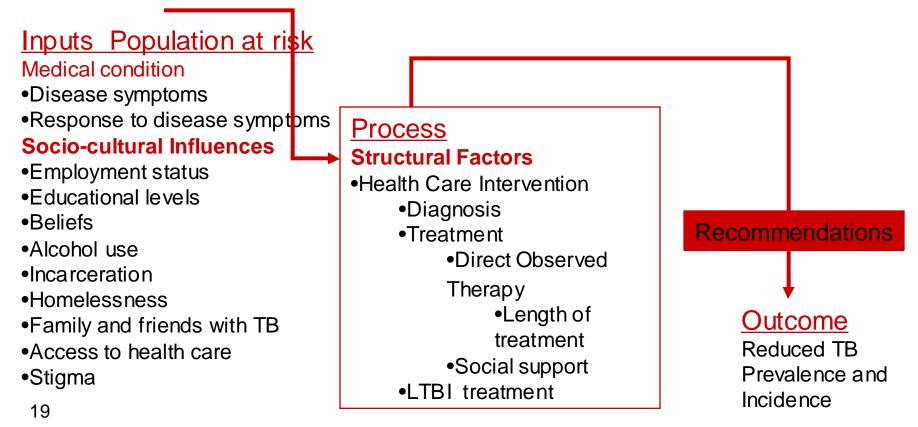
- Face to Face interviews
  - Semi-structured survey
- Interview conducted in respondent's homes
  - Interviews lasted from 45 90 minutes
  - Audio-taped Interviews were transcribed
  - Data entered into qualitative software NVivo 2.0
  - Data coded by two trained researchers based on agreed upon code book

# Results



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# **Conceptual Framework**



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## *Inputs* Health Status

## *Inputs* Health Status

#### Symptoms of Disease

- 54% identified coughing
- 25% identified night sweats and difficulty breathing
- 18% identified fever

Other symptoms identified included: fatigue, stomach pains, knot in hand, nausea, weight loss and loss of appetite



## *Inputs* Health Status

#### Response to symptoms

- 89% identified their symptoms as serious or very serious
- "I didn't know what I had. I figured it would go away, but it got worse and I said that it's time for me to go to the emergency room now."

"Cause I just thought I had a cold and just take a little of whatever, cross the counter medicine that it would go away, but it didn't."

"I didn't know what I had. I figured it would go away, but it got worse and I said that it's time for me to go to the emergency room now."



## *Inputs* Health Status

- Factors influencing response to symptoms
  - Lack of health insurance and cost of health care

"Well I didn't have any kind of health insurance."

"Yeah because doctors are expensive. If it got real bad then you know and I think there's something else wrong then I'll go."



## Inputs Socio-cultural Influences



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## Inputs Socio-cultural Influences

#### Employment status

- Most worked in low paying jobs
  - 30% in the service industry (clerical, food, retail)
  - 25% were unemployed or disabled
  - 11% in social services

#### Alcohol use

18% consumed alcohol at the time of diagnosis
"vodka"; "beer"; "I couldn't keep up. It was over, it was a lot."

#### Incarceration

10% had been incarcerated

"Well, I've been in jail 3 times.. I had some kind of pain pill, I had a falling down fit when I was coming home, police stopped me. Took me to jail - DUI."



## Inputs Socio-cultural Influences

#### Educational levels

- 40% had a high school education or less

#### Knowledge of TB

"A lot of people says you can get it from smoking and all that. I don't know how you get it."

*"I never heard of TB or nothing. All I heard is that it's a lung disease. That's about all I know."* 

"First time I ever heard about it was when my husband had it."



## Inputs Socio-cultural Influences

#### Knowledge of TB

- Many did not know or had misconceptions about TB transmission
  - "Drinking a lot."
  - "Drinking with others."
  - "Passing the bottle."
  - "From cleaning up after people."
  - "Don't know. Didn't have a dream that I had it."

## Inputs Socio-cultural Influences

#### Homelessness

Nobody in this sample admitted to being homeless

#### Attitudes and Beliefs about TB

"Yeah, but you know, I'm going to get the full definition of it, see if you say tuberculosis to some people they don't know it's the same thing as TB unless you tell them, if you say tuberculosis, it ain't no bad thing, if you say TB, Oh!, oh! Uh! Oh!"

"I think TB is something that runs down through the years and just sits there in the body and all of a sudden you get it."



## Inputs Socio-cultural Influences

#### Use of Home Remedies

"The old people used to take sassafrass... [Now] they'd use castor oil and all that stuff or some fish oil. They also take some turpentine and put it on a towel and lay it across your chest to break it up and make you cough it out, but you can't do that too much now. It don't work like it used to."





## Inputs Socio-cultural Influences

#### Family and Friends with a History of TB

- 100% said they knew of or knew family members who had TB previously
- 32% said they knew friends who had TB

"My brother, they diagnosed him and then the next [thing] I had to go up there to take care of him and they see something on my lungs."



## Inputs Socio-cultural Influences



- 17.9% did not tell anybody about the TB diagnosis and most only told family
- " If you say TB, you know somebody's all.. Shame. And that is really what is was. I was ashamed to tell people I had TB. Although it wasn't my fault."
- "I don't want to broadcast it to everybody. Some things you don't tell everybody."
- "When you have something that's contagious and people don't want to come around, you know that's just not a good feeling."



## Inputs Socio-cultural Influences

#### Stigma

- 21.4 % said TB affected their jobs
- 14.3% said TB affected their relationships
- "They would be afraid to come by. They would be afraid and I don't want anybody to scorn me. Somebody say, oh, she got TB."

"Well, to tell you the truth, most of them stayed away."



## Inputs Socio-cultural Influences

 Poor understanding of the importance of disease containment

"I felt I said well ya'll slipping by a long shot because if ya'll saying I'm contagious why don't you make sure that I'm inside where I won't go out, because you telling me to stay in the house, that's like that's not gonna work."





## Process Structural Factors



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## Process Structural Factors

- Testing for Tuberculosis
  - Respondents had varying experiences

"He [doctor] wanted to give me the skin treatment but I refused since I had a previous bad reaction."

"No, I didn't feel it was serious because see I didn't, I wasn't worried that it was anything bad because I'd had the first test and it was negative."



## Process Structural Factors

#### Understanding the diagnosis

- Many had trouble accepting the diagnosis

"Well they figured you know you never heard of nobody with Tb in the hand, nobody asked where you got it from, how you got it in your hand. It was real for me to believe that if I had it in my lungs, I had it somewhere else, that made sense. That don't make sense right there."



## Process Structural Factors



"Like, I was doing my treatments at the clinic, I kept complaining that I had to have extra blankets- I was cold all the time. They kept doing blood work and nothing was coming up, I mean they did it every other treatment I had, some blood work for me.. That went on till, uh... late January to May..."



## Process Structural Factors

#### Missed Diagnosis

"I kept going to the doctor. He was giving me antibiotics [7 days] but I just wasn't feeling good... I would go to work and after 2-3 hours I wouldn't have any energy and first they sent me to the heart center..then they put a needle in my chest, it is like an x-ray.. Then [my doctor] found a mass in my lungs."



## Process Structural Factors

#### Treatment

- Direct Observed Therapy (DOT)
  - Treatment varied between 5 and 10 months
- "Oh, I thought I was treated unkindly when he came with detectives and stuff looking all around the projects for me and people on the street say, girl the department, the health department looking for you."
- "I fought with the woman from the health department, I fought with the infectious disease doctor. I fought with him over and over and over. Is there anything they can do to make this easier."



## Process Structural Factors

#### Social Support

- All respondents reported support from family, friends and/or staff
- Social Support (Family)

"You know just my family tell me to take my medicine, not talk about how nasty it was."

#### Social Support (TB staff)

"Just give me my medicine, sit awhile. She always have some candy cause the medicine nasty. Brought some candy to give me."

#### Additional Support

"And they supplied the bus ticket you know, my transportation and made sure I had it to go there and come back."

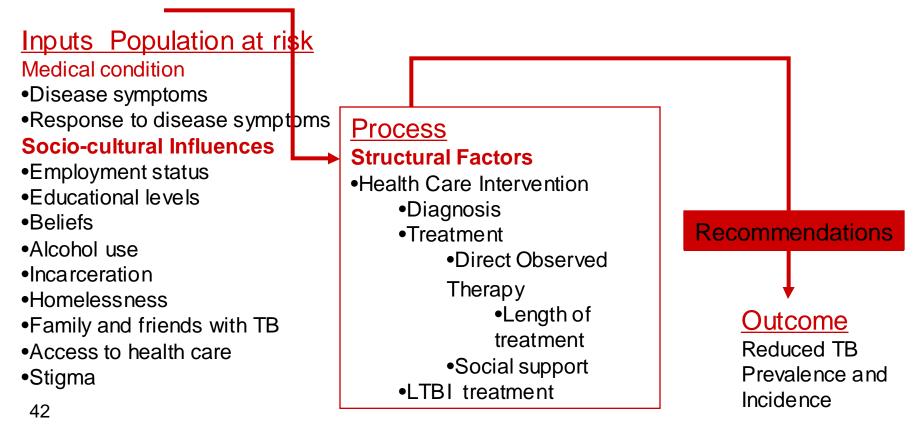


# Recommendations



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# **Conceptual Framework**



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## Improving Outcomes: Reducing Incidence and Prevalence

Develop culturally appropriate systematic broad-based, multifaceted approaches to information dissemination

"Well, I don't know what is TB, where it come from, nothing, so you know I was just blindsided the whole way around this."

(respondent with latent TB infection)

 Develop extensive partnerships with the community and collaborate to ensure holistic programs that address social and economic barriers to health care seeking and access



## Improving Outcomes: Reducing Incidence and Prevalence

- Create culturally appropriate patient centered and outcomes focused approaches
  - 15% of women in this sample had previous latent TB
  - Contact tracing and disease identification
    - Improve disease identification and patient's experiences of testing
    - Improve treatment completion rates for persons with latent tuberculosis (30% of the study participants did not complete treatment)

"They made sure that I knew that treatment was optional, but encouraged me strongly." (respondent with latent TB infection) 44

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### Improving Outcomes: Reducing Incidence and Prevalence

- Make treatment completion mandatory
  - Provide flexibility in treatment delivery options within the DOT framework

"The length of time... yeah... I believe I honestly had it. Yeah. Because we didn't take any follow-up tests! You know, it was just recommended after that initial one that I take the medicine. They didn't try again to test it."

".....And we fought about that and he fought with us and finally we finally got it every day... It was much better. The nurse come one day a week and she would fill up her little container with daily medication. Sometimes she would call to make sure she was taking it......"





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