How Testing Serves African Americans in Epidemics, Past and Present:
Applying Lessons from Tuberculosis to COVID-19 in the United States

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Abstract

Rather than lacking the resources, knowledge or empirical evidence to successfully address testing inequities in the African American community, the U.S. lacks the imagination and commitment to directly confronting structural inequities that lead to failures in testing strategies for tuberculosis (TB) and COVID-19. Historical case studies showing successes and failures of TB testing campaigns in the African American community hold lessons that we can incorporate into our current and future public health measures in infectious disease outbreaks. This way—whether it’s an ancient bacteria like TB or a novel virus like COVID-19—we can work toward ensuring that insufficient trust in and access to high-quality, reliable tests will not be obstacles to improving equity in health outcomes. Further research on the nuances of how infectious disease testing has served other minority groups in the U.S. is recommended.
Research Question:

Using TB as a comparative historical case study, how has testing in infectious disease containment served Black populations in the U.S. for the COVID-19 epidemic?

Introduction:

Testing in the U.S. has played a critical role in informing public health policies that enable health-care workers and communities to curb the transmission of infectious diseases. However, testing of viruses and bacteria for infectious diseases was not utilized until the last 100 years. The epidemic of tuberculosis (TB) has taken a backseat in the public consciousness today to that of COVID-19, but it has important current and historical lessons that can inform the progression of testing policies of the United States’s COVID-19 response.

Unequal access to testing and outcomes for coronavirus in African American communities was one factor that built up to the Black Lives Matter protests in June 2020 (New York Times, 2020). In a *UCSF Magazine* feature story, Kirsten Bibbins-Domingo, vice dean for population health and health equity at the UCSF School of Medicine, said that COVID-19 and Black Lives Matter are coming together in the same time and space, stemming from the same set of structural issues (Daube, 2020). The killing of George Floyd was the spark for the magnified anger, frustration, and pain of police brutality on top of the already disproportionate burden of disease brought upon Black people in the United States. Systemic racism meant that racial disparities in access to health care, housing, nutrition, education, and other social determinants of health led to suffering compounded by the pandemic (Yancy, 2020). Instead of being a societal equalizer, COVID-19 has widened those gaps.
In November 2020, Duke University President Vincent Price said to the *Duke Chronicle*,

“One of the decisions we made over the summer was to build up a large-scale testing program that would regularly surveil asymptomatic members of the community… I’d say the bigger maneuver actually was with the development and rollout of the Duke Compact, and our emphasis on the fact, and it is a fact, that you cannot test your way through this pandemic successfully. You behave your way through the pandemic.”

*COVID-19 test site for students at the Levine Science Research Center at Duke University, photo by Chen*
Although this quotation is in the context of how everyone at Duke University is indeed able to practice social distancing, it also illustrates how testing is effective only when the population being tested has access to education, counseling, and the means to “behave.” While testing was highly available to Duke students—once or twice a week to a healthy, young, and largely affluent student population, and daily to Duke’s student athlete population—historically disadvantaged groups in Durham and across the nation, who have had much high exposures to COVID-19, struggled to obtain COVID-19 tests. This demonstrates how groups that are at disproportionate risk for acquiring an infection often have barriers to equitable testing measures. Ongoing research led by the Pennington Biomedical Research Center aims to increase COVID-19 testing in Louisiana’s African American communities, which have been hit hard by the virus (Wendland 2020). Pennington Biomedical Executive Director John Kirwan believed that efforts to implement testing in underserved Black communities had so far been limited. Data from the Epic Health Research Network and the Kaiser Family Foundation for patients from 53 health systems, representing 300 hospitals across 21 states, was analyzed by public-health experts to show that, despite being at increased risk of exposure to COVID-19, people of color did not have significantly higher testing rates compared to white patients and had higher test positivity rates. This analysis concluded that the data suggested that people of color may face increased barriers to testing that contribute to delays in them obtaining testing until they are in more serious condition. (Rubin-Miller, 2020).

The first step in containing a stealthy disease that is asymptomatic in most people is to test them, recommended Dr. Nathan Thielman, an infectious diseases physician and a professor of medicine and global health at Duke University (N. Thielman, personal communication, Dec 9,
In order for health care to be equitable during an infectious disease outbreak, testing strategies must take into account historical differences in various subpopulations. The ways testing campaigns have impacted previous epidemics and pandemics with asymptomatic transmission can give guidance to how policymakers can shape testing strategies in a way that draws lessons from past mistakes and successes in the context of each distinct disease.

**Literature Review:**

Infectious disease testing is often thought of in the scientific context of efficacy and reagents, but the sociocultural contexts of testing have serious implications on how testing strategies affect different populations. Both TB and COVID-19 can persist easily within a population due to their ability to spread undetected, which means that testing is critical in protecting high-risk populations from these diseases. At the same time, high-risk populations are also likely to receive less access to tests, participate in lower-quality tests, and have lower priority in testing and tracing. Although TB is an ancient disease that has existed for thousands of years, first appearing in medical texts in the mid-600s B.C. (Haas, 1996), it has applications and parallels to the current dual pandemic of COVID-19 and racism in the U.S. Samuel Kelton Roberts, Jr., in *Infectious Fear: Politics, Disease, and the Health Effects of Segregation*, argued that modern TB has always had a socioeconomic and political profile.

As important as testing is, there is limited research on the sociocultural aspects of testing that play into pandemic control efforts. In *Risky Rhetoric: AIDS and the Cultural Practices of HIV Testing*, J. Blake Scott wrote, “Despite its far-reaching cultural implications, HIV testing has largely escaped the analytic eye of rhetoricians and cultural critics of science, technology,
and medicine." Scott defines two of the primary functions of testing to be surveillance and identification.

TB and COVID-19 are both infectious diseases that primarily attack the lungs. TB is caused by bacteria—not a virus—and is spread through droplets. Similarly to the COVID-19 pandemic, TB is a serious public-health concern because it can spread easily through the air when someone with active TB disease speaks, coughs, or sneezes. Both diseases have overlapping symptoms like coughing, fevers, and difficulty breathing, but TB has a much longer incubation period with a slower onset of disease (WHO, 2020). By the end of the 19th century, TB killed 1 out of every 7 people living in the United States. Almost one-third of the world is a carrier of TB and is at risk of developing the active form of the disease. TB infection presents no symptoms but requires monthslong treatments to prevent progression to TB disease (WHO, 2020). When active TB is left untreated, TB infects lung tissue, making it difficult or impossible to breathe. In 1952, isoniazid began the modern era of treatment for TB. In the early 1960s, ethambutol was shown to be effective and better tolerated and in the 1970s, rifampin emerged as a keystone in the treatment of tuberculosis. French researchers Albert Calmette and Camille Guérin developed the Bacillus Camille–Guérin (BCG) vaccine in 1921. The BCG vaccine doesn’t prevent infection, but it does provide protection against TB spreading beyond the lungs, which is much more dangerous. BCG vaccines are not common in the U.S.-born population because TB is less common there (Smithsonian, 2019).

Common symptoms of TB are a persistent cough of three weeks or more, fever, night sweats, fatigue, loss of appetite, and weight loss. Since these symptoms overlap with many other diseases, testing is necessary to confirm the disease. Also, like COVID-19, TB tends to infect the
lungs but can also infect other parts of the body, which can be more fatal. Patients were quickly noninfectious after being given effective drug treatment. Most sanatoriums—one crucial to containing community TB spread—were closed by the mid-1960s (Murray, 2015).

Early diagnosis and treatment—both of which are known to be impacted by low trust and accessibility to medical care in the Black population (Shavers, 2001)—are critical to lower infection and death rates from TB, and the same trend has surfaced in COVID-19 (Kim, 2020). Nonspecific and easy-to-miss symptoms, along with diverse radiological presentations, make TB—like COVID-19—difficult to diagnose (Bento, 2011). Early COVID-19 data indicates a reproduction number ($R_0$) of 2.2 for COVID-19 which means that each person infected can transmit the virus to 2.2 more people. Currently, $R_0$ value for TB in low-incidence countries like the U.S. is below 1, which means that there are essentially no more TB outbreaks occurring. However, in high TB-burden nations, the $R_0$ value for TB is greater than that for COVID. $R_0$ for TB was recorded at 4.3 in China in 2012 (The Union, 2021).

Inequitable testing rates have created barriers for these various stigmatized populations to know their status and seek timely care, which has been seen in the COVID-19 epidemic as a whole. The inequities in testing also goes beyond simply testing rates, as the effects of testing also rely on the accessibility of the tests, stigma around testing, the way the results are interpreted, and steps taken after receiving the results. Dr. Tom Frieden—head of the Centers for Disease Control (CDC) during the 2009 H1N1 pandemic, and now the president and CEO of the global-health initiative Resolve to Save Lives—said that testing data are only as useful as the actions they inform (The World staff, 2020).
In “A Historical Lesson in Disease Containment” for *The Atlantic*, Annika Neklason wrote that isolation spaces can contain a disease only if the people carrying it have the motivation and the means to utilize the quarantine units. By going beyond testing and altering the living conditions of people who may not have access to isolation and a comfortable bed, TB rates—which used to be the second leading cause of death in early 20th-century America—plummeted. Considering the stark differences in infectious disease testing, care, and treatment, this paper will examine how testing has served the African American community through three time periods of TB spread in the U.S. from the 20th century until now, and apply these case studies to COVID-19 testing in the U.S. in 2020–2021.

**Methods:**

Three time periods of TB epidemics from 1930 to 2020 in the United States will be examined using a set criteria to illustrate how Black people in the U.S. were affected by TB testing, noting the parallels to issues with testing during the COVID-19 pandemic along the way. These parameters are below:

1. What tests existed?
   a. Who created each test and how was it discovered?
   b. How long did the test take to be approved?

2. What were the barriers to getting tests?
   a. Highlight a high-risk subpopulation within the Black community that will be the focus of each comparative historical case study.
      i. Examples include: immigrants and the LGBT+ community
b. Were there particular cultural perceptions or stigmas surrounding testing?

c. Were tests proportionally distributed to these high-risk groups when compared to the general population?

3. How was testing for these groups portrayed in the mainstream media?

   a. What were some perceived problems? Were there issues of trust in the quality and usefulness of these tests?

   b. Was there misinformation that spread about the tests, and, if so, through what mediums was it spread?

4. How were testing campaigns rolled out?

   a. How well did testing reach vulnerable/underrepresented populations?

   b. What did the timelines for each test look like? How long does it take for test results to come back?

   c. What were the steps taken after a positive test? What were the steps taken after a negative test? What kind of support was provided to these patients that tested positive?

   d. What are the false-negative and false-positive rates for each test? How are the possibilities of incorrect test results dealt with in each epidemic?

5. What were the economic and social implications of a test result?

   a. Was there an effective cure discovered for the disease?

6. Is the epidemic still ongoing?

   a. Has the burden of disease shifted over time?

   b. Has access to testing become more equitable?
c. Were there changes in testing protocols or targeted populations?

**Results/Analysis**

**Tuberculosis:**

*Tuberculosis: Test History and Development*

In 1890, German bacteriologist Robert Koch pioneered an injectable tuberculosis derivative, tuberculin, which failed as a cure for TB. In this time period, TB killed 1 out of every 7 people living in the United States, and the only prescribed treatment available was rest and adequate nutrition (CDC). In 1907, the failed cure that Koch developed became the foundation for the tuberculin skin test pioneered by Clemens von Pirquet. This skin test led to the discovery of latent TB (LTBI), where infected patients do not present symptoms. Adopted by the U.S. government in 1940, this standardized TB skin test is the same test that continues to be a critical measure in the management and containment of TB today (Smithsonian, 2020).

Treating LTBI has been shown to reduce the risk of TB disease by 90% and thus reduces the number of potential future infections (Denholm, 2010). Another testing method used mostly before the 1960s was mobile X-ray vans to test for TB disease (CDC). LTBI can be tested for using the blood test (IGRA) or the skin test (TST) to predict future risk of active TB; which test is used depends on setting, cost, and availability. The blood test requires only a single patient visit to conduct the test, and results are usually available within 24 hours, but the skin test requires a follow-up visit 2–3 days after the initial injection of tuberculin (CDC). However, the blood tests are far more expensive in the U.S. compared to the skin test. Populations that historically have poor rates of return for the skin-test (TST) reading are preferred for IGRA
testing (Ahmed, 2020). I could not find the data on the frequency of TST vs. IGRA tests because the National TB Surveillance System did not keep track of those details, but I infer that areas in the U.S. with less funding and infrastructure for public-health initiatives likely use the cheaper TST tests, even if the IGRA tests are more suitable. There are many other types of TB tests, but this paper will focus on TST and IGRA tests, which are the most common in the U.S.

"Healthy looks can hide Tuberculosis"

American Lung Association 1935 public awareness materials, depicting the importance of testing for TB

With greater than 80% sensitivity and specificity, the TST and IGRA tests are reliable in detecting TB (Ruhwald, 2017). While testing is the first barrier to identifying patients, the
lengthy months-long medication regimens for TB disease is yet another barrier. Failed or inadequate treatment can lead to further infections in the population and drug-resistant TB. Considering LTBI is asymptomatic, patients might not prioritize treatment for an infection that they cannot see or feel (CDC, 2019).

Test Accuracy

The TB skin test is popular because it is simple, inexpensive, and robust, but it has very low specificity (Purohit, 2015). This means that rates for false positives and negatives are high compared to those of other testing methods. The IGRA test has lower false positives and negatives and is good for detecting latent TB in low-endemic areas like the present-day U.S. Neither test differentiates between latent and active TB, so both require further testing, like chest X-rays and sputum smears. Positive sputum tests mean that patients are recommended to wear a mask until their sputum tests turn negative during their course of treatment (WHO).

1930–1962: pre-Civil Rights Act

As mortality rates for TB in the U.S. rapidly declined from 1910 to 1933, racial disparities in TB mortality in growing urban areas rose. The long delays between acquiring a TB infection and progression into TB disease makes TB mortality an indicator of long-term effects of “migration, inequality in access to care, increasing population density, and racial residential segregation in northern cities” (Zelner, 2017). Because of this delay in the progression of TB, the divergent TB mortality rates in African American and white populations could be reflecting
increased disparities in infection risk, the unequal distribution of advances in TB detection and treatment, or perhaps both (Blower, 1995).

I chose this time period for TB because the 1930s was a time of urban migration and increased living density for African Americans, and the 1960s marked the introduction of effective treatment for TB, when testing positive for active TB was no longer a death sentence. In 1940, before the introduction of these antibiotic therapies, TB remained a leading cause of death. The chart below shows how TB remained in the top 10 causes of death for nonwhite males and females, but not for white males and females (National Office of Vital Statistics, 1956).
Given how TB remained in the top 10 leading causes of death in the time period for nonwhites, it can be inferred that the initial rollout of the TB skin tests did not prioritize the
African American population that was at higher risk. Testing statistics by race were not found for this 1930–1962 time period, but, based on literature on medical leaders’ attitudes toward African American TB rates, there was little interest in carrying out targeted testing of these populations; instead, much of the rhetoric centered around the othering, or racialization (Canales, 2000), and blaming of African Americans themselves. Additionally, the high mortality rates recorded in the African American population could be attributed in part to the lower rates of testing and diagnosis of TB that did not lead to death. Historical records from 1931 include statements from doctors on how most of the hospital admissions of African American TB patients were in the “far-advanced stages” of TB disease (Torchia, 1975).

Likewise, a COVID-19 study on African American patients in California suggested that Black populations had lower levels of access to medical care or that they tended to postpone seeking medical care until the disease was more advanced (Azar, 2020). This conclusion was supported by how Black patients were far less likely than white patients to have been tested for COVID-19 before visiting the emergency room, even though Black residents were bearing an already greater burden in mortality rates. This study, published in Health Affairs, assessed medical records of COVID-19 patients at a large integrated health network in Northern California, analyzing 1,052 confirmed COVID-19 cases from January 1 to April 8, 2020. The researchers found that—even after adjusting for age, gender, comorbidities, and income—compared to non-Hispanic white patients, African Americans had a 2.7 times higher chance of hospitalization (Azar 2020). Furthermore, the California Department of Public Health’s data showed that African Americans made up 6% of the California population and 6% of the COVID-19 cases, but 10.3% of the deaths. Azar concluded that race plays a pivotal role in
determining method and time that medical care is accessed, and that the greatest risk of
hospitalization was borne by African Americans.

In 1931, Dr. Lawrence Royster—a prominent Virginia pediatrician and member of the
state Board of Health—called attention to the “menace of Negro tuberculosis,” stating that the
majority of the cases of tuberculosis in white children that he had witnessed probably came from
Negro servants (Connolly, 2011). In order to provide better care to TB disease-positive patients
in the African American community in Maryland, a regionalized network of sanatoriums was
proposed but never materialized. Henryton, located in Marriottsville, was the only multipurpose
“Negro sanatorium” in the state in 1933; it was supposed to provide a space for African
Americans to receive the same level of treatment as white people, although The Washington Post
reported that this sanatorium was under scrutiny for cremating and discarding the remains of an
African American child before the parents were contacted (Washington Post, 1945). According
to Melvia Hawkins, a Black nurse who from 1930 worked at the sanatorium for 40 years,
Henryton was chronically underfunded. Henryton was also led by a medical director, Dr. John T.
O’Neill, who lamented how African Americans did not seek treatment sooner while also not
proposing active case-finding efforts (Torchia, 1975). O’Neill further viewed educational
programs about TB for the African American community as a “difficult task.” Sanatorium care
of African Americans was also said to be trailing by 40 years (Torchia, 1975).

Perceived “difficulty” in public-health efforts in diverse populations has led many
medical experts like O’Neill to take the easy way out, which is to keep the focus on white
Americans who do not carry the baggage of racial oppression. However, studies have shown that
it is in these historically oppressed populations that knowledge and education is incredibly influential on behavior and outcomes in TB patients. One such study found that increasing TB knowledge for TB patients was associated with healthy behaviors and greater favorable outcomes. Of 477 participants, Blacks were observed to have significantly less overall knowledge and more misconceptions about TB transmission and LTBI than whites (Howley 2016). Substantial misconceptions lay in the confusion on differences between TB and LTBI, the mode of TB transmission, and how to access effective treatment for LTBI. The authors concluded that simply improving TB knowledge will not erase the existing TB disparity between Black and white populations, but understanding what influences knowledge of TB in African American communities “will allow us to better tailor messages and education to the populations who need it most” (Howley 2016).

The National Tuberculosis Association in the 1930s was focused on the South because tuberculosis societies in the North sheltered themselves in “color-blind” policies and tended to ignore the “race question” entirely. For example, the New Jersey Tuberculosis League said that since African Americans were largely of low socioeconomic status, improving care shouldn’t “over-emphasize the racial issue” (Torchia 1975). This is reflective of common present-day reactions of white Americans to discredit the Black Lives Matter movement that occurred during the COVID-19 pandemic (Wilkie, 2020)—such as saying “we’re all the same human race,” or accusing those who shed light on racial inequities of sowing division, which the former President Trump did repeatedly. Oversimplified statements like these minimize the true suffering and damage that historical and ongoing structural racial inequality inflicts. Being “color-blind” is merely an excuse for white people to not confront their place in an unjust system that upholds
white supremacy. “Color blindness” is not accidental; rather, it is a function of white fragility, which sociologist Robin DiAngelo in *White Fragility: Why It's So Hard for White People to Talk about Racism* describes as “a state in which even a minimum amount of racial stress becomes intolerable, triggering a range of defensive moves.” These avoidant behaviors work to reinstate “white racial equilibrium” (DiAngelo, 2018).

Unlike the “color-blind” North, the South’s leaders in the fight against TB in the 1930s had no choice but to grapple with race questions, and the achievement of public health goals necessitated improvements to care for Black TB patients. Despite these steps toward more equitable public-health measures, TB workers were careful to not disrupt the existing social structure and its inequities, avoiding advocating for more radical social change that would ultimately improve public health and the TB crisis. Furthermore, it was common that public-health officials who wanted to improve TB outcomes in the African American population were motivated not by a shared humanity or to lessen suffering, but by the economic loss generated by TB outbreaks in Black workers (Connolly, 2011). This was made even more clear by the lack of care available for Black children with TB—not yet economically beneficial to white people—as compared to white children. While many preventoriums were built for white children, only one preventorium for African American children ever existed (National Tuberculosis Association Directory, 1931). Rehabilitative care was unavailable for Black children with TB in the bones and joints in Virginia until 1940 (Report of the State Dept of Health to the Governor of Virginia, 1940).
In *The “White Plague” and Color: Children, Race, and Tuberculosis in Virginia* 1900–1935, Cynthia Connolly wrote that in the first half of the 20th century, the preventorium was an alternative to orphanages or homelessness for poor children with tuberculosis in the family. These “pre-tubercular” kids were not ill but were at risk of becoming ill with tuberculosis based on analysis of family history. As preventative treatment for their increased exposure to TB, “fresh air, ample nourishment and moral fostering” with the “values of an idealized, white, American middle-class home life” were implemented (Connolly, 2011). In 1933, John Donnelly, a medical doctor from Huntersville, N.C., wrote an article titled “Tuberculosis in the Negro” and opened his argument with how the morbidity and mortality in African American TB patients is of grave importance “because of the great loss in productive power in this very necessary class of laborers.” The focus on testing African Americans for TB was primarily geared toward working Black people who had frequent contact with white people. Donnelly goes on to blame housewives for being “extremely careless” in failing to ensure that “household servants” were free from TB and stated that “servants in private families” will be tested without charge. Testing to carry out case-finding of TB was not for the benefit of Black patients, but for the white people they worked for.

In 1930, the mortality rate from TB was 2–3 times higher in African Americans than white Americans. Data from North Carolina health records showed death rates at 45.1 per 100,000 in white populations and 127.4 per 100,000 in Black populations. Donnelly blamed these differing rates on not only a supposed inherent lack of resistance to TB, but also low levels of education and an innate lack of ambition in the Black population. He cited a lack of attention to symptoms of disease as the reason for not seeking testing and medical advice until it was too
late; factors including deeply rooted superstition, “worthless concoctions” (traditional medicine), distrust in sanatoriums, and unwillingness to be isolated made it “impossible” to convince Black people to take TB seriously (Donnelly 1933). Other problems in the African American community that Donnelly pinpointed included low wages, poorly prepared food, and less sensitivity to pain. These exact stereotypes and biases of biological differences, personal responsibility, and cultural failings in the African American populations are very much present in modern medicine in the U.S. today (Hoffman 2016). Distrust from the Black community and low priority from U.S. medical and governmental leaders continue to plague testing efforts of infectious disease today.

Donnelly goes on to support preventative measures like yearly TB clinics in Black schools that would include skin testing and X-rays along with contact tracing. He added that the interpretation of skin reactions in Black people is “considerably more difficult than in the white race” but can still be done relatively successfully. This perceived difficulty, or extra hurdle, in testing African Americans for TB echoes bioethics research on how clinical studies in the U.S. favor white men over all other populations due to their perceived convenience and role as the default, normal population (Dresser, 1992). Instead of looking at the factors of structural inequity that lead to perceived differences in ease of communicating and providing care to Black populations, Black people’s supposed social and biological inferiority were blamed.

In the 1940s, mortality rates for TB were high in Atlanta and 2.5 times higher in Black populations than white ones, and African American women in Atlanta led one of the most successful anti-TB associations in the South (Fields, 1942). These women understood “the power of the state and the politics of the white supremacist public sphere” and leveraged this to improve
the survival of African Americans in Atlanta. Using white fears of Black people infecting white Atlanta residents with TB, these women combined with the white-led anti-TB groups to advocate for African Americans in a segregated health system. Unlike Dr. Donnelly who did not believe in the learning capacity of Black people, these women believed in the successes of educational campaigns for the whole African American community.

The mobile health clinic that circulated around the Black neighborhoods in Atlanta concurrently ran a medical educational campaign in an era when the city’s hospitals and clinics—even if they existed and saw Black patients—were not accessible to most African Americans. Because these clubwomen were part of the Black community themselves, they strategically selected mobile clinic sites that were the most accessible to their neighbors, including African American churches. Instead of denigrating the “worthless concoctions” like Dr. Donnelly had, these clubwomen decided that it was critical for the mobile clinics to reach these very neighborhoods that relied on traditional remedies. Each week, the mobile clinic, run by medical professionals, moved from one African American neighborhood to another to test for TB in each community (Judson, 1999).

With a positive TB test, the patient was set up in a quarantine facility at either a hospital or a sanitarium to prevent further community spread. Other diseases and ailments were also looked at, care was prescribed, and the clubwomen personally followed up with the patients to increase adherence to various treatments (Judson, 1999). From 1947 to 1953, the U.S. Public Health Service organized mass X-ray screening in urban areas with populations greater than 100,000. More than 20 million people were examined, and the mobile X-ray vans continued to
be used until the 1960s.

1980–1995: stigma of HIV coinfection with TB patients

Originally called gay-related immune deficiency (Altman, 1982), HIV was believed to have originated around 1920 (Gao, 1999), but the modes of transmission and identification of HIV-positive patients were unknown up until the 1980s. 1980–1995 spanned the beginning to the peak of the HIV epidemic in the U.S. HIV infections are not accompanied by noticeable signs or symptoms and are spread through bodily fluids—largely linked to unprotected sex and syringe use. In early 1985, the FDA approved the enzyme-linked immunosorbent assay (ELISA)—an accessible assay for the presence of HIV antibodies (Petrow, 1990). First used for testing of blood supplies in hospitals, ELISA was phased in as a test to monitor and reduce the spread of HIV in America.

Coinfection of TB in HIV patients quickly became the No. 1 killer of people with HIV. Previously well-functioning national TB campaigns became overwhelmed by the multiplicative challenges of TB and HIV coinfection. Improvements in TB control were temporarily set back (Coggin, 2010). 1988–1992 recorded increased TB rates in the U.S. after decades of near consistent decreases (CDC, 2020). TB–HIV coinfection qualifies as a convergence of two or more diseases that magnify the burden of disease, called a syndemic (Kwan, 2011).

The highest risk factor for developing active TB disease is HIV infection—a risk that is 20–30 times higher in those who are HIV-positive (Minnesota Department of Health, 2020). This makes treating LTBI in HIV-positive patients a priority, and the CDC recommends that all HIV-infected patients receive TB testing. Worldwide, one-third of HIV-positive people are
infected with TB. Integrated HIV testing for TB patients and timely TB testing for those living with HIV became standard and necessary (Fenton, 2012).

The former director of the TB program in the Arkansas Department of Health, Dr. William Stead, concluded that the principal discovery from their TB database from 1976–1997 was the “significant difference in innate resistance between whites and blacks to TB infection” (Stead, 2000). Blacks with active TB in this dataset were 50% more likely than such whites to be positive for TB disease, which is highly infectious. Stead recommended that, while health departments try to find all the close contacts of active TB cases, “a particularly great effort should be made among the African American and Native American contacts because of their greater risk both of infection and of becoming infectious.” He also highlighted dormitories, nursing homes, shelters, and prisons as other high-risk TB sites that should be tested and traced. Although Stead—a leader in public health of a Southern state in a post-segregation era—saw the need for addressing the disparities in the higher rates of TB infection and development of TB disease in African Americans, he incorrectly believed “innate resistance” and biological differences were the reason for poor TB outcomes in Black people.

It is widely accepted and conclusive scientific knowledge that race is not a biological concept but a social one (Blackburn, 2000). In fact, there is more genetic variation within a racial population than between populations (Witherspoon, 2007). Without understanding and incorporating the historical trauma and subsequent enduring structural inequalities in the lived experiences of African Americans, public health will not address the root of where differences in infection, morbidity, and mortality come from. Stead is correct that there must be a focus in testing among African American groups that have higher rates of TB, but he is incorrect and
racist in placing the blame on genetics; mindsets like this widen the gap of trust in public-health officials in nonwhite communities that face these racist biases, leading to lower levels of cooperation with treatment and testing. At the same time, this shows the very real potential for new infectious diseases to exponentially worsen other epidemic diseases while also exacerbating preexisting conditions, all of which are already a result of systemic racial inequity.

The “othering” of African American communities is a social aspect that leads to decreased trust in public health aimed at the “general public,” which often excludes or views the Black population as not equal. As HIV was spreading uncontained across the U.S. in 1985, Harvey V. Fineberg, the dean of the Harvard School of Public Health, said “bisexual men and prostitutes who are drug addicts are spreading the virus to the general population.” A subsequent New York Times article titled “Panel Disagrees over AIDS Risk for Public” did not ask for the meaning “general population.” Walt Odets, a gay man and clinical psychologist who lived and worked through the AIDS epidemic in San Francisco, pointed out that the Times article did not even “question why gay men, African Americans, and intravenous drug users were not considered part of the general population” (Odets 2019).

Stigma and fear stirred as politicians around the U.S. advocated for a public national registry of people who tested positive for HIV. Scott wrote that the rhetoric around HIV tests was laced with presumptions about the “immorality” of homosexual behavior, equating all homosexual behavior with high risk for HIV infection. Scott’s analysis included how “HIV testing practices also function in a more overtly ideological way to judge people as risky or clean, vulnerable or invulnerable, deviant or normal.” As much as we label various
communities—including the African American community—vulnerable, this label doesn’t come without judgement and stigmatization.

The risk of TB doubles in the year after an HIV infection and active TB increases the likelihood of death in HIV patients (Kwan, 2011). According to the CDC, HIV testing has become less stigmatized, more widely accessible and more equitable. However, from 1981 to 1995, the percentage of Americans with AIDS who were Black increased from 25.5% to 38%, while the percentage of Americans with AIDS who were white decreased from 59.7% to 42.4%. In this same time period, the Northeast saw a decrease of representing 38.9% to 30.3%. AIDS cases in the West decreased from 26.9% to 21.6%, while those in the South increased from 25.7% to 34.8%, and those in the North Central Region increased from 7.5% to 10% (CDC 2001). These trends mimic how the rates of COVID-19 were at first higher in cosmopolitan areas with more population density and international travel, but the epidemic has moved into the less populated and less globally connected regions of the U.S. as the virus became endemic.

AIDS was and is disproportionately high among minority and marginalized populations. The way the burden of disease shifted more toward Black Americans than white Americans over the beginning of the HIV epidemic is indicative of how public health efforts to contain transmission were less effective in African American populations and more effective in white ones. Voluntary, anonymous testing and counseling became critical to San Francisco’s overall HIV prevention effort.

“In short, the HIV epidemic has exacerbated long-standing problems of prejudice and bias. The potential for using HIV test results to foster discrimination has been obvious to all parties in the debate; the more vocal advocates of mandatory testing have made it
clear they think that such discrimination is appropriate. Discrimination would discourage vital cooperation.” (Scott, 2003)

To effectively address the problem of HIV and TB coinfection, the WHO recommends collaborative TB–HIV testing. This means that those with HIV should be tested for TB and those with active TB tested for HIV, preferably in the same location. Eliminating HIV-associated TB deaths would be a significant public health accomplishment. This all points to how TB is frequently associated with stigmatizing conditions like HIV. Other aspects of TB that lead to stigma include the association of TB to poverty, drug abuse, homelessness, imprisonment, and refugee status (TB Alert, 2020). These stereotypes surrounding TB can have real, grave consequences. People with symptoms may fear discrimination and be discouraged from seeking care, leading to serious progression of disease and possible transmission of infection to others. In this vicious cycle, the delayed treatment is less effective and people may be less likely to adhere to multi-month long treatment because they are afraid of being discovered as someone with active TB (TB Alert, 2020).

2010–2020: a modern case of a TB epidemic in Alabama

The Advisory Council for the Elimination of Tuberculosis, along with most TB elimination campaigns, recommends the following: identify and treat individuals with active TB, search for and test individuals who have had contact with TB patients to determine whether they are infected, provide appropriate treatment, and screen high-risk populations for infection to provide therapy to prevent progression (U.S. Institute of Medicine, 2000). Even with these
science-based recommendations, funding and interest in applying this “search, treat, prevent” method to African American populations have often fallen through the cracks, as evidenced by continued inequities in the burden of TB in the U.S. Additionally, HIV continues to disproportionately affect minority communities with African Americans accounting for 42% of the new HIV diagnoses in 2018, but only 13% of the population (CDC, 2018).

In 2019, the CDC reported TB disease in 1,753 non-Hispanic Black or African American persons in the United States out of a total of 8,916 TB cases. While African Americans account for around 13% of the U.S. population, they accounted for 20% of people reported with TB nationally. Furthermore, the rate of TB disease is 8 times higher for African Americans than for non-Hispanic Whites. From 1994 to 2016, TB rates in white Americans decreased by 82.3%, from 3.4 to 0.6 per 100,000, and TB rates in African American decreased by 81.8%, from 26.9 to 4.9 per 100,000 (Khan, 2018). The CDC recommends “increasing efforts to identify and treat latent TB infection in populations at risk for TB disease” in order to combat TB in the U.S. (CDC, 2019). Even with the introduction of IGRA (the TB blood test), lower rates in LTBI testing still persist in the U.S. among African Americans. One reason could be that IGRA is far more expensive than the TB skin test. As a result of inadequate targeted LTBI testing, increased active TB rates and transmission could occur in the U.S. in the future (Vozoris, 2016).

A study on community perspectives of TB knowledge, awareness, and stigma among African Americans gathered qualitative data between April, 2006 and March, 2007. 115 participants were from Montgomery County, N.C.; DeKalb County, Ga.; and Davidson County, Tenn.; and about one-third of TB patients, LTBI patients, and at-risk individuals in this cohort
did not finish high school. 92.0% of at-risk individuals, 85.7% of community leaders, and 100.0% of TB program staff reported having been tested for TB. While some participants could accurately identify that TB spreads in the air through an infectious individual’s cough, most participants demonstrated a widespread lack of TB knowledge. Even among patients who had been on TB treatment for two months already, only 28% of patients with TB infection or disease said that they knew what TB was (Royce, 2017). Some respondents described contracting TB as only for unsanitary, dirty, poor, incarcerated, or homeless people. In almost all participants, people thought that both TB disease and LTBI were contagious, when, in reality, LTBI and treated TB disease are not contagious. Some respondents thought the TB skin test was a vaccine or prevented TB, rather than just being a diagnostic tool. Other misconceptions included thinking that TB was a virus, could not be cured or was only in foreign-born populations. The only group that described TB as a major health concern in their town was rural North Carolina that could be linked to an outbreak that happened around the time of the survey. One North Carolina community leader said that, until the outbreak, you did not hear too much about TB.

At-risk participants in Georgia were familiar with diseases like herpes simplex and HIV, but not TB, even though they were tested annually for TB. The at-risk participants in Tennessee received TB testing in homeless shelters and jails, but they also were not confident in their TB knowledge. These participants reported feeling that they are rarely or never educated about TB. As a result of these findings, the researchers who conducted this study suggested further research aimed at developing and testing interventions to address the need in improving knowledge and awareness regarding TB, including highlighting the role of all health-care providers in dispelling misinformation about TB. It was also concluded that local community leaders, in the study and
beyond, represent an untapped resource for public health departments; these local leaders were “potential partners to champion TB health equity in their communities,” which is especially useful in a resource-scarce setting (Royce, 2017).

TB has also been labeled as an “urban health penalty,” which describes lower-quality health outcomes linked to impoverished areas in the U.S. (Weiss, 1998). While U.S.’s wealth gap continues to widen (Horowitz, 2020) and “public sector financial support of the poor is curtailed, the prevention and control of tuberculosis will be difficult to achieve” (Weiss, 1998). With effective and innovative treatment-delivery strategies like directly observed therapy and other prevention methods that could eliminate TB, Weiss expressed disappointment that federal, state, and municipal health-care administrators lack the will to fund this TB elimination effort adequately. Epidemics, much like famines (Gallo, 2017), are highly political events in which those in power decide which people to save and which to neglect.
Data from the U.S. CDC, 2019
However, public health that does not directly challenge the entrenched racial structures has led to “persistent disparity in the tuberculosis morbidity of the two races” that is “still a reminder of society’s unfulfilled obligation toward black Americans” (Torchia, 1975). This opinion from 1975 resonates today with an example from a 2016 TB outbreak in Marion, Ala., where effective public-health responses were impeded by historical racial inequalities and mistrust.

2016: Marion, Alabama

By January 2016, Marion, Ala.—a majority-Black town with a population of less than 3,600 and a poverty rate of over 50%—reported 253 TB cases per 100,000 people (US Census, 2018; Zielinski, 2016). This was 100 times higher than Alabama’s overall TB rate. State public-health workers delivered observed TB treatment, where patients were watched as they swallowed the medicine they needed. In return for their cooperation, patients were rewarded with $100. In February, 2016, STAT News reported that 2,200 residents in Marion were tested for TB, 27 had active TB, while 100 tested positive for latent TB (LTBI), and 3 deaths from active TB were recorded.

Dr. Allen Perkins, former president of the Alabama Rural Health Association, told The New York Times that there was a mistrust of government-delivered medicine in the community because of the Tuskegee Experiments in nearby Tuskegee, Ala. This infamous breach of bioethics lasted from 1932 to 1972, where the U.S. Public Health Service and the CDC infected African American men with syphilis and withheld lifesaving treatment for syphilis under the guise of free health care (Reverby 2009).
Much like Donnelly’s observations of TB in African Americans in 1933, the culture of waiting until advanced progression of disease to seek care has continued on to today. “There’s not a culture of care-seeking behavior unless you’re really sick,” Perkins said in the Times article. “There’s not support for local medical care, so when something like this happens, you have a health delivery system that’s unprepared.”

In an attempt to increase interest in TB testing in Marion, a $20 incentive was offered to local residents to take a TB test and $20 to come in for the results (Samuel, 2016). So many people came in to be tested one morning that the waiting room was packed and some were wearing surgical masks in line. Pam Barrett, director of Alabama’s Division of Tuberculosis Control, told STAT News that this incentivized testing backfired because outsiders came for the cash reward, and the residents did not want to wait inside a crowded clinic. A Marion city council member said that Marion residents were feeling targeted for being possibly diseased. Local civic leaders were not involved in the outreach effort. Frances Ford, a registered nurse and health-care coordinator for Perry County where Marion is located, said, “You can’t just show up. There is a history of racial tension here. To have white people come in from outside and asking questions… I know they’re just doing their job. But people start thinking, ‘Who are they looking for?’” (Samuel, 2016).

Barrett recalled a previous state-sponsored health fair that saw beer bottles thrown in the direction of public-health workers (Samuel, 2016). Beyond the town of Marion, African Americans accounted for 37% of U.S.-born TB cases while making up only 13% of the U.S.-born population (Howley, 2015). Instead of approaching a community as an outsider, we should look at the clubwomen of the 1940s who strategically constructed their TB testing
campaign around their local knowledge and with cultural nuance that led to trust and increased testing rates. To further improve upon TB-testing effectiveness in the African American community, future inevitable outbreaks necessitate proactive outreach rather than costly reactive containment of disease that has already spread unnoticed.

Conclusion

“Efficient public health machinery is quite as necessary to the welfare of the people as elaborately equipped police and fire departments.”(Donnelly 1933)

This paper analyzed testing for asymptomatic and symptomatic infection throughout the history of TB in three different time periods from 1930 on to better understand how testing was carried out in TB outbreaks in African American populations. I also assessed how different cases of TB testing from each time period could be applied to COVID-19 and other current and future infectious disease outbreaks that entail testing. As a result, it is clear that we have enough historical evidence and data from TB to look at to create a basic framework of what works and what does not when it comes to successful infectious-disease testing in African American populations. Here are five lessons we can take away:

1. Much like Donnelly in 1933, who advocated for TB testing measures in the Black community on the basis of sick Black workers hurting the white population, COVID-19 testing rhetoric for essential workers had similar echoes. A Brookings Institute report, How to Protect Essential Workers During COVID-19, rationalized that the reason we need to provide free testing to essential workers is because “many of these workers risk
their lives to protect ours” and thus, “the nation has a responsibility to protect the health and financial stability of these individuals and their families” who were already in economically precarious positions before the pandemic hit. Situating essential workers as “their lives” which protect “ours” is insinuating that essential workers are separate from “us” and the general population. Although Black workers make up 1 in 9 workers overall, they constitute 1 in 6 essential workers (Gould, 2020). This parallels Fineberg’s comment on the HIV epidemic in 1985 that outlined African Americans as not a part of the general population. In order for African Americans to have equitable access to infectious disease testing and lessen their burden of disease, they must be considered as the general population and not ‘othered.’ Notions of racial ‘otherness’ have promoted white superiority throughout history with examples in the imperialism of the ‘American West’ and the ‘Nazi East’ (Kakel, 2011). This way, testing outreach is conducted not because Black people are essential workers, but because they are essential humans. Inequitable morbidity and mortality rates that are in part due to unequal access to testing will not be solved in a public-health framework that mirrors systemic racism and that differentiates the value of a life based on race.

2. The local strategies Atlanta clubwomen employed for their education and outreach to African American communities made all the difference in determining Atlanta clubwomen’s success in the 1940s and Marion’s failure in 2016 in responding to TB outbreaks in predominantly African American populations. The Atlanta clubwomen understood their own communities’ needs and set up their test sites in spaces that were known and easy to access for the African American community. They saw the gaps in
knowledge and medical services and filled them while reaching out and making interpersonal connections, checking in on the community and building trust through support and communication. On the other hand, state public-health officials in 2016 neglected to work with Marion’s local community leaders and were met with suspicion and poor TB-test enrollment. In July 2020, Voice of America reported that getting COVID-19 tests was harder in America’s poorer Black neighborhoods because they were far from chain pharmacies and urgent-care clinics where most test sites were located. In contrast, the Atlanta clubwomen set up their mobile clinics in spaces like Black churches and other places their community members were familiar with; this was met with far greater testing turnout. In order to achieve effective infectious-disease testing that leads to more equitable health outcomes, it is especially critical for outreach to African American populations to meet people in the places they are, both physically and educationally. Unsuccessful approaches have failed to meet communities where they are because of a lack of commitment to understanding the community’s needs.

3. High levels of TB-related fear and stigma in the African American community will continue to negatively impact public-health delivery of TB services unless these stressors are tackled directly. This means that there must be an active effort to bridge the gap between the “health department experience of TB-affected individuals and the perception of these services by local community leaders” (Royce, 2017), which stems from historical mistreatment, persecution, and disparities in medical care that persist today. Instead of addressing the distrust of medical workers after an outbreak has already begun—a time when the disease and panic has already taken hold in the community—public-health
officials should prepare before it hits. Consistent and proactive public-health education and outreach will help prevent the outcomes that played out in Marion in 2016. The clubwomen of Atlanta personally followed up with patients’ treatment regimens and not only made but also maintained personal connections to the community. We know that there will continue to be a global rise in human infectious-disease outbreaks (Smith, 2014), so we need to start preparing and reaching out to African American communities now to prevent falling behind on future epidemic diseases.

4. Given that both health-care professionals and Black Lives Matter supporters called racism a pandemic (Godlee 2020), we should consider all epidemics in the African American population to be syndemics. Due to how the U.S. “tacitly tolerates large inequities in access and disparities in health,” a legacy of this ambivalence is that testing disparities according to race are prevalent as a result (Larson, 2008). For all future infectious-disease outbreaks, we should be prepared for the dual epidemics of racism and disease that interact to place a greater burden of disease on the Black population in the U.S. Additionally, as we have seen with TB–HIV coinfection, disparities in one epidemic can magnify and further disparities in subsequent epidemics. If we do not aggressively address the disproportionate suffering in one epidemic, each successive future epidemic will increase racial inequality in health outcomes as comorbidities and contributing risk factors combine multiplicatively.

5. Simply ramping up testing capacity, even if applied fairly in the numerical sense, fails to address the political, historical, socioeconomic, and environmental factors that allow for the spread of these infectious diseases in high-risk communities in the first place. Justice
that is restorative must be carried out by public health organizations and the medical medical community, or else symbolic gestures of an emphasis on African American outreach will be empty and lead to ineffective public health strategies that attempt to target disparities in the Black community. One example of this is how the CDC recommended racial minorities be prioritized for the COVID-19 vaccine (Aguilar, 2020). Even with efforts at equitable distribution, African Americans were receiving vaccinations at dramatically lower rates than white Americans (Recht, 2021). Too often—as in how Maryland medical director Dr. O’Neill lamented how Black people avoided medical care for TB in the 1930s—the Black population’s hesitancy to trust public-health officials is blamed on Black people themselves instead of the root cause of systemic racism. Public-health measures that attempt to distribute care equally fail to confront the deeply entrenched structural inequities that leave the African American community short of equality even when funneled the same amount of resources.

“The scourge of COVID-19 will end, but health care disparities will persist... Public health is complicated and social reengineering is complex, but change of this magnitude does not happen without a new resolve. The US has needed a trigger to fully address health care disparities; COVID-19 may be that bellwether event.” (Yancy, 2020)

When it comes to whether COVID-19 is an indicator of change for health-care disparities, the way TB continues to exploit health disparities to spread in the U.S. is perhaps an indicator that COVID-19 is not a bellwether event. COVID-19 has yet again highlighted racial
disparities like TB always did and continues to do. Even with statistics and case studies that
document the TB outbreaks in the U.S., we continue to accept disproportionate suffering in
infectious-disease epidemics. The U.S. does not lack the resources or knowledge to address
testing inequities in the African American community. Instead, it is a lack of imagination and
commitment to concrete steps that directly confront structural inequities the Black population
faces that allow for TB and COVID-19 testing campaigns in the U.S. to fail time and time again.
With historical examples of TB testing successes in the African American community, we can
start by implementing those lessons into our current and future infectious-disease containment
strategies to ensure that, at the very least, the first step—having access to high-quality, reliable
tests—will not impede improvements in public-health equity. Further research on the nuances of
other oppressed identity groups will be beneficial, and the findings in this paper can likely be
applied to other minority groups in the U.S., like Native Americans, who have faced and
continue to face persecution and injustice.
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