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Tuberculosis Knowledge, Awareness, and Stigma among African Americans in Three Southeastern Counties in the United States: A Qualitative Study of Community Perspectives

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Abstract

To inform strategies to address the tuberculosis (TB) excess among US-born African Americans, we sought to understand the TB experience in the most highly-affected Southeastern communities.

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Research Involving Human Participants or Animals: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors.

Informed Consent: Human Subjects Committees at each participating institution approved the protocol. All individual participants provided written informed consent.

We conducted semi-structured interviews and focus groups in three communities with a TB excess - urban (Georgia and Tennessee) and rural (North Carolina). Participants from five groups provided diverse perspectives – African Americans: patients with TB disease or latent TB infection (LTBI), or at high risk of contracting TB; and local community leaders and TB program staff. Few differences emerged between sites. Many participants demonstrated low levels of knowledge and awareness and held many misconceptions about TB. Patients expressed a preference for verbal communication of medical information. Patients reported fear of stigmatization and shunning, but few experienced discrimination. Patient trust for TB program staff was high, though community leaders often assumed the opposite. The findings will help guide interventions to improve knowledge and awareness regarding TB, including specific attention to the role of public and private health care providers in dispelling persistent misinformation about TB. The insight from these communities will help build the scientific foundation required to effectively eliminate health inequities.

Keywords

African American; tuberculosis; health disparities; stigma; qualitative research; health knowledge, attitudes, and practices (KAP)

INTRODUCTION

The Healthy People (HP) 2020 initiative provides the United States (US) with goals and objectives to improve the nation's health, including an overarching goal of achieving health equity [1]. This agenda maintains a specific objective (11D-29) to reduce the tuberculosis (TB) burden to 1 case per 100,000 population. Although TB rates have dropped substantially over the past decade, TB continues to consistently affect African Americans and other minorities disproportionately compared to whites [2]. In acknowledgement of TB disparities, the CDC has set separate national TB program targets for 2020 for different population groups based on nativity and ethnicity [3]. Thus, the goal for US-born versus foreign-born persons (the most highly affected group) is 0.4 and 11.1 cases per 100,000 population respectively. The target for US-born African Americans is 1.5 cases per 100,000. Among the US-born, African Americans account for 37% of all reported TB cases, while only comprising 12% to 14% of the total population [4, 5]. The most recently published rates show that US-born African American TB rates remain more than seven times higher than US-born white rates (6.3 cases per 100,000 versus 0.8 cases per 100,000 population respectively) [4, 6]. Several reports have documented outbreaks disproportionately involving US-born African American individuals in a wide variety of locations – rural [7], urban [8], low-TB incidence states [9], and high-TB incidence states [10], with 77% to 96% of these outbreak cases described as African Americans.

From this point forward we focus exclusively on TB among US-born African Americans, a group whose rate of TB is seven times higher than US-born whites [4]. TB control approaches are likely to be most effective if tailored to differences between foreign-born versus US-born populations; these population groups differ in many key TB aspects such as transmission, prevalence of infection, and proportions receiving the bacille Calmette-Guérin

(BCG) vaccination, as well as by cultural traditions. However, it is important to note that most reports, including the national surveillance data, aggregate together both US-born and foreign-born African Americans.

Achieving health equity will require addressing the relative excess in TB rates for African Americans; however, the drivers of TB disparities and effective avenues for intervention are not well-understood. TB is strongly correlated with poverty. It is well-known that social and economic disadvantages correlate inversely with health care quality and health status [11]. Poor people are more likely to live in crowded housing or congregate settings, and to have less access to health care [12-15]. Poverty disproportionately affects African Americans by a factor of 2.2 [16]. However, the concentration of African American populations in socio-economically deprived neighborhoods does not fully account for TB disparities [14-15].

Stigma associated with TB may be critical to addressing TB disparities because it may lead at-risk individuals to avoid screening and TB patients to avoid seeking health care for themselves. These behaviors become barriers to effective prevention that can circumvent TB disease and treatment that can cure TB disease and prevent serious long-term disability among TB cases [7, 17-19]. Little is known about TB stigma in the US, or more particularly, among the African American community [7, 19]. Low knowledge about TB could affect health-protective behavior directly, or through its association with stigma. While many studies have reported low knowledge and awareness about TB among at-risk populations [7, 20-29], few were conducted specifically with African Americans [7].

The purpose of this study was to examine TB perspectives among US-born African Americans by investigating TB knowledge, awareness, beliefs, stigma, and health communication in five groups in high-morbidity rural and urban counties in the southeastern US: African American patients with TB; African American patients with latent TB infection (LTBI); African Americans at risk for TB (because of HIV/AIDS, homelessness, or local TB outbreaks); local community leaders; and local TB program staff. We focused on this region because over half of TB cases in African Americans were found in nine southeastern states [30], a region with the majority of African Americans [31]. We used qualitative research techniques, an approach that allows researchers and others to hear directly the voices of those affected by TB. We believe the findings will inform public health practitioners to develop programs and strategies that more effectively serve African Americans. The results will help build a scientific foundation about TB disparities to guide efforts to reduce health inequities for a preventable and curable disease.

METHODS

Design

Between April 2006 and March 2007, we collected qualitative data in three states through individual interviews and focus groups with members of several groups affected by TB. We used individual interviews for groups whose members had potentially private, direct, specific, individual TB experiences (patients, community leaders, and TB program staff). We used focus groups when the interaction among the group members would provide fruitful data on social norms, values, beliefs, and expectations (at-risk persons) and for practical

reasons (community leaders) [32]. As described below, we selected study participants based on objective criteria established a priori. Study participants completed a self-administered, socio-demographic questionnaire. We developed the research protocol in collaboration with TB program staff from nine southeastern states (Alabama, Arkansas, Florida, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, and Tennessee). Human Subjects Committees at each participating institution approved the protocol. Participants provided written informed consent.

Site Selection

Based on three county-level criteria, we selected three study sites from among counties most affected by TB disparities within the nine southeastern states: TB burden among US-born African Americans, TB disparities comparing rates between US-born African Americans and whites, and proportion of population residing in rural areas. States provided the number and ethnicity of US-born TB cases in each of their 698 counties. We used US Census data to compute county-level rates [33]. To be considered, a county had to have: 1) TB rates exceeding the national average for three of the five prior years, 2) sufficient numbers of TB cases (> 20) diagnosed in African Americans during the eighteen months preceding data collection, and 3) at least a two-fold higher rate of TB for African Americans versus whites. Urban counties were those classified by the US Census as belonging to metropolitan statistical areas while rural counties were those classified as more than 50 percent rural. Consideration was also given to local health departments' commitment to obtain IRB approvals, to access the community, and to assist recruitment efforts. Two urban counties (DeKalb County, GA and Davidson County, TN) and one rural county (Montgomery County, NC) best fit the selection criteria compared to all other counties in the nine states. TB rates per 100,000 among African-Americans in DeKalb, Davidson, and Montgomery counties around the time of data collection were 7.5, 15.4, and 179.1 respectively (Table 1).

Study Population and Recruitment

We recruited participants from five groups at each site. We included three groups of African Americans, age 18 or older who were affected by TB -- two patient groups (those with TB or with LTBI) and one group of African Americans at high risk for TB. For patient recruitment, the TB programs at each site provided us a census of all patients diagnosed in the past 18 months and on medication for at least 2 months (so that the study staff could avoid exposure to infectious cases and so that the patients would have sufficient perspective on their treatment experience). Local TB program staff secured permission from the patients for study staff to contact them for recruitment for individual interviews. Because we wanted to learn about the treatment experience of persons receiving customary TB care and not in a clinical research environment, individuals participating in other TB studies were excluded.

We used surveillance data to identify epidemiologic risk factors for TB at each site and then recruited a group of at-risk US-born African Americans for a focus group. In DeKalb County HIV/AIDS was a predominant risk factor. With the help of the TB program, we identified a clinic for HIV/AIDS patients and obtained permission to recruit the clinic clientele for the focus group to be held at that clinic. For Davidson County, homelessness was a strong risk factor for TB. We sought permission to conduct a focus group at a

homeless shelter. In Montgomery County TB cases clustered among residents in a small town with a very high rate of TB among African Americans. We recruited residents at-large in that small town to participate in a focus group held in a church social room.

The fourth group was comprised of community leaders at each site (including representatives from local religious, social service, educational, and public health institutions and advocacy groups). These participants were identified through purposive sampling. TB and LTBI patients and at-risk individuals named them as trusted sources of information or, local and state TB program staff recognized them as community leaders. We held a focus group for community leaders in Montgomery County. For the other counties, due to scheduling constraints we interviewed the community leaders individually.

To provide a fifth perspective we interviewed all TB program staff, including both licensed and non-licensed personnel. In many cases, these individuals also worked on other communicable diseases. Race and country of origin were not restricted for community leaders or TB program staff.

Data Collection

We developed semi-structured interview and focus group guides to stimulate discussion on six topics: TB Knowledge, Community Issues, TB Diagnosis and Treatment, Facilitators and Barriers to Improving Treatment Services, Increasing Testing and Treatment Adherence, and Sources and Preferences for TB/Health Information. African American field staff experienced in qualitative data collection conducted audio-recorded interviews and focus groups, distributed a self-administered questionnaire on socio-demographic data, and transcribed data using a transcription protocol [34]. Data collection concluded at each site when data saturation occurred – that is, when field staff determined that additional interviews did not reveal new information [35]. Participants received monetary incentives for participating in focus groups or semi-structured interviews.

Data analysis

We imported transcriptions of interviews and focus groups into NVivo 7.0 [36] and used the “constant comparative method” [37-38] to reach consensus on coding categories [39] based on two independent codifications of the first quarter in sequence of all interviews conducted. When coding discrepancies occurred, they were discussed and resolved by consensus. Codes were grouped into the six topics. We report each group's responses in aggregate across sites because the content of participant comments did not differ greatly between the three sites. We detailed any notable differences and included illustrative quotes.

RESULTS

Participant characteristics

We conducted 88 individual interviews and five focus groups with 115 participants in total at the three study sites (Table 2). Twenty-seven TB patients and 24 LTBI patients participated in individual interviews. Seven additional patients proved ineligible and were excluded due to recent TB diagnosis or participation in another TB study. We conducted four focus groups

among 31 individuals at risk for TB: one each in DeKalb and Montgomery counties, and two in Davidson County. Of 20 community leaders, three participated in focus groups and 17 were interviewed individually, as were all 13 TB program staff.

The mean age for individuals in each group was approximately 50 years; approximately two-thirds were men (Table 3). All participants were African American, with the exception of three community leaders and 11 TB program staff. About one-third of TB patients, LTBI patients, and at-risk individuals did not finish high school, while all community leaders completed at least some college. Almost all (92.0%) at-risk individuals who completed the demographics survey reported having been tested for TB, as well as most (85.7%) community leaders and all (100.0%) TB program staff.

Knowledge, awareness, and misconceptions

A number of respondents were able to correctly state that TB spreads through the air by an infectious person's cough. Beyond that, participants demonstrated a widespread lack of knowledge about TB. Among patients who had been on treatment for two months, only 28% of patients with active TB or LTBI said that they knew what TB was. When asked "What do you think TB is?" one patient with LTBI responded:

I don't know. I don't even know how folks catch the TB. I don't even know how it got started.

Many participants reported common misconceptions regarding TB transmission, prevention, and treatment. For example, participants reported that TB could be transmitted by sharing toilets, by sharing cigarettes or dishes for drinking and eating, by touching, or by sexual contact. This exchange between at-risk community members during a focus group discussion demonstrates strongly entrenched 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 from a 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.

When the participants were asked if they felt that some individuals are more vulnerable than others, the majority mentioned the following groups as being at high risk: those with compromised immune systems, drug addicts, smokers, infants, the homeless, the elderly, inmates, and healthcare providers. Others reported that contracting TB was restricted to "only unsanitary or 'dirty' people, poor people, incarcerated people, or homeless people." Some recognized general susceptibility as one patient with TB disease noted:

No, I think everybody can get TB. I know if I got it, I know everybody else can get it. I thought I was immune to it.

By and large, TB and LTBI patients thought that they acquired their TB from being around someone with TB. However five TB patients and six LTBI patients did not know how they had become infected with TB. Also, six TB patients and six LTBI patients thought they were

infected with TB from drinking, smoking or touching something “behind” an infected person, from infected hospital linen, from smoking, or from doctors in the hospital.

Participants expressed belief that the TB skin test is an immunization or a form of prevention for TB, rather than a diagnostic tool. One at-risk participant reported:

We [husband and wife] try to take a TB shot every year because we don't want to catch it.

Participants also stated misconceptions about TB diagnosis and treatment; for example, “TB does not require treatment because it is like a cold,” and “consuming alcohol will kill TB germs.” Other misconceptions included, “TB is a virus,” “TB cannot be cured,” “TB is only in foreign-born populations,” and “TB stays in the air for two weeks.” Additionally, there was a lack of understanding about the distinction between TB disease and LTBI; participants from all four groups (other than TB program staff) believed that both latent TB infection and TB disease were contagious.

We asked participants how TB is viewed in their community and if it is discussed. Urban and rural participants differed. Rural North Carolina participants reported TB as a major health concern in their town, perhaps because of a recent outbreak. Regarding public discussions, one North Carolina community leader said:

Until the outbreak you don't hear too much about TB. I hear you have to take the TB shots or something like that. It is not that much talk about it. Mostly the talk about when it is a big outbreak in [this town]. That is mostly what they are really talking about.

Urban participants in Georgia and Tennessee assumed that many within their community were not aware of TB, stating that TB was not commonly mentioned. At-risk participants in Georgia mentioned that they frequently hear about other diseases (e.g., herpes, HIV), but not TB. They are tested annually for TB but feel that they are never (or rarely) educated about it. Similarly, at-risk participants in Tennessee stated they received TB testing in homeless shelters and jails, but felt uncertain about their knowledge. Community leaders in Georgia and Tennessee felt that their communities were generally unaware and did not prioritize TB as a problem relative to other concerns. One community leader reported:

It's not an important concern because they are not aware of it. Like AIDS is really publicized. We do have concerns, but TB is not really publicized and you can't really know that many people who have it. Those that do have it try to keep it a secret so, therefore, we just don't know.

Regardless of level of awareness, most participants across all groups remarked on widespread community-level misinformation and lack of understanding about TB.

Stigma related to TB

Participants shared their thoughts, perceptions, and experiences of TB-related stigma. In general, TB and LTBI patients did not want to disclose their status due to fear of stigma. However, only a few TB and LTBI patients reported experiencing mistreatment from family members or the general public. They noted that reactions of family, friends, and co-workers

were generally supportive. Enacted stigma appeared to be particularly important in rural North Carolina where the social dimension of stigma had the potential to end vital informal support systems. A TB program nurse said:

[This town] is a very social and friendly community. If someone doesn't have supper, they can go to someone else's house down the street. If someone doesn't have a car, someone will give them a ride. A lot of my patients are very poor, there are a lot of them that don't work and they are used to being able to go to other people's houses to do things. Eat or sleep, hang out. Some of them have been told you can't come in here anymore because you have TB.

All participants cited instances of TB-related fear. Many expressed fear of exposure to infectious individuals who were either unaware of their infectiousness or were purposely concealing it. One community leader in North Carolina noted widespread fear:

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.

A few individuals cited instances where they were shunned or knew of others who were shunned due to inappropriate fear of contagion. Shunning was thought to be primarily related to concern about contracting disease. A TB patient said:

Even after I have been on treatment, they don't want to be around. It makes you feel bad, but I try to hold my head up and still speak.

An LTBI patient reported:

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.

Another LTBI patient related that when their cousin had TB disease:

No one wanted to be around him and when he go to the store, didn't nobody want to serve him, they didn't even want to take his money.

Community leaders were more likely to assume that people would treat people differently who they knew had TB. Several community leaders felt this was due to a lack of TB information and “fear of the unknown”:

They want them out and away from them. They feel like they are going to get it and why did you let them live here. If they find that somebody has it or may have it, then they are frightened and afraid that they might get it.

Participants expressed negative judgments associated with TB. A TB program staff person noted:

I think there is a lot of stigma attached to TB. It is not very well understood and it might be viewed as something that happens to people who don't do what they are suppose to do and hence the stigma. It does have a negative connotation.

Many NC TB patients reported stigma from other community members that they attributed to ignorance about TB. A TB patient from NC acknowledged TB-related stigma compounded with issues of social class:

If it is a high society class black then they [community] don't say nothing, they are afraid, some people think they got money and they are better than everyone else. They think it's a low class disease.

Other participants cited misconceptions about TB transmission that provide evidence of compounded TB-related stigma stating that only unsanitary or “dirty” people, poor people, incarcerated people, or homeless people can contract TB.

Several LTBI patients stated that people might treat someone with LTBI or TB differently, but most said that family, friends, and co-workers reactions related to their knowledge about the disease and that those with more knowledge, particularly about contagiousness, were considered to be less likely to shun or stigmatize a TB patient. An at-risk individual in Georgia stated:

TB, other than the fact that it can be fatal, doesn't have negative connotations behind it like HIV. HIV the people associate that with immediate death and homosexuality and associated with drug use. TB is just something you can just get and you could be a choir preacher and you can get it...Tuberculosis is something you got to deal with it and that is your attitude -- just deal with it.

Views of Health Department Services

Among TB and LTBI patients, the majority had a positive view of the health department, stating that it was “a nice place” and that staff were helpful and treated them well. Several LTBI patients noted that although they had no problems with health department services, the negative perceptions often came from people who do not access public health care. These participants expressed concerns about what others might think if they were seen receiving health department care. Fourteen patients (of 51) had negative views, complaining about lack of confidentiality, long waits, and attention to other groups, giving the impression that African-American patients were devalued.

The majority of community leaders and at-risk participants also described negative perceptions of the health department held by the African-American community and that getting care there is stigmatizing both because of its association with certain diseases and because of views about public services being underfunded and inferior.

Some at-risk participants and community leaders, in particular, felt strongly that health departments should reinstate the use of sanitariums to protect other community members. They said:

At risk participant: 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?

Community Leader: 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.

The majority of community leaders, regardless of site, stated that they did not know of anything being done in their community to address TB.

Most TB program staff recognized that many African Americans held negative views of the health department, but that most people who actually utilized health services were satisfied.

Sources, modes, and preferences for receiving medical information

TB patients cited physicians and a variety of health care centers as their primary source for receiving information in general about health. Secondary sources of information included the public health department and the internet. For TB-specific information, TB patients reported the health department as their primary source, supplemented by the internet and brochures as secondary sources. TB patients reinforced the need for receiving verbal communication from health care workers, which could be supplemented with written educational materials:

I would want the doctor to tell me if anything is wrong with me. I wants to know.

Notably, although many patients cited the television for providing health information, they were concerned about not having their questions answered. One TB patient noted:

TV I can understand [television spots] but some I would be wanting to ask questions about.

Sources of medical information for LTBI patients varied by site. Many from Georgia and Tennessee reported private physicians and health care centers as their primary source for receiving medical information, whereas LTBI patients in North Carolina cited the public health department. LTBI patients consistently stated a preference for verbal communication:

R1: I think it is important when I got somebody in my face telling me what is going on. If you give me something to read, I will throw it away. But if you are in my face telling me, then I ain't got no choice but to accept it.

R2: ...the little pamphlet I got really doesn't say anything. I understood more when I went across the street and it was because of the one-on-one thing.

Overall, at-risk individuals reported that television was their major preference for receiving health information. There were some differences related to geography. Those located in urban settings cited the internet as an additional source; and brochures supplemented with videos as secondary sources. At-risk participants from Georgia also preferred oral communication, particularly with a physician or nurse practitioner. One noted:

Well, I can't say, it seems to me that the pamphlets ain't working too well.

At-risk participants from North Carolina said that word of mouth was a major source of TB information, while Georgia and Tennessee participants were more likely to receive information from a health care provider. One participant responded by stating:

I think if you have any questions about your health you should be able to talk to your doctor and he should be open with you and answer any questions that you have concerning what you have.

Community leaders reported that the internet and word of mouth were their primary sources of medical information. One noted:

I have access to the internet and I talk to my friends who are professionals...

When asked where community members access information about health, the majority saw the health department as having primary responsibility for disseminating such information.

Addressing Stigma and Engaging the Community

The majority of patients felt that the community would be interested and had a need to receive information about TB because raising awareness would reduce stigma and lead to increased support and encouragement to patients to complete treatment. Respondents across all sites and groups consistently suggested disseminating TB information by mass media. One community leader said:

The scare has to be taken out of it... a public service announcement with radio and TV.

Others thought that one-on-one oral talks were most effective. As one community leader put it:

Word of mouth can do so much more...

Several TB patients mentioned that the best way to get information out to the community was through informal talks and presentations, but also stated that mailing pamphlets or brochures would also be a good method.

Many LTBI patients felt that the best avenue for achieving an increased community understanding of TB would be to convene the community to discuss TB. LTBI patients' statements about this included:

R1: Get together so you will know what's going on.

R2: I think they should all get together in a group and talk about it.

R3: Everybody get together and discuss it [TB].

Although many respondents across sites and groups recognized the church as an integral partner in raising community TB awareness, community leaders offered some barriers to be cognizant of when planning to partner with this resource:

There are so many things that are going on in the church...the pastors do what they are there for and they don't want to do nothing else during the time but that.

Community leaders did offer that organizations might be willing to help through literature distribution and hosting or sponsoring speakers or workshops.

TB program respondents provided many suggestions to better serve African American patients and at-risk individuals including additional training in cultural competency and HIV

comorbidity, more patient education, additional support services, and satellite clinics, but noted that these would require more health department resources than currently available.

DISCUSSION

This qualitative study fills an important gap in understanding the experience of TB in African Americans in the southeastern US with regard to knowledge, stigma, and preferred modes of health communication. Results suggest that African American participants directly affected by TB/LTBI or at risk of TB lacked information and held many misconceptions about TB, LTBI, and the level of TB risk in the community. TB and LTBI patients had recently received information about TB from health care providers in conjunction with their diagnosis and ongoing treatment, yet still had low levels of knowledge. These knowledge gaps, common to all participants, may negatively influence health behavior and may contribute to continued TB transmission or development of TB. In other studies, African Americans often reported not knowing much about TB, but actually scored as well as other racial groups and persons at high risk of TB (e.g., homeless, drug users) on many knowledge items, such as modes of transmission and whether TB is curable [20-29].

Health care providers should be aware that comprehension of TB is low, even after months of interacting with the health care system for treatment. This lack of understanding among patients may indicate that current public health messaging may not be effective.

Study participants reported experiencing all four key dimensions of stigma [19]: inappropriate fear of contagion, negative judgments about TB and LTBI patients, enacted stigma or discrimination, and compound stigma (perceptions of the association between TB and other marginalized groups). Consistent with other studies, we found that the inappropriate fear of contagion was more common than enacted stigma [17-19]. Although only a few TB and LTBI patients experienced enacted stigma, community leaders felt that stigma would result if patients disclosed their status. TB program staff articulated the subtle ways that a TB diagnosis could provoke enacted stigma and marginalize patients who rely on close knit communities to meet their basic needs. Fear of stigma was high and may be a barrier to critical TB services such as screening for infection and contact tracing. These services are essential components of an effective TB control program.

Interestingly, several participants suggested that community-wide educational efforts may be a useful approach to reduce stigma, echoing public health recommendations [7]. Fears may be assuaged through reassuring messages about the modes of transmission, the actual risk, and the effectiveness of available services (e.g., directly observed therapy, frequent clinic visits, repeated adherence counseling) to reduce the risk to others. A recent literature review of TB and stigma acknowledged the importance of community and institutional norms in mediating TB stigma, but noted the difficulty in shifting these norms, citing the case that for HIV-related stigma, widespread educational efforts have had only a small effect [19]. Another approach that may help counterbalance TB-related stigma is “TB clubs” for those affected by TB, an approach that has shown promise in the developing world [19]. It is unknown whether this approach would be effective in the US with a different culture of social connections.

TB and LTBI patients, who had actual experience with public health department services, generally held positive views about services and treatment by staff members. In contrast, community leaders and at-risk participants tended to hold negative perceptions of the health department related to stigma and general distrust of the quality of the public health system which they perceived as inadequately funded. TB program staff recognized this discrepancy. It presents an opportunity for the health department to build political will for TB services by sharing more widely its success in providing care to TB-affected members of the community.

The two patient groups and the at-risk group clearly expressed a preference that health professionals provide TB information verbally through in-person interactions. This may be due to several factors in African American culture, especially a preference for oral communications from a trusted “expert” [40-42]. Also, use of a pamphlet or video precludes the chance to ask questions [43]. Additionally, comments from several TB and LTBI patients suggest the inadequacy of existing printed TB health education materials. Finally, some may shun print materials due to unacknowledged literacy issues [41].

Participants generally viewed the physician as the primary source of information, although many providers may not envision themselves in that role, with neither the time nor expertise to serve as health educators. Apart from increased efforts from physicians, TB training for all health professionals is needed to more effectively communicate risk of TB, with the hope that increased awareness of risk would lead to a greater acceptance of TB testing among at-risk populations. Because these African American patients consistently indicated a preference for verbal communication, developing more effective ways for health professionals to communicate the basics of TB could be a promising avenue for improving TB prevention and care.

One limitation of these findings is that they are based on views of a relatively small number of African American participants in three states in southeastern US and may not represent the views of the entire southeastern US African American population. However, they do represent five vantage points from three separate locations with high TB incidence. The qualitative interviews and focus groups from a robust selection of study participants provide detailed information about knowledge, attitudes, and experiences, offering insights into the challenges of providing TB services. The TB patients were recruited from public TB programs which are responsible for finding and reporting all TB cases in their jurisdiction, for caring for the majority of TB patients, and for tracking those not in their care until treatment completion. TB programs employ a variety of evidenced-based methods to find and track cases such as incentives, directly observed therapy (DOT), use of field staff, and case management, all of which have been shown to be effective in ensuring treatment completion. TB programs hold the legal power, if necessary, to hospitalize patients in detention to comply with treatment. TB programs use these methods, as well as rigorously monitoring program performance, so that even the most marginalized people affected by TB receive appropriate treatment. Due to the potential threat to public health, TB prevention and treatment remains a federal and state responsibility and is, in most places, free for patients. For these reasons, the collaboration of the TB programs with the recruitment of the study

participants gives assurances to the extent possible, the patients enrolled represent cases under the care of the TB programs.

Another limitation is that we did not elicit views to determine the basis of the distrust of the health department by community leaders and at-risk individuals and cannot distinguish whether differences in values or in views of competence fuel the distrust [39]. Further, we are not able to determine if feelings of stigma may be underrepresented among study participants if those who felt particularly stigmatized declined participation.

Lastly, these data were collected in 2006-2007. In the time since these data were collected, there are no indications of sentinel events that would have shifted public knowledge or public health practice with regard to TB diagnostics or standards of care. The US health system has undergone major changes, including the passage of the Affordable Care Act (ACA) in 2010. The ACA has had an impact on access to health insurance and changes in access to health care are likely to follow [44]. The study sites happen to be in states that have opted not to expand Medicaid coverage, following the 2012 ruling of the Supreme Court, and thus have had much smaller changes in the proportion of the population with insurance [45]. Some believe that this coverage gap will lead to a widening of health disparities [44]. While the ACA could evolve to play a larger role in TB services, most notably the shift of TB care towards private medical providers (PMP), to date it has had little impact in this area [46]. However, a recent study concluded that TB patients under PMP care were less likely to receive the level of recommended care that TB cases routinely receive at public health departments such as directly observed therapy and documented culture conversion, cornerstones of public health practice with proven utility in stemming TB [47]. A major change in the public health system has been the constriction of funds for TB programs [48] due to the US economic crisis which was most intense in 2008. TB programs have lost front line staff who have not been replaced. These two changes have the potential to slow or even reverse the steady progress towards national goals for TB elimination and to exacerbate TB disparities.

CONCLUSION

The current study shares the perspectives from several vantage points experienced by African Americans in three states in the southeastern US. These findings may inform TB services and initiatives seeking to reduce TB disparities. The findings suggest the need for research aimed at developing and testing interventions to improve knowledge and awareness regarding TB, including specific attention to the role of public and private health care providers in dispelling persistent misinformation about TB. Further, we illuminate the high level of TB-related fear and stigma in the community, which may negatively impact TB services unless addressed directly. Lastly, these findings point out the discrepancy between the health department experience of TB-affected individuals and the perception of these services by local community leaders. Local community leaders represent an untapped resource for public health departments and potential partners to champion TB health equity in their communities, a strategy that may be particularly useful for health departments to make efficient use of scarce resources.

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REFERENCES

1. Department of Health & Human Services. Healthy People 2020. Office of Disease Prevention and Health Promotion; Washington, DC: [November 26, 2013]
2. CDC.. Reported Tuberculosis in the United States, 2014. U.S. Department of Health and Human Services, CDC; Atlanta, GA: Oct. 2015
3. CDC.. [October 29, 2015] National TB Program Objectives and Performance Targets for 2020. at <http://www.cdc.gov/tb/programs/evaluation/indicators/default.htm>
4. CDC.. Tuberculosis in blacks. www.cdc.gov/tb/publications/factsheets/specpop/resources_TB_Blacks.htm
5. CDC.. National TB Program Objectives. <http://www.cdc.gov/tb/programs/Evaluation/Indicators/default.htm>
6. Centers for Disease Control. Reported Tuberculosis in the United States, 2014. U.S. Department of Health and Human Services, CDC; Atlanta, GA: Oct. 2015
7. Centers for Disease Control. Transmission of Mycobacterium tuberculosis associated with failed completion of treatment for latent tuberculosis infection-Chickasaw County, Mississippi, June 1999-March 2002. MMWR. 2013; 52:222–224. [January 27, 2014] from <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5211a3.htm>.
8. Centers for Disease Control. Notes from the field: Tuberculosis cluster associated with homelessness-Duval County, Florida, 2004-2012. MMWR. 2012; 28:539–540.
9. Centers for Disease Control. Brief report: Tuberculosis outbreak in a low-incidence state-Indiana, 2001-2004. MMWR. 2014; 53:1134–1135.
10. Chin DP, Crane CM, Diul MK, et al. Spread of Mycobacterium tuberculosis in a community implementing recommended elements of tuberculosis control. JAMA. 2000; 283:2968–2974. [PubMed: 10865275]
11. Fiscella K, Franks P, Gold MR, et al. Inequality in quality: addressing socioeconomic, racial, and ethnic disparities in health care. JAMA. 2000; 283(19):2579–2584. [PubMed: 10815125]
12. Cantwell MF, McKenna MT, McCray E, et al. Tuberculosis and race/ethnicity in the United States: impact of socioeconomic status. Am J Respir Crit Care Med. 1998; 157(4 Pt 1):1016–1020. [PubMed: 9563713]
13. Lopez De Fede A, Stewart JE, Harris MJ, et al. Tuberculosis in socio-economically deprived neighborhoods: missed opportunities for prevention. Int J Tuberc Lung Dis. 2008; 12(12):1425–1430. [PubMed: 19017452]
14. Olson, NA., Davidow, AL., Winston, CA., et al. [February 11, 2014] A national study of socioeconomic status and tuberculosis rates by country of birth, United States, 1996-2005.. BioMed Central Public Health. 2012. from <http://www.biomedcentral.com/1471-2458/12/365>
15. Oren E, Koepsell T, Leroux BG, et al. Area-based socio-economic disadvantage and tuberculosis incidence. Int J Tuberc Lung Dis. 2012; 16(7):880–885. [PubMed: 22583660]

16. Macartney, S., Bishaw, A., Fontenot, K. [November 26, 2013] Poverty Rates for Selected Detailed Race and Hispanic Groups by State and Place: 2007–2011.; American Community Survey Briefs. 2013. p. 11-17. from <http://www.census.gov/prod/2013pubs/acsbr11-17.pdf>
17. Kelly P. Isolation and stigma: the experience of patients with active tuberculosis. *J Community Health Nurs.* 1999; 16(4):233–241. [PubMed: 10628114]
18. Macq J, Solis A, Martinez G. Assessing the stigma of tuberculosis. *Psychology, Health & Medicine.* 2006; 11(3):346–352.
19. Courtwright A, Turner AN. Tuberculosis and stigmatization: pathways and interventions. *Public Health Rep.* 2010; 125(suppl 4):34–42. [PubMed: 20626191]
20. Colson PW, Franks J, Sondengam R, et al. Tuberculosis knowledge, attitudes, and beliefs in foreign-born and US-born patients with latent tuberculosis infection. *Journal of Immigrant and Minority Health.* 2010; 12(6):859–866. [PubMed: 20237847]
21. Durante AJ, Selwyn PA, O'Connor PG. Risk factors for and knowledge of Mycobacterium tuberculosis infection among drug users in substance abuse treatment. *Addiction.* 1998; 93(9): 1393–1401. [PubMed: 9926545]
22. Kirtland KA, Lopez-De Fede A, Harris M. Knowledge and perceived risk of tuberculosis: US racial and regional differences. *Ethn Dis.* 2006; 16(2):468–475. [PubMed: 17682250]
23. Marinac JS, Willsie SK, McBride D, et al. Knowledge of tuberculosis in high-risk populations: survey of inner city minorities. *Int J Tuberc Lung Dis.* 1998; 2(10):804–810. [PubMed: 9783527]
24. Marks SM, DeLuca N, Walton W. Knowledge, attitudes and risk perceptions about tuberculosis: US National Health Interview Survey. *Int J Tuberc Lung Dis.* 2008; 12(11):1261–1267. [PubMed: 18926035]
25. Ailinger RL, Lasus H, Dear M. Americans' knowledge and perceived risk of tuberculosis. *Public Health Nurs.* 2003; 20(3):211–215. [PubMed: 12716401]
26. Nyamathi A, Sands H, Pattatucci-Aragon A, et al. Tuberculosis knowledge, perceived risk and risk behaviors among homeless adults: effect of ethnicity and injection drug use. *J Community Health.* 2004; 29(6):483–497. [PubMed: 15587347]
27. Peterson Tulskey J, Castle White M, Young JA, et al. Street talk: knowledge and attitudes about tuberculosis and tuberculosis control among homeless adults. *Int J Tuberc Lung Dis.* 1999; 3(6): 528–533. [PubMed: 10383067]
28. Wolfe H, Marmor M, Maslansky R, et al. Tuberculosis knowledge among New York City injection drug users. *Am J Public Health.* 1995; 85(7):985–988. [PubMed: 7604926]
29. West EL, Gadkowski LB, Ostbye T, et al. Tuberculosis knowledge, attitudes, and beliefs among North Carolinians at increased risk of infection. *North Carolina Medical Journal.* 2008; 69(1):14–20. [PubMed: 18429559]
30. Centers for Disease Control and Prevention. Racial disparities in tuberculosis--selected southeastern states, 1991-2002. *MMWR.* 2004; 53(25):556–559. [PubMed: 15229413]
31. Rastogi, S., Johnson, TD., Hoeffel, EM., et al. [November 26, 2013] The Black Population.; US Census Bureau, 2010 Census Briefs. 2011. p. C2010BR-06. from <http://www.census.gov/prod/cen2010/briefs/c2010br-06.pdf>
32. Ulin, PR., Robinson, ET., Tolley, EE. *Qualitative Methods in Public Health: A Field Guide for Applied Research.* Jossey-Bass; San Francisco: 2004.
33. U.S. Census Bureau. American Community Survey 1-year estimates. 2014 Tables B05003A-B.
34. McLellan E, MacQueen KM, Niedig J. Beyond the qualitative interview: data preparation and transcription. *Field Methods.* 2003; 15(1):63–84.
35. Bernard, HR. *Research methods in anthropology: Qualitative and quantitative approaches.* 3rd ed.. AltaMira Press; Walnut Creek, CA: 2002.
36. NVivo qualitative data analysis software. Version 7. QSR International Pty Ltd; 2006.
37. Boeije H. A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Quality & Quantity.* 2002; 36:391–409.
38. Thome S. Data analysis in qualitative research. *Evidence-Based Nursing.* 2000; 3:68–70.
39. Pope C, Ziebland S, Mays N. Analysing qualitative data. *BMJ.* 2000; 320:114–116. [PubMed: 10625273]

40. Resnicow, K., Braithwaite, RL., Dilorio, C., et al. Applying theory to culturally diverse and unique populations.. In: Glanz, K.Rimer, BK., Lewis, FM., editors. Health Behavior and Health Education: theory, research, and practice. 3rd ed.. Jossey-Bass; San Francisco: 2002.
41. Viswanath K, Emmons KM. Message effects and social determinants of health: its application to cancer disparities. *J of Communication*. 2006; 56S238-S264
42. Kreuter MW, McClure SM. The role of culture in health communication. *Annu Rev Public Health*. 2004; 25:439-455
43. Beach MC, Saha S, Korthuis PT, et al. Patient-provider communication differs for Black compared to White HIV-infected patients. *AIDS Behav*. 2011; 15:805-811
44. Kaiser Family Foundation. [January 24, 2015.37] Status of state action on the Medicaid expansion decision. 2014. <http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/>.
45. NY Times. [October 31, 2015] <http://www.nytimes.com/interactive/2015/10/31/upshot/who-still-doesnt-have-health-insurance-obamacare.html?emc=eta1>.
46. Balavan V, Marks SM, Etkind SC, et al. Tuberculosis elimination efforts in the United States in the era of insurance expansion and the Affordable Care Act. *Public Health Rep*. 2015; 130:349-354
47. Ehman M, Flood J, Barry PM. Tuberculosis treatment managed by providers outside the public health department: lessons for the Affordable Care Act. *PLoS One*. 2014; 9:1-9.
48. [October 31, 2015] Advisory Council for the Elimination of Tuberculosis. http://www.cdc.gov/maso/facm/pdfs/ACET/20150303_ACET_Minutes.pdf

Table 1

Characteristics of TB cases in the three study counties.

| Geographic area | TB Cases in US-Born African Americans ^a | TB Rate per 100,000, US-Born African Americans ^b | TB Rate Ratio, US-Born African Americans/US-Born Whites | Percent of Population in Rural Area |
|-----------------------|--|---|---|-------------------------------------|
| Montgomery County, NC | 10 | 179.1 | - | 82.2 |
| DeKalb County, GA | 25 | 7.5 | 15 | 0.3 |
| Davidson County, TN | 22 | 15.4 | 3.3 | 4.5 |

^aNumber of cases in each county provided by each state TB control program at the time of study design.

^bRate denominators and percent of the county population residing in a rural area from US Census data [33].

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Table 2

Study participants by group and site.

| Group | Montgomery County NC | DeKalb County GA | Davidson County TN | Total |
|---|----------------------|------------------|--------------------|-------|
| Patients with TB ^a | 9 | 8 | 10 | 27 |
| Patients with LTBI ^b | 9 | 9 | 6 | 24 |
| Individuals at risk for TB ^c | 8 | 8 | 15 | 31 |
| Community leaders ^d | 5 | 6 | 9 | 20 |
| TB program staff | 3 | 5 | 5 | 13 |
| Total | 34 | 36 | 45 | 115 |

^aTB is tuberculosis.

^bLTBI is latent tuberculosis infection.

^cRisk for TB defined by local epidemiologic patterns: DeKalb County - people living with HIV/AIDS, Davidson County - homeless individuals, Montgomery County - residents in a small town with a very high TB rate among African American residents.

^dRepresentatives from local religious, social service, educational, and public health institutions and advocacy groups.

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Table 3

Characteristics of study participants.

| | Patients with TB ^a (N = 27) ^b | | Individuals with LTBI ^c (N = 24) | | Individuals at risk (N = 31) ^b | | Community leaders (N = 20) | | TB program Staff (N = 13) | |
|---------------------------------------|---|------|---|------|---|------|----------------------------|------|---------------------------|-------|
| | N | % | N | % | N | % | N | % | N | % |
| Average age (Range) | 47.9 (22-81) | | 48.1 (18-82) | | 47.5 (22-75) | | 51.9 (25-71) | | 46.6 (26-65) | |
| Gender | | | | | | | | | | |
| Male | 17 | 65.0 | 9 | 62.5 | 14 | 67.7 | 12 | 57.1 | 1 | 7.7 |
| Female | 9 | 35.0 | 15 | 37.5 | 10 | 32.3 | 9 | 42.9 | 12 | 92.3 |
| Race/Ethnicity | | | | | | | | | | |
| African American | 26 | 100 | 24 | 100 | 24 | 100 | 18 | 85.7 | 2 | 15.4 |
| White | 0 | 0.0 | 0 | 0.0 | 0 | 0.0 | 3 | 14.3 | 11 | 84.6 |
| Education | | | | | | | | | | |
| 8 th grade | 2 | 7.7 | 1 | 4.2 | 1 | 4.2 | 0 | 0.0 | 0 | 0.0 |
| Some HS ^d | 8 | 30.8 | 6 | 25.0 | 6 | 25.0 | 0 | 0.0 | 0 | 0.0 |
| HS graduate | 7 | 26.9 | 8 | 33.3 | 10 | 41.7 | 0 | 0.0 | 1 | 7.7 |
| Some college | 6 | 23.1 | 7 | 29.2 | 7 | 29.2 | 4 | 19.1 | 5 | 38.5 |
| College graduate | 2 | 7.7 | 1 | 4.2 | 0 | 0.0 | 7 | 33.3 | 5 | 38.5 |
| Postgraduate | 1 | 3.7 | 1 | 4.2 | 0 | 0.0 | 10 | 47.6 | 2 | 15.4 |
| TB test | 27 | 100 | 24 | 100 | 22 | 92.0 | 18 | 85.7 | 13 | 100.0 |
| HIV/AIDS ^e | 3 | 12.0 | 1 | 4.0 | 7 | 29.2 | - | - | - | - |
| Jail resident or employee | 8 | 30.0 | 6 | 25.0 | 6 | 25.0 | 4 | 19.1 | - | - |
| Homeless shelter resident or employee | 5 | 19.0 | 4 | 17.0 | 10 | 42.0 | 8 | 38.1 | - | - |
| Close contact with TB patient | - | - | - | - | 8 | 33.0 | 8 | 38.1 | - | - |
| Alcohol/drug dependence | 4 | 15.0 | 5 | 21.0 | 4 | 17.0 | - | - | - | - |

^aTB is tuberculosis.

^bMissing data for one TB patient and seven individuals at risk.

^cLTBI is latent tuberculosis infection.

^dHS is high school.

HIV/AIDS is human immunodeficiency virus/ Acquired Immunodeficiency Syndrome.

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