

# Health disparity in CF: Perspectives from a lived experience

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## Abstract

In this commentary, we discuss health disparities, reflecting on our experience in delayed diagnosis of cystic fibrosis based on race and bias in healthcare practitioners.

## KEYWORDS

cystic fibrosis, health disparity

What is Health Disparity, and how is it defined in the literature and in reality? To understand the word in its full context, let us first focus on what is most evident and that is the word “disparity.” The [HealthyPeople.org](https://www.healthypeople.org) website notes, “Although the term *disparities* is often interpreted to mean racial or ethnic disparities, many dimensions of disparity exist in the United States, particularly in health. If a health outcome is seen to a greater or lesser extent between populations, there is disparity.”<sup>1</sup>

We, a person with CF whose diagnosis was delayed by decades (Terry Wright) and his wife (Michele Wright), have experienced a significant disparity in health care and appreciate that this definition of disparity is not one-dimensional or fitting in a particular box, because disparity, especially health disparity, profoundly impacts individuals, especially those from historically marginalized groups sometimes called “racial and ethnic minorities,” medically, physically, mentally, emotionally, and financially. You cannot effectively address health disparities without addressing larger societal disparities.

Michele Wright knows this all too well both personally and professionally. Ironically, she was born in the historic black town of Tuskegee, Alabama at John A. Andrew Memorial Hospital, the same hospital in which the infamous Tuskegee Syphilis Study took place. As noted on Wikipedia, “The *Tuskegee Study of Untreated Syphilis in the Negro Male...* was an ethically abusive study conducted between 1932 and 1972 by the United States Public Health Service and the Centers for Disease Control on a group of nearly 400 African Americans with syphilis. The purpose of the study was to observe the effects of the disease when untreated, though by the end of the study it was entirely treatable. The men were not informed of the nature of the experiment, and more than 100 died as a result.”<sup>2</sup>

The Tuskegee study has not only had a defining impact on Michele but has been often noted as a major cause for ongoing medical mistrust by African Americans. With advanced degrees in

engineering and public policy, Michele was committed to further focusing on the importance of addressing health disparities throughout her extensive career in pharmaceuticals, biotechnology, healthcare administration, as well as her tenure as a regional Chief Executive Officer with the American Red Cross.

Michele's background was advantageous in addressing her own health challenges and eventually the unforeseen complex health disparities of her husband Terry Wright, a certified personal fitness trainer, master gardener, and avid health advocate. The complex nature of health disparity is noted by the US Centers for Disease Control and Prevention (CDC): “Health disparities are preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations... Health disparities are inequitable and are directly related to the historical and current unequal distribution of social, political, economic, and environmental resources.”<sup>3</sup>

This definition ideally defines our journey as we struggled to find a name for the disease that relentlessly haunted and tormented Terry Wright for the greater first five decades of his life. Ultimately, at the age of 54, Terry would be diagnosed with cystic fibrosis (CF), a disease for which the majority of people are diagnosed by age 2, according to data from the Cystic Fibrosis Foundation (CFF).<sup>4</sup> The CFF further notes, “Most people with CF are diagnosed quickly, although in some cases the diagnosis is not clear and subsequent tests may be recommended.”

Oh, how desperately we wished Terry Wright could have been counted among the fortunate and privileged group of CFers who were diagnosed quickly. But that is not our story nor journey. Instead, Terry is a 59-year-old African American man who was diagnosed with CF at the age of 54, although he had been hospitalized, seen by an array of healthcare practitioners, and was unknowingly dealing with the devastating consequences of CF throughout his entire life. The

logical question is: how could an individual with the classic “textbook” symptoms of CF go undiagnosed for 54 years? The valid answer is under the term “health disparity” as we both can attest to this reality firsthand through our perspectives from a lived experience.

A striking example is that in early 2000, Michele encouraged her soon-to-be husband Terry to go to a walk-in clinic. Her professional pharmaceutical experience made her suspect that he could have pneumonia. Upon arriving and being examined, the doctor told Terry that if he were not Black, he would say he had CF. Those words “if you weren't Black” and “cystic fibrosis” would come back to haunt us 17 years later. But first, let us revisit the assumption, “If you weren't Black.”

This statement stems from stereotypes, biased diagnosis, misperceptions, and contributed to “health disparity” due to delayed diagnosis and major negative impacts of poor healthcare services and progressively worsening quality of life. In the 54 years leading up to Terry's CF diagnosis, he spent more time in the hospital than we spent on dates (including Terry having to leave our honeymoon to head to the emergency room). Terry was never able to enjoy a meal because eating was synonymous with gut-wrenching stomach pains followed by extreme nausea and violent uncontrollable vomiting.

To make matters worse, the diagnoses that Terry was given for his different ailments, including chronic pancreatitis, were assumed to be a consequence of Terry's own behaviors. It was assumed that this disorder was caused by alcohol abuse and not any particular underlying ailment. This was one of many examples of being told but not being heard. A healthcare professional does not truly listen to a patient when they already have a foregone conclusion. A Washington article Post reported:

“Doctors, like the rest of us, make mistakes. Every year, upward of 12 million Americans see a physician and come away with a wrong diagnosis. The top cause? Bad judgment, says David Newman-Toker, director of the Johns Hopkins Armstrong Institute for Patient Safety and Quality's Center for Diagnostic Excellence. Newman-Toker found that judgment errors accounted for 86 percent of 55,377 medical malpractice claims he evaluated where misdiagnosis led to death or disability. The judgment blame bucket includes an assortment of knowledge gaps, inattentions, misinterpretations and ...implicit bias.

Implicit bias occurs when a well-intended physician's unconscious assumptions get in the way of objectively gathering or assessing a patient.

Is implicit bias a gateway to healthcare disparities? It's hard to tease out whether some diagnostic errors are caused by racism or sexism, or simply a lack of knowledge about how certain diseases appear differently because of a person's race, age, or gender, says Newman-Toker, also a professor of neurology at the Johns Hopkins University School of Medicine. 'Bias thrives in the void of expertise.' Implicit bias in clinical settings is hard to measure and good data is lacking. '[Bias] may be a bigger problem than we think,' Thomas Yuen, on the faculty of the Family Medicine Residency Program at Crozer-Chester Medical Center in Upland, Pa. says. 'The final frontier [for physicians] could be our own judgment and emotions.'”<sup>5</sup>

Health disparities have also resulted in Terry undergoing more surgeries than many people have endured years in school. In 2001,

Terry had a pancreatojejunostomy to alleviate severe pain associated with chronic pancreatitis. The pain that Terry endured is indescribable. Can you imagine a child being put on a concoction of Demerol and Phenergan before they had even advanced to first grade? It is interesting how this concoction became just as much Terry's norm as his unbearable pain. Nonetheless, in all his pain, surgeries, and an array of medical health professionals, no one ever bothered to connect the dots of the root causes of his issues. Not even a gallbladder removal surgery earned him such rights.

This makes Terry's story all the more frustrating. He was finally prescribed pancreatic enzyme replacement therapy after his 2001 pancreatojejunostomy. To learn after the fact that something as simple as taking pancreatic enzymes could have significantly improved Terry's quality of being is heartbreaking in itself. If only we had the option to have checked with Terry's multitude of doctors, nurses, or dietitians on the subject of enzymes, Terry might have avoided potential unnecessary surgeries, weight and appetite loss, emergency room visits, hospitalizations, and insecurities eating in public. Would we have been able to enjoy our November 4, 2000 sacred union and honeymoon in peace instead of Terry spending most of this time at the emergency room if he had been able to digest food and absorb the nutrients to keep his body healthy?

In addition, would we have foregone all the time, money, and specialists that were invested for us to get pregnant, never realizing that our infertility issues were a result of Terry's unknown CF? This was another missed opportunity to diagnose Terry earlier due to another sign of CF. If one healthcare professional had explored his medical history further when it was discovered that Terry had sperm production in his testicles but an absent vas deferens could have connected the dots and led us to an earlier diagnosis. Terry went through a painful sperm retrieval procedure in which sperm were collected directly from his testis to be frozen and reserved for us to ultimately use during our twice-failed attempt at in vitro fertilization without having the opportunity for earlier diagnosis of CF.

The definitive reason that so many classic signs and symptoms were missed throughout this period in Terry's life may never be known. But what we do know is that it took 54 years for Terry to be diagnosed with CF. And to think about how everything had to finally add up for us to ultimately learn of Terry's CF diagnosis is still unnerving considering it could have just as easily never happened.

In 2016, Terry was hospitalized with pneumonia yet again. This time, the hospital threw everything but the hospital bathroom sink at him to get him well including an aggressive combo of high-powered antibiotics. Because Michele had a pharmaceutical background including promoting antibiotics, she knew something was seriously wrong, because this time Terry continued to get worse and not better. He was hospitalized in critical condition all the way through Christmas 2016 and New Year's 2017. She knew that if we did not find answers soon, Terry would not be around to see 2018.

Albert Einstein said, “The definition of insanity is doing the same thing over and over again but expecting different results.” Well, we were not insane and realized that what Terry had been through and the medical care he had received in the 17 years leading up to that

point was not working and resulted in a critical point of life and death. During Michele's tenure with Pfizer pharmaceuticals, she promoted a newly released broad-spectrum antibiotic in the class of drugs called fluoroquinolones. Because it was used to treat the most serious of infections, she often called on Infectious Disease Doctors (IDDs) to help promote this particular drug's multiple indications and remembered the IDDs as being the ones that could solve the unsolvable.

Once this came back to Michele's remembrance, she was suddenly amazed that Terry was never (not once) referred for evaluation by an IDD. So, in early 2017, following Terry's release from his prolonged stay in the hospital, she was determined to find an IDD for Terry. She felt the best success in finding one would be at a major research teaching hospital like the University of Arkansas for Medical Sciences. To her pleasant surprise, not only did they have IDDs on their roster, but an entire Infectious Diseases Clinic.

She immediately made an urgent appointment. And within 30–45 min of listening to Terry and Michele, the hosts of physicians we saw that day concluded their belief that Terry, although African American, had the classic signs of CF. All Terry and I could do is look at each other in disbelief as we reflected back 17 years earlier on hearing the haunting words, "if you weren't Black." But these healthcare professionals decided to not make any assumptions, stereotypes, or misperceptions and sent Terry back to the same children's hospital that he spent so many years hospitalized throughout his childhood to take a sweat test to measure the amount of chloride in his sweat.

We knew something was wrong when the hospital called and wanted to repeat Terry's sweat test again! Michele asked why and was informed that we would have to contact our physician for more information. We knew then that something was seriously wrong. After the second sweat test was concluded, it was confirmed that Terry indeed (at the age of 54) had CF. A blood sample was subsequently sent to Johns Hopkins where both of Terry's gene mutations were identified, further confirming the CF diagnosis.

We were fortunate because although it took 54 years for Terry to obtain the diagnosis of CF, it could have been yet another instance of deadly health disparity. But it was not. After so many trials, tribulations, pain, suffering, and lost hope, Terry finally had a name for the disease that haunted him his entire life. And without a doubt, our perspectives from a lived experience clearly imply this devastating 54 years late diagnosis was the direct result of "Health Disparity" based on what we believe is the misperception that CF is a "White" people's disease.

According to the latest data published from the Cystic Fibrosis Foundation Patient Registry,<sup>6</sup> 93.4% of individuals with CF identify as White, 9.4% are Hispanic, and 4.7% are Black/African American, and 3.8% are classified as "other race." These percentages are increasing; among infants diagnosed with CF between 2010 and 2018, 6%–7% are Black/African American and 13% are Hispanic.<sup>7</sup> It is undeniably clear that CF affects White, non-Hispanic people predominately. However, given Terry's 54-year journey to CF diagnosis, we do not believe these numbers represent a true reflection. We believe that

the numbers could potentially be significantly higher if the Black people with CF who have not been diagnosed or died without a diagnosis would have been afforded the opportunity to be counted.

This is why it was our passion to cofound the National Organization of African Americans with Cystic Fibrosis (NOAACF), a 501(c)(3) non-profit organization with a mission to engage, educate, and raise CF awareness in the African American community and to help bring valuable resources, knowledge, empowerment, and support to CF patients, families, healthcare professionals, and the community.

Through widespread involvement, partnerships, and outreach, NOAACF's program scope is to ensure that the public is educated, informed, and made aware of CF's existence, prevalence, and impact on underrepresented communities. And through these efforts and NOAACF's national platform, we hope to address not only health disparities, but misperceptions and stereotypes based on race, ethnicity, age, socioeconomic status, and other demographics.

We believe this will require a concerted effort where varying communities across the CF spectrum come together on one accord and first acknowledge that CF does not belong to any one specific demographic group and that the umbrella of "Healthy Disparity" impacts not only the quality of healthcare services but the short and long-term health outcomes of those who have been affected by these biased healthcare assumptions. This also requires education of and commitment from healthcare practitioners. The American Medical Association (AMA) concurs: "Recent studies have shown that despite the improvements in the overall health of the country, racial and ethnic minorities experience a lower quality of health care—they are less likely to receive routine medical care and face higher rates of morbidity and mortality than nonminorities. The American Medical Association (AMA) encourages physicians to examine their own practices to ensure equality in medical care. The AMA's mission is to achieve health equity by mitigating disparity factors in the patient population."<sup>8,9</sup>

## 1.1 | Research on eliminating healthcare inequalities

The Institute of Medicine (IOM; now the National Academy of Medicine) performed an assessment on the differences in the kinds and quality of health care received by U.S. racial and ethnic minorities and nonminorities.

The IOM report found that:

- Disparities in health care exist and are associated with worse health outcomes.
- Healthcare disparities occur in the context of broader inequality.
- There are many sources across health systems, providers, patients, and managers that contribute to disparities.
- Bias, stereotyping, prejudice, and clinical uncertainty contribute to disparities.
- A small number of studies suggest that racial and ethnic minority patients are more likely to refuse treatment.

The IOM concluded that a comprehensive, multilevel strategy is needed to eliminate these disparities.<sup>10</sup> The National Healthcare Quality & Disparities Report,<sup>11</sup> published annually by the Agency for Healthcare Research and Quality, assesses measures of access to care, affordable care, care coordination, effective treatment, healthy living, patient safety, and person-centered care, including disparities related to race, ethnicity, income, and other social determinants of health.

While we are located and focus on reducing and eliminating health disparities in the United States, we also recognize that health disparities in CF are seen across the globe. Black children with CF in South Africa are diagnosed later than White children and are more likely to be malnourished at diagnosis.<sup>12</sup> Low socioeconomic status is a risk factor for more severe disease and early mortality in people with CF from many countries.<sup>13</sup> In the United Kingdom, newborn screening does not reduce differences in early outcomes associated with social inequalities.<sup>14</sup> We also recognize that while people with CF who are from racial and ethnic minority groups are less likely to be eligible, by CFTR gene variant, for highly effective modulator therapies,<sup>15</sup> they are not available at all to people with CF in many parts of the world.

NOAACF is fully committed to relentlessly working to reduce health disparities one step, one patient, one difference at a time. We also realize that this is not a race but a continual journey as we look forward to working in synergy and collaborating with the CF and healthcare community on an array of platforms, tools, and resources that will help to not only address “health disparity” but minimize it.

#### AUTHOR CONTRIBUTIONS

**Michele Wright:** Conceptualization (equal); investigation (equal); writing original draft (lead); writing review & editing (lead).

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**How to cite this article:** Wright M, Wright T. Health disparity in CF: Perspectives from a lived experience. *Pediatric Pulmonology*. 2021;1-4. doi:10.1002/ppul.25727