

# Tackling Health Care Disparities

Disparities in patient care are present throughout medicine. An overview of how these inequities play out in the care of patients with glaucoma.

By Lori Baker-Schena, MBA, EdD, Contributing Writer

**T**HIS PAST YEAR, LEON W. HERNDON Jr., MD, spent countless hours on Zoom calls discussing what the twin crises of COVID-19 and racial injustice laid bare—the glaring disparities in eye care delivery and research among underrepresented minority groups.

Glaucoma specialists like Dr. Herndon are well aware of the social determinants of health. After all, research has shown that primary open-angle glaucoma (POAG) is six times more prevalent among Blacks than in age-matched Whites, with Blacks exhibiting more severe disease that is resistant to intervention and results in higher rates of blindness.<sup>1</sup>

## Toll on Patients' Vision

While the genetic underpinnings of glaucoma continue to be studied, the relationship between socioeconomic status, ethnicity, access to eye care, and reduced quality of life also play a role in glaucoma development and disease severity. And in a March 2021 keynote talk to the International Agency for the Prevention of Blindness, Dr. Herndon noted that this web of intersecting factors is taking a direct toll on patients' vision.

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**OUTSIZED IMPACT.** *The likelihood of developing POAG—and experiencing its complications—is higher in Black patients.*

“I am not a social sciences researcher, but I have lived my entire life witnessing inequities in health care,” said Dr. Herndon, at Duke University Eye Center in Durham, North Carolina. “There is so much information that many ophthalmologists are not aware of. If we as a profession are to make an impact, we must be aware of the problems, educate ourselves, and be open to change.”

## One Step Forward, Two Steps Back?

Three decades ago, when Eydie Miller-Ellis, MD, was a resident at the University of Pennsylvania in Philadelphia, she became interested in glaucoma after witnessing patient after patient fall through the cracks of the health care system.

“A lack of follow-up, marginal patient education, and low treatment compliance was resulting in needless vision loss in individuals with glaucoma,” Dr. Miller-Ellis said. “Glaucoma is the No. 1 cause of preventable blindness, disproportionately affecting individuals of African descent—and glaucoma runs in my family. I thought glaucoma is where I could make the biggest difference.”

**Ongoing economic fallout.** Thirty years later, while Dr. Miller-Ellis has seen great progress in treatment, disparities in glaucoma care have actually become worse, as even more patients are not able to access—or have become lost in—the health care system, or have needed to sacrifice their health in general because of a lack of a societal safety net.

**Role of insurance coverage.** “While the Affordable Care Act has tried to close the coverage gaps, extensive access challenges still exist,” Dr. Miller-Ellis said. “Patients in underserved communities are less able to navigate the current insurance system, which prevents them from receiving the health care they need.”

For example, the insurance authorization process for medications and procedures often places barriers between the physician and their glaucoma patients. “In some offices, the situation is so difficult that the staff give up trying, and the patient suffers,” Dr. Miller-Ellis said.

She also argues in favor of universal, basic health care insurance: “Individuals should not have to choose between paying rent and paying for their health care and medications.”

**Impact of COVID.** During the pandemic, Blacks and Hispanics have been more likely to visit the emergency room for—or be hospitalized with—SARS-CoV-2.<sup>2,3</sup> And once sick, they were more likely to die of COVID than were Whites.<sup>4</sup> The pandemic also had a significant impact on socioeconomic measures of well-being, such as employment rates (see “The Statistics Tell the Story”).

Despite the abrupt and severe impact of the pandemic, “we didn’t get this way overnight,” Dr. Herndon said. “We cannot solve these inequities without taking into consideration the structural racism rooted in our society. It is going to take a lot of awareness, education, and empathy.”

### Disparities in Delivering Care

As Dr. Herndon noted, the social determinants of health have deep and complex roots.<sup>5,6</sup> For instance, the systemic disinvestment in segregated neighborhoods has resulted in under-resourced medical facilities. In turn, this pattern of disinvestment makes it difficult to attract experienced primary care providers—which, in turn, impacts patient access to and utilization of health care.<sup>6</sup>

**Who gets tested?** In the age of big data, individual utilization of health care resources is becoming easier to ascertain. For example, Dr. Miller-Ellis pointed out, data can show whether a patient with a diagnosis code for glaucoma is receiving the appropriate diagnostic tests.

“Research has demonstrated that minority populations do not receive all of the testing they need, as opposed to majority populations,” Dr. Miller-Ellis said, citing study findings indicating large disparities in the receipt of glaucoma care between Medicaid enrollees and patients with commercial insurance.<sup>7</sup> For this study, researchers followed 21,766 patients with newly diagnosed open-angle glaucoma (OAG) enrolled in Medicaid or a large U.S. managed care network. The results showed that patients with Medicaid insurance were less likely to receive glaucoma testing in the 15 months following initial diagnosis than those in the managed care program.

Additionally, nearly half (49%) of all OAG patients with Medicaid insurance had no record of any glaucoma testing in the first 15 months following the initial diagnosis, while only 1 in 5 (21%) with commercial health insurance had no record of any glaucoma testing. Moreover, the odds of receiving no glaucoma testing in patients with Medicaid coverage, when compared with those with commercial coverage, were 198% higher for Whites, 291% higher for Blacks, and 167% higher for Hispanics.

“Even within the Medicaid group, all of whom have lower socioeconomic status, Black patients with a blinding eye disease are less likely to be adequately followed than their majority population counterparts,” Dr. Miller-Ellis said.

**How can compliance be encouraged?** Compliance in glaucoma treatment is essential. “Yet if someone has a complicated life, it is harder to keep up with treatment maintenance,” Dr. Miller-Ellis said. “If your home situation is unstable or chaotic, it is more difficult to care for your own health issues.”

This scenario is exacerbated in women, who often are caretakers for children and aging parents. That’s because caretakers tend to neglect themselves, Dr. Miller-Ellis noted. In addition, people who are economically disadvantaged have a hierarchy of concerns, including securing food and shelter, so eye care

## Factors That Drive Health Outcomes

Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
<b>Racism and Discrimination</b>					
Employment	Housing	Literacy	Food security	Social integration	Health coverage
Income	Transportation	Language	Access to healthy options	Support systems	Provider availability
Expenses	Safety	Early childhood education		Community engagement	Provider linguistic and cultural competency
Debt	Parks	Vocational training		Stress	Quality of care
Medical bills	Playgrounds	Higher education		Exposure to violence/trauma	
Support	Walkability				
	Zip code / geography				

**OVERLAPPING CHALLENGES.** Determinants of health outcomes include myriad social and economic factors. SOURCE: Adapted from the Kaiser Family Foundation.

may not even be on their list. “These factors greatly impact whether patients can return for follow-up visits,” Dr. Miller-Ellis said. “And it takes many office visits to get a glaucoma patient under control.”

**Educating patients.** Getting patients to buy into using daily eyedrops and sticking with their treatment plan involves health literacy and education, Dr. Miller-Ellis said. “As physicians, we are charged with having to communicate with our patients in ways they can understand. Since many of my patients are visual learners, I provide written instructions that are clear so that key directions can be easily followed.”

**Choosing treatment.** Issues of compliance also may prompt a clinician to recommend surgery instead of medication. “I advocate early intervention with laser trabeculoplasty or incisional glaucoma surgery to lessen the long-term challenges with medication compliance,” Dr. Miller-Ellis said.

### Disparities in Research

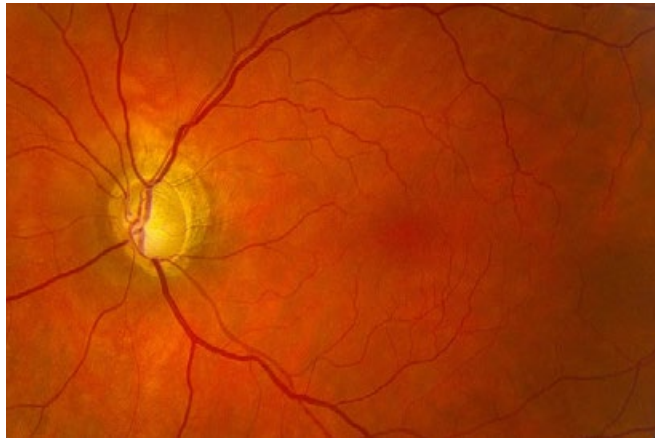
One of the major burdens facing marginalized people with debilitating eye conditions is the lack of relevant research.

**Who gets studied?** Glaucoma serves as a key example of this, as most research has been conducted in Whites. This leads to huge gaps in understanding and clinical care, Dr. Herndon said. He quoted Liu et al.: “To tackle the elevated burden of eye disease facing marginalized communities, we need to promise and fulfill our commitment to increase racial and ethnic inclusion in clinical trials. Without addressing this important issue, we risk perpetuating rather than resolving current health disparities.”<sup>8</sup>

**Focus on genetics.** Janey L. Wiggs, MD, PhD, at Harvard Medical School in Boston, noted that the majority of genetic studies in glaucoma have been in Whites who are of European ancestry. “When you think about the translatability of genetic information from glaucoma research to clinical care, the patients who are going to benefit the most from genetic studies are White because of the nature of the data.”

She added, “Historically, information from genetic investigation of individuals of African ancestry has been missed, which limits the diagnostic and therapeutic applications. To help gain more insight into glaucoma, we need more research on large populations of African ancestry, and this is a crucial step for the field.”

Dr. Wiggs noted that these disparities are seen throughout medicine, as many genetic studies



**TOLL ON VISION.** *The likelihood of glaucoma complications is higher in minority populations.*

have primarily been conducted in White populations. She cited the use of polygenic risk scores derived from genome-wide association studies (GWASs) to assess disease risk. “These risk scores are beginning to be used in diseases with complex inheritance such as glaucoma for risk stratification and treatment consideration.”

“However,” she added, “currently these polygenic risk scores have been primarily tested using White patients. This is because the studies that generated the scores were mainly performed in Caucasian individuals. We cannot yet predict if these scores have any relevant predictability in African ancestry populations, and we need more research to determine whether these scores are transferable to individuals of African ancestry.”

**Promising shift in direction.** Research inequities are beginning to be addressed, however, as efforts by the following research groups indicate:

**Genetics of Glaucoma in People of African Descent Consortium.** This group performed a GWAS of African-ancestry populations for POAG.<sup>9</sup> The study discovered a genetic variant in the *APBB2* gene associated with a higher risk of POAG, and the genetic association was discovered only in individuals of African ancestry.

**International Glaucoma Genetics Consortium.** This group recently published a study showing that many glaucoma genetic risk factors have similar effects on disease risk in people of European Caucasian, African, and Asian ancestry.<sup>10</sup>

“This study, which identified risk loci contributing to the development of POAG across ethnic groups, is an advance over prior POAG GWAS studies that have mainly focused on individuals from a single ancestry group,” Dr. Wiggs said. “However, it is important to note that further research in ethnic groups not currently well represented in genetic research is needed.”

**University of Pennsylvania.** Penn researchers

have been investigating the genetics of glaucoma in Blacks through the POAAGG (Primary Open-Angle African American Glaucoma Genetics) study.<sup>11</sup> “Our study has recruited more than 10,200 African Americans from the city of Philadelphia,” Dr. Miller-Ellis said.

Community outreach was an essential part of this study. The researchers partnered with community leaders to spread the word about the study and glaucoma risk. “We also offered free glaucoma screenings at our institute,” Dr. Miller-Ellis said. “These efforts allowed us to collect full

phenotypic information on more than 90% of glaucoma patients.”

In addition, Penn researchers performed a GWAS on cases and controls in this population, as well as whole-exome sequencing in collaboration with Regeneron Genetics Center. “Thus far, we have identified a novel variant on chromosome 11 near the *TRIM66* gene,<sup>12</sup> as well as several genes associated with POAG-related quantitative traits,” she said. “These results confirm that POAG is a heterogeneous disease characterized by distinct phenotypes. Our long-term goals are to define the genetic subtypes of POAG and to develop more targeted diagnostic and therapeutic interventions for this most affected population.”

## The Statistics Tell the Story

Evidence of social and health inequities to consider:

**Median household assets.** In 2011, these figures were \$110,500 for White, \$7,683 for Hispanic, and \$6,314 for Black households.<sup>1</sup>

**Unemployment.** In March 2020, the unemployment rate was 6.8% among Blacks, 6% among Hispanics, and 3.9% among Whites. The next month, these percentages skyrocketed to 16.7% for Blacks, 18.9% for Hispanics, and 14.1% for Whites. By March 2021, these rates improved to 9.6% for Blacks, 7.9% for Hispanics, and 5.4% for Whites.<sup>2</sup>

**Life expectancy at birth.** In 2014, Whites could expect to live to age 79, versus age 82 for Hispanics and 74 for Blacks.<sup>1</sup> But the pandemic could be expected to reduce U.S. life expectancy in 2020 by 0.68 years for Whites, 2.10 years for Blacks, and 3.05 years for Hispanics.<sup>3</sup>

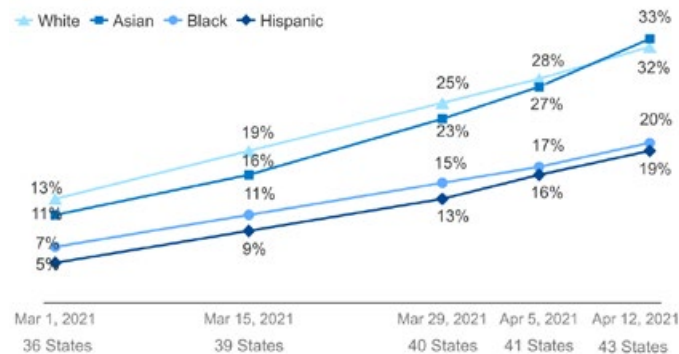
**Heart disease and mortality.** In 2014, the age-adjusted mortality related to heart disease—the No. 1 cause of death in the United States—per 100,000 population was 166 for Whites, 116 for Hispanics, and 206 for Blacks.<sup>1</sup>

1 Bailey ZD et al. *Lancet*. 2017;389:1453-1463.

2 U.S. Bureau of Labor Statistics. Current Population Survey. [www.bls.gov/cps](http://www.bls.gov/cps). Accessed April 15, 2021.

3 Andrasfay T, Goldman N. *Proc Natl Acad Sci*. 2021;118(5):e2014746118.

### COVID-19 Vaccination Rates



**WHO'S VACCINATED?** Estimate of vaccination rates by ethnicity, from March 1 to April 12, 2021, based on publicly available data on state websites. SOURCE: Adapted from the Kaiser Family Foundation.

### An Often-Overlooked Factor

Dr. Herndon noted that a key factor contributing to health care disparities is the lack of diversity in the physician workforce. (*EyeNet* will cover this topic later this year.)

“There is strong evidence that communication in racially discordant medical interactions is usually less productive and positive in content and tone than in racially concordant interactions,” Dr. Herndon said. “A variety of studies have shown that racial discordance leads to less relationship building, less health information exchange, and less treatment planning.”

This discordance can be traced to the low percentage of members of minority groups in the physician workforce, Dr. Herndon noted. For instance, he said, “In 2015, only 2.5% of practicing ophthalmologists were Black. Our numbers are not improving, yet for the health of the patient it is essential that providers reflect the community they serve.”

To address these inequities, ophthalmology as a profession must focus on creating a pipeline of underrepresented minority groups to enter the field. Role models are a key component of these efforts. Dr. Herndon recalled his own experience as a medical student when he reached out to Dr. Miller-Ellis, who was at the University of North Carolina, Chapel Hill, at the time.

“Here was someone who looked like me doing ophthalmology,”

Dr. Herndon said. “Dr. Miller-Ellis was such an inspiration and gave me the confidence to pursue a career in ophthalmology. We need more role models who can inspire young medical students of color to pursue the field of ophthalmology.” (See “Academy Resources.”)

### Moving Forward

Dr. Miller-Ellis noted that the University of Pennsylvania, under the leadership of Eve J. Higginbotham, SM, MD, ML, has been at the forefront of change (see “What’s in a Word?” online with this article at [aao.org/eyenet](http://aao.org/eyenet)).

“While diversity, health disparities, and inclusion have been discussed for years, the events of 2020 have put these issues at the forefront,” Dr. Miller-Ellis said. “We are finally seeing a

real commitment from the government, health providers, and insurers to move these initiatives forward—working on inclusion in bench research and clinical trials while addressing disparities in health care.”

She added, “Sometimes it takes a disaster to see the holes in the safety net, and the COVID-19 pandemic showed how a lot of people—particularly those from minority communities—are falling disproportionately through those holes. However, if we as a society can address issues facing the most disadvantaged of people, it will help everyone. Diverse ideas make organizations better. We need to keep moving forward.”

- 1 Racette L et al. *Surv Ophthalmol*. 2003;48(3):295-313.
- 2 Smith AR et al. *MMWR*. 2021;70(15):566-569.
- 3 Romano SD et al. *MMWR*. 2021;70(15):560-565.
- 4 Ahmad FB et al. *MMWR*. 2021;70(14):514-522.
- 5 Bailey ZD et al. *Lancet*. 2017;389(10077):1453-1463.
- 6 Bailey ZD et al. *N Engl J Med*. 2021;384(8):768-773.
- 7 Elam AR et al. *Ophthalmology*. 2017;124(10):1442-1448
- 8 Liu AJ et al. *JAMA Ophthalmol*. Published online Oct. 8, 2020.
- 9 Hauser MA et al. *JAMA*. 2019;322(17):1682-1691.
- 10 Gharakhani P et al. *Nat Commun*. 2021;12(1):1258.
- 11 Charleson ES et al. *Ophthalmology*. 2015;122(4):711-720.
- 12 Gudiseva HV et al. [www.biorxiv.org/content/10.1101/2020.02.27.968156v1](http://www.biorxiv.org/content/10.1101/2020.02.27.968156v1).

**MORE ONLINE.** For suggested reading and a conversation with Dr. Higginbotham, see this article at [aao.org/eyenet](http://aao.org/eyenet).

**ACADEMY RESOURCES**

For more information, see the following:

**Web page.** Information on health care disparities and diversity, equity, and inclusion (DEI), including two related task forces, is available at [aao.org/diversity-equity-and-inclusion](http://aao.org/diversity-equity-and-inclusion).

**Mentoring.** Three years ago, the Academy, in partnership with the American Academy of University Professors, launched the Minority Ophthalmology Mentoring program. See [aao.org/minority-mentoring](http://aao.org/minority-mentoring).

### Meet the Experts



**Leon W. Herndon Jr., MD** Professor of ophthalmology and chief of the glaucoma division at Duke University Eye Center in Durham, N.C. *Financial disclosures: None.*

**Eve J. Higginbotham, SM, MD, ML** Vice Dean for Inclusion and Diversity at the University of Pennsylvania’s Perelman School of Medicine in Philadelphia. She is also a senior fellow at the Leonard Davis Institute for Health Economics and professor of ophthalmology at the University of Pennsylvania as well as Vice Chair

of the Ocular Hypertension Treatment Study. *Financial disclosures: NEI: S.*



**Eydie Miller-Ellis, MD** Professor of clinical ophthalmology and Vice Chair for Faculty

Affairs and Diversity for the Scheie Eye Institute at the University of Pennsylvania’s Perelman School of Medicine in Philadelphia. She also serves as the chief of glaucoma service and director of the glaucoma fellowship program at the Scheie Eye Institute and director of glaucoma at the Philadelphia Veterans Administration Medical Center. *Financial disclosures:*

*Aerie: C; Allergan: C; NIH: S.*



**Janey L. Wiggs, MD, PhD** Paul Austin Chandler Professor of Ophthalmology

and the Vice Chair for Clinical Research in Ophthalmology at Harvard Medical School in Boston. She also directs the genetic testing laboratory at Massachusetts Eye and Ear and is codirector of the Ocular Genomics Institute and the Glaucoma Center of Excellence. *Financial disclosures: Aerie: C,S; Allergan: C; Editas: C; Maze: C; NIH: S; Regenxbio: C.*

**See disclosure key, page 8.**