WHEN THEY ARE IN PAIN, THEY DON'T GET THE CARE THAT THEY NEED — AND IF THEY DO, IT IS ONLY AFTER UNNECESSARY DELAYS. FOR BLACK WOMEN, A HISTORY OF MISTREATMENT HAS LED TO A DISTRUST OF MEDICINE AND A FEELING THAT THEY ARE

SEEN BUT NOT HEARD

STORY BY NOURA JABIR & ELLA WEST

Due to the sensitive nature of this story, some names have been changed.

ILLUSTRATION AND PAGE DESIGN BY Celine Huang

With her newborn baby and husband by her side, Carla Wall lay on a cot in a hospital hallway as doctors ignored her cries of discomfort for more than four hours. She needed fluids, pain medication and a warm room with blankets, or the consequences could be fatal.

Wall, a Lower School art teacher, suffers from sickle cell anemia. She knew she wasn't receiving the proper care. When she reaches a pain level of 10, signifying the worst possible pain, she should be comfortably resting, not waiting in agony.

"I am supposed to have an IV in my arm and oxygen going up my nose," Wall said.

Even after a doctor finally attended to her, she was denied pain medication because the doctor insisted that a blood sample be analyzed first. When the lab results eventually came in, they showed nothing seriously wrong.

"Sickle cell can happen like that," Wall said. "It doesn't mean I'm not in pain."

The doctor informed Wall that she had to be cautious when fulfilling patient requests for medication because "some people come in here seeking drugs."

At that moment, Wall considered dialing 911.

"I could feel my body shutting down," she said. "This was the worst I'd ever felt — and this woman was telling me that I was drug-seeking."

Seven years later, Wall is still unsure why the doctor refused to give her adequate care.

"I don't know if she didn't care because she actually thought I was taking drugs, because she was racist or because she didn't believe that I was in pain," Wall said. "But I believe that she just did not care for Black women."

Racial and ethnic disparities in pain treatment are rarely intentional, according to the Association of American Medical Colleges. Often, the inequities are "the product of complex influences, including implicit biases that providers don't even know they have."

Doctors like Valerie Lewis, Professor and the Chair of the Department of Orthopedic Oncology at the University of Texas MD Anderson Cancer Center, are cognizant of how some colleagues treat patients "that don't look like them."

"Minority pain isn't addressed as much as the majority's pain," said Lewis, mother of seniors Olivia and Isabella O'Reilly. "Doctors may underestimate a Black patient's pain, and as a result, under-prescribe pain meds."

According to a 2016 National Academy of Science study, nearly half of white medical trainees believe Black people have "thicker skin" or have "less sensitive nerve endings" than white people. These misconceptions demonstrate the destructive consequences of 19th-century racial pseudoscience.

While more medical schools now emphasize bridging the cultural gap between doctors and patients, the term "culturally competent" did not consistently appear in medical literature until the late 1990s. Thus older physicians, many of whom are medical school professors, struggle to adapt.

"A lot of the older faculty didn't have cultural competency as a part of their curriculum when they were first studying medicine," said Daniel Bland (`14), a student at Baylor College of Medicine. "They've had to learn on the job."

The diversity of medical school students and faculty can also affect the education an institution provides, according to Joanne Armstrong, an obstetrician-gynecologist and Associate Professor at the University of Texas Health Science Center.

"When doctors live closer to the experience of their patients, they can understand their challenges — or maybe engineer systems to accommodate some of these challenges," said Armstrong, the mother of an alum and current student. "That understanding is why diversity matters in medicine — at all levels."

MEDICAL GASLIGHTING

For the last few months, junior Kennedy Black has watched anxiously as her grandmother — an 84-year-old African-American woman — was checked in and out of hospitals. While undergoing a recent treatment for a urinary tract infection, her grandmother began displaying Covid-19 symptoms.

Because she has dementia, Black's grandmother often relies upon her son, an ER physician, to communicate with healthcare providers. Black's father identified signs of the virus in his mother and requested that she receive a Covid test. Her doctor, who was white, declined.

"The doctor was so convinced that he was right and that what my dad was suggesting was wrong," Black said. "He didn't want to be told by a man of color that he wasn't doing his job correctly."

The doctor eventually sent Black's grandmother home, where her condition worsened. Concerned, Black's family insisted that she return to the hospital and seek care from a different physician who gave her a Covid test.

It came back positive.

According to Dr. Lewis, who is Black, race impacts relationship dynamics between patients and healthcare providers.

"Because of a history of mistreatment, African-American families may not fully trust the medical establishment," Lewis said. "They're in an all-white, unfamiliar environment, so they can often be very protective of their relative, the patient."

A 2018 Stanford University study suggests that racial and ethnic concordance between physicians and patients improves health outcomes. Black patients were more likely to talk freely with a Black doctor about their health, and Black doctors were more likely to listen to their patients' concerns.

When Savana was in eighth grade, her mother sent her to the pediatrician for a rash. Instead of addressing the issue, her doctor said she should "stop inspecting [herself] with a microscope."

Now a junior, Savana realizes that her doctor was teaching her to disregard her intuition and not listen to her mother when it came to matters of her health and well-being.

'I WAS BASICALLY A TEST DUMMY'

Following her first ever surgery, Angela Anderson was in immense pain. Her nurse did not follow proper post-surgery procedures, and for two hours, she waited in tears.

"I had to actually start crying for her to call my doctor."

Even before Anderson's "disturbing" post-surgery experience, she did not always feel comfortable around healthcare providers. Two years ago, her primary care physician noticed that some of her hormone levels were high. After a 10-minute conversation, her doctor prescribed a medicine that ultimately exacerbated the situation.

When Anderson returned months later, her health had not improved sufficiently, so her doctor prescribed a different medication. Anderson asked him to specify the intended results and side effects of the medicine, but she received a lackluster response.

"They weren't really listening to me, and it was clear they didn't really care about me," she said. "I was basically a test dummy."

Distrust of the medical establishment has long pervaded communities of color, due to a history of experimentation on Black and Brown bodies.

James Marian Sims, often credited as the "Father of Modern Gynecology," pioneered surgical techniques for women's health. In 1876, he was named President of the American Medical Association and later served as President of the American Gynecological Society, which he helped establish.

Sims operated under the misconception that Black people did not feel pain. To advance his practice, he operated on at least 10 enslaved women, never using anesthesia. One of his patients, a 17-year-old named Anarcha, endured nearly 30 surgeries over the course of four years.

When Sims opened the country's first women's hospital in New York in 1855, he treated his white patients with anesthesia.

"Looking at the things he did to some of these women," Wall said, "I could pass out."

More familiar to the American public is the 1932 "Tuskegee Study of Untreated Syphilis in the Negro Male," in which the Public Health Service partnered with the Tuskegee Institute to develop treatment programs for syphilis. Over the course of 40 years, researchers selected a group of 600 Black men, roughly half of whom had syphilis, and began conducting experimental treatment on them. The study was completed without the informed consent of the subjects, according to the Centers for Disease Control and Prevention.

> I could feel my body shutting down. This was the worst I'd ever felt — and this woman was telling me that I was drug-seeking.
>
> CARLA WALL

On their official website, the CDC acknowledges: "In truth, they did not receive the proper treatment needed to cure their illness."

Even when penicillin became the treatment of choice for syphilis in 1947, the Tuskegee Study researchers actively prevented subjects from receiving it.

While the study has been denounced as unethical, its consequences still resonate.

"The Covid pandemic highlights the legacy of institutional racism in the medical field," an SJS teacher said. "I turn on the TV, and all over the nation there are white people standing in line for the vaccine, but I rarely see Black people or people of color. There's so much distrust."

The teacher, who is eager to get vaccinated, cites the large number of white recipients as evidence that the vaccine is safe.

"If the medical community — or the government — were specifically targeting minority groups, saying they'd come to our communities first and give us the shot, then I'd be more hesitant," the teacher said.

HELPING DOCTORS DO THE RIGHT THING

Because the business structure of many medical practices emphasizes efficiency, physicians can struggle to balance compassion and quality medicine.

Time-restricted appointments pose a "fixed challenge" to patient-centered care, according to Dr. Armstrong.

"I have never encountered a doctor who didn't want to do the right thing," Armstrong said. "But they need time to connect with patients, and it's often not there."

As the medical field relies more heavily on technology, maintaining humanity in healthcare is increasingly important.

"We are moving into an age of medicine — machine learning — where artificial intelligence is shaping medical diagnosis and treatment recommendations," Armstrong said. "Regardless of new technologies introduced into clinical practice, the focus should be on the individual patient."

Before she enters a patient's room, Dr. Lewis will pause at the door, grip the handle, take a deep breath and smile.

"It slows me down," she said, "and I enter the room smiling."

Lewis said that sitting down immediately after greeting a patient — as opposed to standing and firing questions at them — sets the stage for collaboration. It also makes the patient feel as though she has spent more time with them.

For Lewis, laying hands on the patient is important, not only for diagnosis but also for establishing trust.

These techniques, which Lewis learned in medical school, help doctors meaningfully connect with patients during brief visits.

In 2014, Lewis edited an orthopedic surgery handbook, "Culturally Competent Care Guidebook," which explains "how to be courteous to patients in their own culture."

"Communication competency is a patient care issue," Lewis said. "Doctors who successfully communicate with their patients provide a better patient experience and thus experience better patient outcomes."

As cultural competency becomes a more integral part of the medical school curriculum, medical school students like Daniel Bland appreciate the value of holistic education.

Bland, who majored in English while on a pre-med track at Notre Dame, said that his work in the humanities has proven useful in medical school.

During clinical rotations, Bland considers himself well-equipped to communicate with patients and colleagues.

"I'm able to think on my feet in terms of how I can phrase things," Bland said, "or how I can rephrase things to make more sense to people."

Bland recognizes that medicine "is not perfect," but he's also observed how medical institutions are attempting to remedy inequities.

"We get a lot of hands-on learning about social determinants of health and how they present in a hospital setting," Bland said. "We're not just learning some medical concept — we're also learning how that concept can manifest as a consequence of disparity."

Senior Carolyn DePinho serves as co-President of the Womxn of Color affinity group and plans to study medicine in college. While she has always "found comfort in science," she has become attuned to the intersections of social justice and medicine.

"Once I stopped viewing science as something removed from the social systems that determine a community's health, it became impossible to ignore inequities in medicine," she said.

Last semester, DePinho collaborated with leaders of the African-American Affinity Group and the Pre-Med Club to host a forum series about medical discrimination, exploring how social identifiers like gender and race play out in a healthcare setting. The next forum, which is scheduled for March, will address classism in medicine.

"People forget that medicine is an institution that has upheld systems of oppression and structural barriers," DePinho said. "We think we can just focus on science because science is fair — but that just isn't true."

As the medical field ushers in a new generation of healthcare professionals, DePinho is hopeful that doctors will recognize and strive to correct its flaws.

"People think that science is an escape from reality," DePinho said. "It absolutely is not."