NEW
ETHICS SERIES

People Who Cannot Afford Boots Cannot Pull Themselves Up by the Bootstraps:

An Evidence-Based Exploration of Health Disparities, Social Determinants of Health, and How Medical Writers Can Help

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SERIES INTRODUCTION

We medical writers walk in a world of evidence-based medicine, and this series of articles was built on both public health data and trial results. At the same time, we medical writers typically pay careful attention to the policies, positions, and guidelines of certain responsible, impartial organizations. It is thus significant that multiple organizations are committed to the widespread effort to reduce health disparities in America, including the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), the American Heart Association (AHA), the American Society of Clinical Oncology (ASCO), the American Hospital Association, and the National Academy of Medicine (NAM).[1-8]

Thus, when the AHA saw recently that, despite great efforts, the improvement in Americans' cardiovascular health targeted by the CDC's "Healthy People 2020" would not be achieved, AHA leaders grasped that they "had not touched adequately the populations at highest risk, the underserved, those people with highest needs in heart disease," and that in pursuing "Healthy People 2030" targets it would be necessary to "combine clinical, social, economic, and educational efforts," explained Keith B. Churchwell, MD, chair of the AHA's Health Equity and Determinants of Health Outcomes Task Force and Senior Vice President, Operations, at the Yale School of Medicine, who spoke in an interview on April 20, 2018.

In this first article in our series we present evidence relevant to the current state of health disparities and social determinants of health in the United States. The second article will describe some of the peer-reviewed publications that discuss interventions that have reduced health disparities. It will also report on current efforts by thought leaders, the CDC, and medical foundations to further address the issues. The third article will offer practical and concrete actions that medical communicators can take to support these efforts in the name of better health for all Americans.

ARTICLE 1: THE PROMISE OF EQUALITY

"That all Men are created equal"
–The Declaration of Independence

Tamara's account: As an emergency department physician, my morning typically began with a patient like Mr G, a 67-year old Latino male with diabetes and hypertension whom I had admitted 2 months earlier for a stroke. He now, per his son, was "talking funny again." I asked his son if he had filled the 2 blood pressure medications that had been prescribed at his previous discharge. "We couldn't afford those pills," he sheepishly admitted. Mr G's family doctor was Dr Swan, so I asked his son, "When you saw Dr Swan, did she offer you a less expensive alternative?" He acknowledged that they hadn't been for a follow-up visit. "We owed her money," he explained. "And besides, the car was broke down." My nurse checked Mr G's blood pressure: 210/114. I quietly sighed and ordered a head CT. I had grown weary knowing that some patients had access to incredible advances in medicine while others struggled to get even basic care. It seemed that 70% to 80% of my patients were in the latter group. Each day, I served witness to patients and their families as they braved the undue burden of pain, suffering, trauma, disability, and death allotted to the disenfranchised of America, the richest country on earth.

Bob's account: In August of 1970, I was participating in a civil rights project in the American South, and one day a few of us drove into town. We reached the downtown area, and the driver pointed out "the hanging tree." It was spectral and

hostile, gloomy and unforgiving. The tree represented a history not only of inequality but also of unequal access to healthy environments (assuming a lynching can be thought of as an unhealthy environment).

HEALTH DISPARITIES IN THE UNITED STATES

These experiences left a mark upon each of us clear and deep in memory, in gut feeling, and in moral outrage—our personal perceptions of health disparities in our country. The state of health disparities in the United States is a national crisis, an international embarrassment, a drain on future resources, and a violation of our founding principles as stated in the Declaration of Independence. Indeed, it is such a crisis that the National Academy of Medicine (NAM) commissioned 19 white papers to authoritatively assay just what is going on.

A qualitative synthesis of these white papers was published in the *Journal of the American Medical Association* in March of 2017.[9] The report stated that "health disparities are persistent and worsening" and that the current "trajectory of health care spending is unsustainable" and is placing the "fiscal capacity" of the United States "at risk." The NAM initiative concluded that in relation to "the steps necessary to deliver better health to all people of the United States at a sustainable cost," it is clear that "the urgency is as compelling as the opportunities."[9] Recently, the American Hospital Association and the Association of American Medical Colleges released a joint statement that "addressing disparities is no longer just about morality, ethics and social justice: it is essential for performance excellence and improved community health."[10,11] So the US health care system must change, and we medical writers and editors have an opportunity—and perhaps an obligation—to help further that positive change toward health equity.

The word "equality" belongs front and center within discussions of health disparities; however, "equity" more precisely focuses on the issues at hand. Whereas equality implies all things are equal, "[h]ealth equity is achieved when every person has the opportunity to attain his or her full health potential and no one is disadvantaged from achieving this potential because of social position or other socially determined circumstances."[2] Yet, as the nonpartisan NAM initiative states, decades of research have shown that "the leading health determinants are outside of healthcare."[9,12]

Equity touches such things as 2 neighborhoods—one with a well-run, well-financed hospital, the other with an overcrowded clinic with outdated technology; one with a high school with magnificent sports facilities, the other with no swimming pool and no doors on the bathroom stalls; one with little air pollution and no boarded-up houses, the other with pervasive air pollution and trash-strewn vacant lots; one where almost all families can easily afford to purchase sunscreen, the other where purchasing a year's worth of sunscreen for the entire family is a financial burden. Health equity may be further measured across subpopulations in terms of rates of adherence to physician-prescribed medical and exercise regimens; of preventive services such as blood pressure, mammography, and prostate screenings; and of premature births; of length of survival postdiagnosis with cancer or acute myocardial infarction; or even of levels of air pollution in neighborhood schools.

DEFINING HEALTH DISPARITIES

It is daunting to define and describe the health disparities existing in our country today—not because of lack of data but because the magnitude of the problem becomes all the more apparent as the evidence is examined.

Racial health disparities exist. Babies born to African Americans are "more than twice as likely to be born with low birth weight or to die in their first year of life," relative to whites.[12] In contrast, the corresponding rates for mothers who emigrated from Africa are similar to those for whites.[12] "American Indians and Alaska Natives born today have a life expectancy that is 4.4 years fewer than the US all-races population."[13] And from 1960 to 2009, blacks had a 2-fold excess risk of premature mortality, as compared with whites.[14]

According to the National Cancer Institute, "African Americans have higher death rates than all other groups for many, although not all, cancer types."[15] "Hispanics have lower rates of the most common cancers in the United States (ie, female breast, colorectal, lung, and prostate) but among the highest rates of cancers associated with infectious agents" (eg, cervical, liver, and stomach cancers).[16]

According to the American Heart Association (AHA), the prevalence of hypertension in African Americans in the United States "is among the highest in the world."[17] An analysis of Medicaid claims and enrollment files for 2006-2008 identified that women of racial or ethnic groups were less likely to get screening mammography as compared with white women.[18] According to the US Department of Health and Human Services, rates of obesity differ among populations. In 2015, "African Americans were 1.4 times as likely to be obese as non-Hispanic whites" and "about 4 out of 5 African-American women are overweight or obese."[19] "That same year, Hispanic Americans were 1.2 times as likely to be obese than non-Hispanic whites," while 77% of Mexican-American women were overweight or obese.[20] "Obesity is twice as common among American Indian children compared with their white and Asian counterparts."[13] That the poor do not have equal access to quality food will be briefly discussed later in this series of articles.

SOCIAL DETERMINANTS OF HEALTH DISPARITIES

Decades of research have demonstrated that underlying health disparities are such matters as where a person lives, who is poor, who has access to good schools and healthy food options, who breathes air with less pollution, how government policies and laws are shaped, and who bears the brunt of racial discrimination.

Environment: Where People Live, Neighborhoods, and Housing

Some neighborhoods have lower-quality schools, less access to quality food, greater levels of air pollution, and more mice and cockroaches in the homes. They also may have access to relatively fewer clinicians, who themselves may not be as well trained as the clinicians in other neighborhoods (Table 1).[21]

Education

According to NAM, "education level is the most powerful determinant of lifelong health prospects."[12] Education can affect health through multiple pathways (Table 2). These include better health literacy and increased health knowledge; better employment opportunities, including healthier physical and psychosocial working conditions; greater earnings, which permit better control of living conditions; better social support; and a greater sense of personal attainment, which may help buffer stress.[34,35]

Government Policies

Government policies have a good deal to do with how resources are allotted, but reducing disparities is not the only item on the government's agenda (Table 3).

Income and Poverty

While not the whole story, income and poverty play a significant role in health disparities (prejudice and ethnic interactions are independent factors), and apparently there has not been improvement over time. For example, the National Academies of Sciences, Engineering, and Medicine measured the gap in life expectancy between the top and bottom income quintiles for two distinct sets of people, one of whom had reached 50 years of age in 1980 and the other had reached 50 years of age in 2010: for women born in 1930, the gap between the top and bottom income quintile was 3.9 years; for women born in 1960, the gap was 13.6 years. For men born in 1930, the gap between the top and bottom income quintile was 5.1 years; for men born in 1960, the gap was 12.7 years.[42,43] For men, that gap continues to widen; according to 2016 reports, compared with the richest 1% of Americans, the poorest 1% are on the wrong end of a life expectancy gap of 14.6.[44] There is a direct, measurable effect of income on health; in the United States, nearly the same pattern

Table 1. Disparities in Environment

Residential patterns in the US support an unofficial segregation of African Americans associated with "adverse birth outcomes, increased exposure to air pollutants, decreased longevity, increased risk of chronic disease, and increased rates of homicide and other crime. Residential segregation also systematically shapes healthcare access, utilization, and quality at the neighborhood, healthcare system, provider, and individual levels."[21]
Rural hospitals typically do not include intensive care units, skilled nursing facilities, psychiatric units, or rehabilitation units, and have fewer medical practitioners, especially medical specialists such as neurologists, anesthesiologists, and psychiatrists.[22]
After adjustment for individual and neighborhood-level covariates, a strong relationship was found between healthy food availability and hypertension rates, and a lower risk of type-2 diabetes mellitus correlated with greater cumulative exposure to indicators of neighborhood healthy food.[23,24]
Air pollution analyzed according to geographic location across the entire continental US found a "greater risk of death associated with air pollutants among blacks" and found that "among black persons, the effect estimate for $PM_{2.5}$[a] was 3 times as high as that for the overall population."[25,26]
Air pollution can trigger heart attacks, strokes, and irregular heart rhythms, particularly in persons with relevant risk factors.[27]
"The estimated percentage of the population living within 150 meters of a major highway" ranged from 3.1% for non-Hispanic whites to "a high of 5.0% for Hispanics and 5.4% for Asians/Pacific Islanders."[28]
"Strategic placement of bus garages and toxic waste sites in or close to neighborhoods where marginalized, racialized groups predominantly reside, selective government failure to prevent lead leaching into drinking water (as in Flint, MI, in 2015-16), and disproportionate exposure of workers of color to occupational hazards" are among the factors making some neighborhoods healthier than others.[21]
Higher levels of mouse allergen, dust mites, and cockroaches and their droppings in housing are known triggers of disease.[29-31]
"Health-care infrastructure and services are inequitably distributed, resulting in predominantly black neighborhoods having lower-quality facilities with fewer clinicians than those in other neighbourhoods. Moreover, most of these clinicians have lower clinical and educational qualifications than those in other neighborhoods."[21]
Studies show the existence of "residential, educational, and occupational segregation of marginalized, racialized groups to low-quality neighborhoods, schools, and jobs (both historical de jure discrimination and contemporary de facto discrimination)."[21]
Rural Americans are more likely to die from heart disease, cancer, unintentional injury, chronic lower respiratory disease, and stroke than their urban counterparts.[32]

[a] *$PM_{2.5}$ is a measure of small particles in the air and is used as an indication of air quality.*[33]

Table 2. Disparities in Education

A 2017 study of air neurotoxicant exposure at 84,969 US public schools found "racial/ethnic minority children are bearing the brunt of air neurotoxicant exposures at school, which may be unequally impacting their school performance and future potential."[36]
"During 2009-2010 the prevalence of smoking was 46.4% among 12th grade-aged youth who had dropped out of school compared with 21.9% among youth who were still in the 12th grade."[37]
In areas of high crime and high density of off-premise alcohol outlets, children between 10 and 18 years of age report fears of violence during their morning travel to school.[38]
Currently available technologies possess the capacity to nearly eliminate the particulate pollution that is emitted from a diesel engine bus and seeps into its interior. Yet, some children and adolescents continue to be exposed to this particulate pollution during school bus rides, which indicates a failure to use these technologies.[39]

Table 3. Disparities in Government Policies

Most studies have shown that "Medicaid patients are less likely to have access to physicians" in outpatient practices and are less likely to have access "to specialists and others who may be perceived as more qualified."[7]
Many states have paid physicians very poorly for treating Medicaid patients.[7]
While organizations that serve communities with limited economic resources, such as safety-net health centers, have a particular role to play in ensuring equitable access to cancer-prevention programs, "given limited resources and high demand, it can be difficult to integrate new [prevention] practices into such organizations."[40]
"Environmental and policy approaches (eg, taxation and restrictive policies) that reduce the rate of risky behaviors and that increase access to treatment are particularly important for tobacco control at the population level. However, the current federal excise tax on tobacco, $1.01, is low as compared with the average of about $3.15 per pack in high-income countries worldwide."[40]
According to a CDC statement about local health departments, "many disadvantaged, disenfranchised persons not only distrust the government, but they may also fear it."[41]

is seen for almost all chronic conditions, from stroke to heart disease to arthritis—prevalence increases as income declines.[45]

More than 1.4 million households in the United States, including 2.8 million children, report incomes of less than $2 per person per day. Things were not always this severe: between 1996 (when welfare reform went into effect) and 2011, the prevalence of extreme poverty rose sharply, with the growth of poverty concentrated among those most directly affected by welfare reform (Table 4).[46] In 2013, family wealth

Table 4. Disparities in Income and Poverty

"76% of orthopedists' offices in a nationwide audit study refused to offer an appointment to a Medicaid-insured child with a fracture, whereas only 18% refused a child with private insurance."[45,47]
"19% of non-elderly adults in the US who received prescriptions in 2014 (after full implementation of the Affordable Care Act [ACA]) could not afford to fill them."[45]
Multiple US studies show that "marginalized, racialized groups" have been subject to "reduced salary for the same work, and reduced rates of promotion despite similar performance evaluations."[21]
Exclusively breastfed infants were significantly less exposed to tobacco smoke and pets, had solid foods introduced later and belonged to higher social classes.[48]

for the non-Hispanic white population was 10 times that of the Hispanic population and more than 12 times that of the African American population.[45] There is no indication that things steadily improving: the decades extending from 1980 to 2015 have seen increased geographical segregation by income in the US.[42] Further, income and poverty connect to such factors as unequal access to technological innovations; reduced economic mobility, which, in turn, leads to the multigeneration persistence of poverty; expanded exposure to the costs of medical care; differential access to fresh fruit and vegetables; and differential access to information on risk factors and new medical procedures.[42]

The poor and middle classes in the United States pay a relatively larger share of their incomes for health care, which translates into their having less disposable income.[45] Yet, we all use disposable income to relieve stress; and stress, as will be discussed later, carries its own health consequences.

Structural Racism

As a recent overview in *The Lancet* explains, racism in America is frequently viewed in relation to interpersonal bias; however, much health inequity rests upon the messy, distasteful, historical and cultural roots of social structures that support or embody racism. *Lancet*'s series "America: equity and equality in health" describes structural racism as referring to "the totality of ways in which societies foster racial discrimination, through mutually reinforcing inequitable systems (in housing, education, employment, earnings, benefits, credit, media, health care, criminal justice, and so on) that in turn reinforce discriminatory beliefs, values, and distribution of resources, which together affect the risk of adverse health outcomes."[21]

A different and equally important definition of structural racism appeared recently in *The New England Journal of Medicine*, where it is described as "a confluence of institutions, culture, history, ideology, and codified practices that generate

and perpetuate inequity among racial and ethnic groups." This definition highlights the fact that "a large and growing body of literature documents disparate outcomes for different races despite the best efforts of individual health care professionals."[49]

Speaking at a 2017 conference at the New York University School of Medicine, Tom Frieden, MD, MPH, Director of the CDC from 2009 to 2017, stated that the health effects of racism are "huge." Further, he explained that to understand structural racism today it is important to include the awareness of what has happened in the past, including the legacy of slavery and the Tuskegee experiment.[50]

As Mary Bassett, MD, MPH, Commissioner, NYC Department of Health and Mental Hygiene, said at this NYU conference, simply using the word "racism" is uncomfortable. Many of us want nothing to do with racism or the word—nothing at all. Contemporary data and the history of our country both show all too clearly, however, that recognizing racism is something we cannot avoid if we want to look at health disparities objectively and in an evidence-based manner.[51] Nancy Krieger, PhD, professor at Harvard's School of Public Health, supported this assertion. "Naming racism is very important," she said, advocating that we look at how we can use this focus to improve health.[52] As Dr Bassett said, it is a misconception that health disparities are "just a reflection of income disparities."[50]

According to Dr Bassett, "by talking about health for everyone we give ourselves an opportunity to speak about racism and inequality. Our focus should be on "equity in all policies. Because if we begin to talk about equity it will support health."[51] (Table 5).

Table 5. Disparities in Structural Racism

A 2017 comparison of Hispanic and non-Hispanic white mothers finds the former "more likely to deliver at hospitals with higher risk-adjusted severe maternal morbidity rates, and these differences in site of delivery may contribute to excess morbidity among Hispanic mothers." This study points to specific deficits in relation to organizational characteristics and the less-than-excellent technology found in certain hospitals.[53]
According to a 2016 study, "black mothers are more likely to deliver at higher risk-standardized severe maternal morbidity hospitals than are white mothers, contributing to black-white disparities."[54]
Nearly 1 in 3 black men are imprisoned.[55] This translates to nearly half of black women having a family member or extended family member in prison. Current literature indicates that the children and adolescents of imprisoned fathers suffer increased rates of behavioral and mental health problems, including depression, anxiety, asthma, and obesity.[55]
As minority patients encounter health systems, even the administrative and clerical staff may be "expected to mirror social attitudes and trends" in relation to race and ethnicity; thus, bias and partiality may appear even as a patient arrives for treatment.[7]

Biologic Effects of Racism

A recent study found that drivers in a high-income neighborhood in Las Vegas were less likely to yield to an African-American pedestrian in a crosswalk in the same half of the roadway than they were to yield to a white pedestrian in the same situation.[56] The NY Times reported on secret recordings of a New York City Deputy Inspector who told policemen to frisk "male blacks 14 to 20, [or] 21" years of age.[57] The experience of racism is embedded in such low-key activities as "walking while black," in seeing landmarks associated with segregation, in applying for a job, in looking for a promotion at work, and in being a patient in certain medical clinics.

Poverty, difficult work conditions, dangerous neighborhoods, feeling disenfranchised or inadequately franchised, structural racism—all of these entail stress. Scientists have researched the biological effects of stress and, specifically, the effects of stress on a person's health. Accumulating evidence links racial discrimination to parameters associated with the effects of chronic stress. According to Bailey et al, "there is burgeoning evidence linking experiences of discrimination to biomarkers of disease and well-being, including allostatic load, telomere length, cortisol dysregulation, and inflammatory markers."[21] In looking at the effects of the various ways people perceive their neighborhood environments, differences in levels of cellular aging and, specifically, telomere length, may be relevant.

Furthermore, accumulating research has linked obesity in African American women and elevated lipid levels in African American men and women with the effects of racism.[58,59] Studies of how stress affects biological dysregulation are somewhat preliminary, but the field may be of great importance in relation to causes of health disparities.[21,35,60-65]

WHAT ABOUT PERSONAL RESPONSIBILITY?

On the one hand, personal responsibility is essential. Nobody can brush your teeth for you. Or exercise for you. Or keep you from eating foods with large quantities of salt and fat. On the other hand, it should be obvious that people cannot pull themselves up by their own bootstraps if they cannot afford to purchase boots.

As James Baldwin said in conversation with Margaret Mead in the book *A Rap on Race* (1971), people might look at someone like Harry Belafonte and at "those people rioting on the South Side" and conclude "that if those people on the South Side washed themselves and straightened up, they could all be Harry Belafonte."[66] Since that time, an enormous quantity of research has completely and utterly discredited the notion that disparities are essentially the product of a deficit in personal responsibility.

If someone lives near the city incinerator, in a part of town where the air is much polluted, where billboards advertise

alcohol, and where vermin are abundant; or if a child attends school in shabby, broken buildings with outdated or missing technology and absent or closed sports facilities; or if fresh produce and other quality food is scarce or unaffordable—that environment will have a negative effect on the residents. If someone else lives in a neighborhood with fresh air and greenspace, with no billboards, and where vermin are not a major concern; or if a child attends school in solid buildings with updated technology and modern sports facilities; or if fresh produce and other quality food is readily available—that environment will have a positive effect on the residents. All this is beyond the reach of personal responsibility. Nothing any individual or community can do substitutes for clean air and water, adequate nutrition, homes free of vermin, good schools, and a lack of chronic stressors.

CONCLUSION

As we conclude this article it seems right to note that a major concern of medical writers and editors is being effective and current in our work. So, it is relevant that the NIH, CDC, AHA, NAM, physician and nurse professional organizations, major foundations, leading medical centers, and schools of both medicine and public health are all engaged in major efforts to reduce health disparities. As these important and influential organizations focus on health disparities, we might pay attention; in fact, to be competent in our work we have no choice but to pay attention.

Now that some of the social determinants of health disparities in the United States have been identified, the next articles in this series will spotlight efforts being made by national organizations and relevant thought leaders—including those in the medical industry; in local, state, and national politics; in mass media (filmmakers, novelists, TV personalities, popular musicians); as well as in religious groups—to address these health disparities and social determinants of health and will offer specific suggestions and insights as to how we medical communicators can support those efforts.

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