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**REVIEW**

# Choosing to End African American Health Disparities in Patients With Systemic Lupus Erythematosus

Matthew H. Liang,[1] Edward R. Lew,[2] Patricia A. Fraser,[3] Cindy Flower,[4] Edward H. Hennis,[5] Sang-Cheol Bae,[6] Anselm Hennis,[4] Mohammed Tikly,[7] and W. Neal Roberts Jr [8]

Systemic lupus erythematosus (SLE) is three times more common and its manifestations are more severe in African American women compared to women of other races. It is not clear whether this is due to genetic differences or factors related to the physical or social environments, differences in health care, or a combination of these factors. Health disparities in patients with SLE between African American patients and persons of other races have been reported since the 1960s and are correlated with measures of lower socioeconomic status. Risk factors for these disparities have been demonstrated, but whether their mitigation improves outcomes for African American patients has not been tested except in self-efficacy. In 2002, the first true US population–based study of patients with SLE with death certificate records was conducted, which demonstrated a wide disparity between the number of African American women and White women dying from SLE. Five years ago, another study showed that SLE mortality rates in the United States had improved but that the African American patient mortality disparity persisted. Between 2014 and 2021, one study demonstrated racism's deleterious effects in patients with SLE. Racism may have been the unmeasured confounder, the proverbial "elephant in the room"—unnamed and unstudied. The etymology of "risk factor" has evolved from environmental risk factors to social determinants to now include structural injustice/structural racism. Racism in the United States has a centuries-long existence and is deeply ingrained in US society, making its detection and resolution difficult. However, racism being man made means Man can choose to change the it. Health disparities in patients with SLE should be addressed by viewing health care as a basic human right. We offer a conceptual framework and goals for both individual and national actions.

## Introduction

Our objectives are as follows: (1) to define and describe the etymology of select terms and concepts in social epidemiology; (2) to review systemic lupus erythematosus (SLE)'s disproportionate toll on individuals of African descent and the risk factors for SLE etiology and adverse outcomes; (3) provide historic examples of legal, sociopolitical, and cultural structural injustices that make health disparity a continued threat to African American citizens; and (4) to put forth a pragmatic framework for personal and societal actions. The focus is on the African American experience in those with SLE in the United States. The data on other non-White US populations do not exist or exist with insufficient numbers (eg, what can be found in the Centers for Disease Control and Prevention [CDC] Wide-Ranging Online Data for Epidemiologic Research [WONDER] database).

SLE is three times more common in women of African descent.[1] Its clinical manifestations are thought to be more severe than in other racial groups.[2] It is unclear, however, whether its severity in patients of African descent is due to underlying genetic risk or structural racism or a combination of both. Race can be social construct and convey risk distinct from underlying genotypes. Being of African descent encompass a genetically diverse population, and generalized risk statements for such a diverse population may themselves perpetuate racism in research and clinical care.

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[1]Matthew H. Liang, MD, MPH: Veterans Affairs Boston Healthcare System, Brigham and Women's Hospital, and Harvard T. H. Chan School of Public Health, Boston, Massachusetts; [2]Edward R. Lew, BA: University of Massachusetts Amherst; [3]Patricia A. Fraser, MD, MPH, SM: Brigham and Women's Hospital, Boston, Massachusetts; [4]Cindy Flower, MBBS, DM, FACP, Anselm Hennis, MD, MSc, PhD: University of the West Indies, Cave Hill campus, Barbados; [5]Edward H. Hennis, MD: Allegheny General Hospital, Pittsburgh, Pennsylvania; [6]Sang-Cheol Bae, MD, PhD, MPH: Hanyang University Hospital for Rheumatic Diseases, Hanyang University Institute for Rheumatology Research, and Hanyang Institute of Bioscience and Biotechnology, Seoul, Korea; [7]Mohammed Tikly, MD: The Chris Hani Baragwanath Academic Hospital, Johannesburg, South Africa, and Life Roseacres Hospital, Primrose, Germiston, South Africa; [8]W. Neal Roberts Jr, MD: University of Kentucky Medical Center, Lexington.

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Address correspondence via email to W. Neal Roberts Jr, MD, at neal.roberts@uky.edu.

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Twenty years ago, the very first US population study of patients with SLE demonstrated an African American mortality disparity.[2] This disparity has existed for more than 40 years at least, and even though the age-standardized mortality rate in patients with SLE has improved, the racial disparity remains.[3] Racial health disparities in patients with SLE are seen worldwide.[4–7] Since the description of SLE syndrome by Kaposi in 1872, our management and understanding of its course, its cause(s) and impact have advanced.[8] These advances include the discovery of the lupus erythematosus cell, demonstration of its autoimmune basis,[9] and identification of therapeutic targets.[10] Going back to the 1960s, case series with relatively small numbers of participants from single or multiple sites gave the first signals linking African American status, lower socioeconomic status (SES), and adverse outcome[11]

Advances in information technology, in the manipulation and interpretation of large data sets and collaborations have allowed us to better understand the long-term course and prognosis of SLE in the population. The 1982 American College of Rheumatology Classification Criteria for SLE standardized a practical, validated case definition for a heterogeneous phenotype[12] and led to the first prototype of a longitudinal chronic disease databank, including SLE in 1970s, the Arthritis, Rheumatism, and Aging Medical Information System, and to the Nurses' Health Study and Physicians' Health Study. Cohort studies in large healthy populations before onset of disease demonstrated their research potential and enabled data pooling of meticulously curated clinical and biospecimens data by national and international groups (Lupus Clinical Trials Consortium, Accelerating Medicines Partnership, Lupus Landmark Study, Milan SLE Consortium, Systemic Lupus Erythematosus International Collaborating Clinics, Latin America Group for the Study of Lupus, and International Consortium on the Genetics of Systemic Lupus Erythematosus). In 2004, the CDC funded lupus registries in counties of Georgia, Michigan, and then California and in select Indian Health Service regions. Various operational definitions of SES (zip code, highest educational attainment, source of health insurance) show being "less wealthy" to be a risk factor and possibly a surrogate for environmental exposures, access, quality care, and/or social stressors. The relationship supported the intuitive view that financial security is necessary to access high-quality health care and to follow known effective treatments for optimal outcomes.[13]

In the first US population–based study of patients with lupus, the marked disparity in deaths due to lupus in African American patients and patients of other races was demonstrated.[2] A generation of investigators sought to understand why. Modifiable risk factors were disproved or identified but with small attributable-risks.[14–17] Important work relevant to SLE health disparities tested novel nonpharmacologic, psychoeducational interventions in improving symptoms, self-efficacy, function, and quality of life.[18–26] As a group, these studies demonstrate proof of concept, little harm, and modest positive effects, but few have become standard practice. No risk factor when eliminated or reduced has been proven to improve outcomes except in self-efficacy or one's confidence in their ability to monitor their disease, manage their regimen, etc.[20] African American race and SES remained difficult to parse out. From an epidemiologic perspective, race could be a confounder or an effect modifier. Controlling or matching for racial differences and SES eliminates their associations with outcomes in patients with SLE and does so in outcomes in patients with cardiovascular disease, supporting SES as an effect modifier.[27] In landmark studies more than a decade after the study by Sacks and colleagues,[2] Lim and colleagues,[28] Chae and colleagues,[29–31] Martz and colleagues,[32] and Spears and colleagues[33] named, measured, and demonstrated racism's adverse effects on telomere length in African American men and on organ damage and disease activity in Georgian African American women with SLE. Whether a risk factor or exposure is a cause or the effect of an outcome is an inherent concern in cross-sectional observational studies employing self-reported measures such as types of racism. The implications of distinguishing cause from effect are profound.

## Definition and etymology of select terms

Racial designations have changed over time. "Black" referred to descendants of slaves in the 1960s. "African American" in the 1980s became a historical term. The words "colored" and "Negro" from the Jim Crow period are now considered dated and offensive (Table 1). We use Black to refer to people and cultures of African ancestry, no matter their nationality. African American without a hyphen denotes those born in the United States with African ancestry, and it is used interchangeably with Black when the distinction is not clear. "Race" can be used either as a social construct for ideas used and accepted without discussion or study or to designate a human trait that is inherited and genetically defined by race (eg, sickle cell disease). We use the term racism defined as follows:[34–36]

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> *The false premise that a group has inherited behavioral traits giving it superiority over another. Racism's legitimacy, justice and legality is often supported by self-appointed "experts" and venerable institutions: government, law, science. It represents belief or action, intended/unintended, scientifically false, unjust, immoral, potentially lethal/destructive.*
>
> *Similar characteristics appear in religious and ethnic persecution/violence, xenophobia, misogyny, sexism, prejudice against gender identity and sexual orientation, cognitive impairment, and even within a racial group (brown paper bag test).*

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The terms, structural injustice, structural violence, and structural racism, emphasize that racism is imbedded in systems and

**Table 1.** Select terms/concepts in social epidemiology*

| Term | Definition | Example(s) |
|---|---|---|
| Brown paper bag test | Within the African American community, comparing one's complexion to a brown paper bag. | If complexion was darker than the bag, the person was barred from public spaces and resources |
| Amygdala hijack | The automatic emotional and behavioral response regulated by the limbic system in response to stress, fear, and aggression that disables reasoned responses.[37] | "Racist" evokes irrational response and inattention to data on racism |
| Miscegenation | Sexual relationships or reproduction between two people of different ethnic groups. | Marriage between a Black person and a White person |
| Social construct | An idea conceived and accepted without discussion, study, or supporting data. | African American people are violent |
| Social determinants of health | Conditions in one's environment that influence health, functioning, quality of life and outcomes | Pollution, crowding, crime |
| SES | Characteristics or surrogates of one's financial security. | Income, zip code, educational attainment |
| Social need | Adverse social conditions for which patients seek assistance. | Travel expenses to attend clinic or educational opportunity |
| Social risk | Adverse social conditions associated with poor health. | Availability of fresh produce |
| Social stressors | Social behaviors and situations that threaten one's relationships, esteem, sense of belonging, and personal safety. | Racism |
| Structural injustice | Political, economic, social structures, and institutions in creating and perpetuating injustice. | Homelessness, racism, colonialism, and climate change |
| Structural violence | Situation in which a social structure or social institution harms people by preventing them from meeting their basic needs. | Lack of universal health care |
| Structural racism | Conditions and institutional policies that limit opportunities, resources, power, and well-being of individuals and populations based on racial and ethnic and other statuses. | Racial segregation |
| Weathering | In population sciences, incessant, ubiquitous, pernicious stress from racism damages the body, causes disease, and accelerates death and aging. | Poverty |

* SES, socioeconomic status.

their effects on populations. Structural injustice emphasizes political, economic, and social structures and institutions that can enable, create, and perpetuate injustice. Structural violence is illustrated by the lack of universal health care, and its monetized underpinnings putting it out of reach of individuals who cannot afford to buy it. Structural racism refers to widespread conditions (eg, residential segregation and institutional policies) that limit opportunities, resources, power, and well-being of individuals and populations or exposes persons to toxic environments such as contaminated water or toxic wastes. Equity is an aspirational goal of society. It is distinguished from equality by the fact that different individuals need different supports to attain their best results; equality acknowledges that everyone will benefit from the same supports and accepts that not all will benefit to the same degree.

We and the reviewers struggled over word choices and the amount of detail describing these complicated phenomena. The word racism can stimulate an automatic reaction to ignore the underlying message ("amygdala hijack").[37] For some, "structural" may evoke strong feelings that the term sanitizes and trivializes the true suffering, injury, and deaths of victims; for others, it invokes unfair attribution and blame and guilt.

In social epidemiology, the etymology of "risk factor" in population studies has evolved. Each change may be seen as attempting more precise and actionable expression. Risk factor has been referred to as environmental risk factor, "modifiable" risk factor, and, over the last decades, features of the social environment and, now, structural injustice/structural racism (Table 1).

## Historical determinants of racism in the United States

Over 497 years,12 generations of enslaved African American people created wealth and helped sustain the US economy. The human toll from slavery and its aftermath on suffering is inestimable, fatal, and has destroyed and scarred individuals and families over generations (Table 2). The negative relationship among racism, wealth, and adverse outcomes is measurable in almost every problem, natural and human made—from maternal and infant death, pain management, chronic illnesses, and SLE to police violence, war, drought, famine, pandemic, extreme weather, and climate change. Its pervasive discrimination and disadvantage damage the body and psyche ("weathering").[49] The recent news of the disparities in risk and survival of marginalized populations during the COVID-19 pandemic, the murder of George Floyd,

**Table 2.** Human toll of racism

| Epoch | Duration | Human toll, estimate | Reference(s) |
|---|---|---|---|
| Chattel slavery | 1619–1865 | 10 million persons of African ancestry | Jones[38] |
| | | 4 million African American people freed | Richardson[39] |
| Civil War | 1861–1865 | 40,000 African American people dead | Jones[38]; Richardson[39] |
| Jim Crow laws | 1877–1954 | Housing and educational segregation and discrimination | Jones[38] |
| | | Racial violence | Richardson[39] |
| Eugenics | | 70,000 African Americans | Carlson[40] |
| Antimiscegenation laws | Late 17th century to 1967 | | |
| Forced sterilization | 1910s to 1920s | | |
| Racial violence lynching | 1878–1939 | 4,340 African American people dead | BlackPast[41]; Waller[42] |
| Tuskegee Syphilis Study | 1932–1972 | 600 African American men and their families | Centers for Disease Control and Prevention[43] |
| Race riots | 1663–1960 | Thousands to hundreds of thousands of African American people | Zinn Education Project[44] |
| Police violence | 1980–2019 | African American people are three times more likely to be killed than White US individuals. | BlackPast[41] |
| Black Lives Matter | – | 12–26 million multiracial individuals | Buchanan et al[45] |
| Mass incarceration | 1965 to present | 4 million African American people | Cullen[46]; Prison Policy Initiative[47] |
| COVID-19 pandemic | 2020–2023 | African American death rates from COVID-19 are 1.6 times higher than those of White individuals. | Kaiser Family Foundation[48] |

and the scholarship from disciplines such as sociology, political science, and moral philosophy has fueled the outrage.

Structural injustice and racism have been considered a root cause of all health disparities.[50] This should be considered a hypothesis. We, like others, notably Thomas Sowell, believe the assertion that racism is the cause of all health disparities may be overly simplistic, and the prescriptions for governmental solutions could lead to unintended adverse consequences.[51]

We give historic examples of racism in the United States and discuss their relevance to people with SLE from the record and our own diverse lived experiences as individuals—intergenerational, in interracial marriages; as Black, White, and other minorities in White-dominant United States; Black and other minorities in Black-majority nations; US immigrants; Asian in a Asian-dominant nation; living in Southern United States; first individual of a family to attend college; rheumatologists; laypeople; etc. Over time, there have been efforts to document racist practices and policies and earnest efforts to acknowledge and correct them. Vestiges of racism remain, and their relevance to the management of lupus is drawn from our collective experiences in health care. An anonymous reviewer summarized our effort: "[the] horrors of the past are in fact the horrors of our present and future unless we do something."

## Residential housing

After the Civil War and slavery ended, during the Jim Crow era, 1877 to the 1950s, many Southern states legalized racial segregation.[52] Racial segregation was treated as private preference, but state and federal governments institutionalized de jure segregation or structural racism in every facet of life, including where people lived, were educated, and worked and who they married. Some of these restrictions persist to this day.

The Fair Housing Act of 1968 provided modest enforcement to prevent discrimination but did nothing to reverse centuries of state-sanctioned violations of the Bill of Rights, particularly violations of the Thirteenth Amendment, which banned treating former enslaved persons as second-class citizens. Residential areas became segregated in the early 20th century, largely by prohibiting Blacks from buying homes in White areas. Although the Supreme Court struck down explicit practices in 1917, communities perpetuated segregation by "exclusionary zoning," requiring neighborhoods to be exclusively single-family dwellings or homes with minimum lot sizes or minimum square footage requirements, excluding apartments and multifamily homes from entire neighborhoods. Some also had subtle practices that excluded working families, such as trash pickup only during the week, precluding families in which both parents had to work.

Today, exclusionary zoning is still widespread and creates adverse environmental conditions (air, water, and toxic exposures), and often with governmental sanction. The Fair Housing Act of 1968 prohibited discrimination based on race, color, religion, national origin, and disability, but its real impact is still coming to light. Covenants requiring purchasers to not sell their homes to Black buyers were recommended by the Federal Housing Administration (FHA) until 1977, when such covenants were declared unconstitutional. The FHA also established "redlining," which refused to guarantee mortgages for homes in minority neighborhoods—regardless of the wealth of those neighborhoods or of the applicants. By the end of 2019, homeownership, the usual wealth-building tool of the middle class, was 44% among Blacks, only 1% higher than when the Fair Housing Act was enacted, compared with about 74% for Whites. Since 1994, the gap between White and Black homeownership has widened.[53]

**Impact on African American patients with SLE.** Limiting housing options exposes African American patients with lupus to neighborhoods with toxic exposures,[54] limited dietary options and educational resources, and inadequate health care infrastructure (see discussion below on safety-net health care), just to name a few deleterious effects. Our African American patients with and without lupus living blocks away in segregated neighborhoods hear stories of neighbors dying in our teaching hospital. They experience microaggressions and disrespect in our waiting rooms (called by their first name, whereas others are addressed as Mr or Ms), see few if any physicians of color, feel uncomfortable and bewildered by the accoutrements of modern hospitals, and never fully trust their providers, who they view as "experimenting on them" and change every time they are seen. They can hardly understand what they are being told but are too embarrassed to ask and do not know who they can ask. Their treatment plans, such as exercise prescriptions and dietary changes, are often impossible for them to fulfill.

## Police violence and mass incarceration

The United States has 5% of the world's population but 25% of its prisoners in the largest prison system in the world. Of the roughly 2 million people incarcerated, African American people make up 38% of the incarcerated population despite being only 12% of US population. The discrepancy is attributed to differences in policing practices, crime rates, poverty, child rearing, etc, but whatever its cause, this scars people and their families for life and in succeeding generations. US policing has roots from Europe and from the slave patrols in some states in the South where slaves were seen as property without rights rather than as people.[55] By the end of the 17th century, every slave state in the United States had slave patrols who apprehended escaped slaves, used terror to deter potential insurrections, and disciplined slaves not covered by plantation rules. Without permission, slave patrols could enter the home of anyone—Black or White—who was suspected of sheltering escaped slaves.

After the Civil War ended, sometimes slave patrols became incorporated into police departments and monitored the behavior of newly freed slaves, many of whom, if not landowners, worked on plantations owned by White people. Patrols worked to enforce codes passed after the ratification of the Thirteenth Amendment, which banned slavery. The codes specified how, when, and where freed slaves could work, live, and travel and restricted their right to vote as well as how much they could be paid, essentially perpetuating the oppression of African American people. From the 1880s to 1965, Jim Crow laws were enacted across Southern states, prohibiting Black and White people from sharing public spaces in schools, hospitals, libraries, bathrooms, and restaurants.

During the 1960s, the country was in turmoil with widespread opposition to the Vietnam War, protests for civil rights, women's rights, etc, and successive administrations attempted to quell the unrest. Academics like Daniel P. Moynihan popularized the idea of a self-perpetuating "tangle of pathology" among Black families. Black poverty and Black crime and violence were seen as innate and Black cultural pathology, not poverty, arguably the most common cause of crime. "The War on Crime and the War on Drugs are two of the largest policy failures in the history of the United States."[56] These penalize those who cannot pay fines with exponential fining policies and/or extreme jail time for minor offenses, so-called "Two Strikes" rules.[57] Racial profiling results in disproportionately large numbers of racial and ethnic minority people being incarcerated for nonviolent crimes.

Police violence and mass incarceration persist. On May 25, 2020, Minneapolis police arrested George Floyd, a 46-year-old Black man, after a convenience store called 911 and told the police that he had bought cigarettes with a counterfeit $20 bill. In Floyd's last 9 minutes and 29 seconds of life, his neck pinned beneath three police, his words, "I can't breathe" became a rallying cry against police brutality toward Black people and reignited the Black Lives Matter movement all over the world for 12 to 26 million supporters, Black and non-Black. There has been about a 10% reduction in the incarceration rate, but at the current rate of decline, omitting the atypical period during the COVID-19 pandemic, the incarceration of African American people would only match that of White people after 100 years.[47]

**Impact on African American patients with SLE.** Jail breeds criminality and limits educational and rehabilitation and exposes persons to violence; disruption of long-term medications, medical surveillance, medical care; and new pathogens from crowding. Incarceration impairs social and family support systems and childcare responsibilities; its ripple effects are documented.

**Medical care.** US academia and medicine have been complicit in, enabled, and provided rationales for racism. Eugenics, the "normal" science of the 19th century, legitimized race as an innate biologic and genetic attribute.[40] By late 1920, 376 US colleges offered courses on eugenics. Researchers at Harvard, Yale, University of Michigan, University of Wisconsin, and Stanford conducted "studies" of skull size and volume, correlating them with morality, intelligence, and superiority of races. These legitimized laws prohibiting miscegenation and forced sterilization of undesirable "races" to create a better, more intelligent, more White nation.

Prominent physicians Oliver Wendall Holmes,[58] Sir William Osler,[59] and Harvey Cushing[60] were not immune from these attitudes. US health policies, bias, and stereotyping contributed to widespread differences in health care by race and ethnicity.[61,62] The American Medical Association discriminated against Black physicians until the mid-20th century.[63]

Before 1965 and the advent of Medicare, many US hospitals had separate White and Black wards, White and Black toilets, White and Black dining areas, and White and Black water fountains. In White segregated hospitals, there were no Black doctors, medical students, or nurses. African American patients experienced substandard treatment, exploitation, and unethical experimentation. Months before the inauguration of Medicare, more than 4,000 segregated hospitals rapidly desegregated to meet the requirements for receiving Medicare payments but never addressed racist practices.[64]

US medical policy has often been biased against African American people in structural injustices often in hidden, unintended ways. Examples include our national policy on drugs[65] and protocols for managing congestive heart failure,[66] for end of life, and for pain[67] to name a few. Embedded algorithms such as the estimated glomerular filtration rate in clinical practice guidelines[68] assumed race as an intrinsic biologic difference systematically and, unintentionally, perhaps, harmed a racial group. However, there has been progress. These include initiatives in medical schools, professional societies, and teaching programs revisiting their roles in racism, and faculty development and recruitment to increase diversity and studing of racism's adverse impact.

The biggest problem remains health care access. About 58% of US citizens are covered by health insurance through work. Those without employer-sponsored health insurance are often uninsured. The Affordable Care Act (ACA) was a giant leap forward toward universal health care. The political and legal backlash and overt attempts to undermine its key conceptual and legal basis—such as the act's banning insurers from denying coverage based on risk and pre-existing conditions and providing subsidies for people of certain income levels—impair it. Private equity is aggressively buying and selling components and systems of care and privatizing Medicare and Medicaid to make them more profitable to sell. A Supreme Court 2012 ruling[69] upheld Congress's power to enact most provisions of the ACA and made Medicaid expansion optional for states. Among those too poor to afford private insurance but who do not meet the eligibility categories of Medicaid and fall into the Medicaid coverage gap, about 60% are people of color living in Southern states that chose not to expand Medicaid. Structural racism imposes eligibility restrictions on Medicaid expansion populations, especially recent work-reporting requirements reflecting the racist trope that Black people are lazy and have a poor work ethic.

Medicaid provider reimbursement and disproportionate share hospital payments subsidize uncompensated care provided by hospitals that serve low-income individuals, the uninsured, and those on Medicaid. Medicaid reimbursements are notoriously low and are a major reason for low provider participation. The War on Poverty funded community and neighborhood health centers in Black and minority neighborhoods, but in the years since, disinvestment in these areas eliminated or downsized these, or merged them to make them financially viable, or moved them to predominantly White communities. Safety-net hospitals still exist in approximately 300 or more urban and rural sites. These include legendary teaching hospitals such as District of Columbia General, Boston City, Hahnemann, Harlem, Montefiore, Bellevue, Metropolitan, Cook County, San Francisco General, Harbor–University of California, Los Angeles, Charity, and others. With strong commitment to caring for disadvantaged patients who can't pay or who need care and are not fully covered, they also partially address the social determinants of health such as food insecurity, homelessness, and expensive but unprofitable services such as mental health care.

**Impact on African American patients with SLE.** Structural racism hinders African American patients with SLE directly through worse access to care, lower rates of evidence-driven treatments, poorer intermediate outcomes like blood pressure control, and worse outcomes like higher mortality and rates of end-stage renal disease. Weaker insurance coverage adds to this burden. Between 9% and 22% of patients with lupus are on Medicaid.[70,71] They are part of the current 86.7 million US citizens getting Medicaid, including eligible low-income adults, children, pregnant women, elderly adults, and people with disabilities. Medicaid is administered by states and is funded by states and the federal government.

A huge public health crisis is looming, and *low-income US people with and without lupus are at risk of losing health insurance. Due to a federal policy change on April 1, 2023*, an estimated 8 to 24 million people will lose Medicaid coverage.[48] Black enrollees, Latino enrollees, kids, and young adults are most at risk of getting inappropriately terminated. Another group who will lose Medicaid are those in states that haven't expanded the program under the ACA, like Florida and South Carolina.

## Approaches in a polarized America

**Choosing individual responsibility and action.** Of the adverse effects of racism toward African American people over hundreds of years, many are now structural. They occur in a wealthy country, a driver of health innovations and of the world's economy, but one that is also performing near the bottom by population health measures.[72] Racism's pervasive effects mitigate against a simple solution and beget humility. Complex systems have multiple, unexpected, unavoidable accidents that occur because of their complexity and tightly coupled system failures are often inevitable.[73] To accomplish one's task as a health care provider, to ensure that our prescriptions can be implemented and followed, we need to be dealing with health's social determinants. There are paths forward for both personal responsibility and for society. For both, it starts with changing the premise. As Amos Tversky and Ed Kahneman showed, "The framing of a problem drives the choice."[74]

**Defining disparities in health as a moral problem.** Basic health care is a basic right of all persons and subserves other rights considered basic: freedom of expression, of worship, from want, and from fear. Individuals have the choice to speak out: acknowledge, remember, and honor those who suffered, persevered, and triumphed despite all odds one act and one relationship at a time. Though one act might not work, doing nothing will make it worse. There is no magic bullet that will end racial health disparity in patients with SLE or any other condition.

Social equity is an aspirational goal of society. Equity is different from equality and acknowledges that different individuals need different supports to attain their best results; equality acknowledges that everyone will benefit from the same supports and accepts that not all will benefit to the same degree. Implementing the best health care possible involves the identification of the practical and cognitive barriers to adhere to evidence-based management.[75] We should not assume to have the answers but try things and evaluate the results in partnership with the aggrieved. The personal actions result from first defining disparities in health as a moral problem. We put forth goals and actions under our personal control and responsibility in Table 3.

To pursue even more change and scale, we should take the long view and partner, support, elect, and grow the alliances and leaders enabling substantive societal changes. Some would be "blue-sky" changes not possible or envisioned now but that might be even more impactful. In this vision and with humility, we present a sampling of thoughtful ideas from many individuals and groups worthy of our attention and conversation (Table 4). They are admittedly complicated and affect many aspects of society but, we believe, commensurate with the centuries' destruction of every aspect of human life in a group.

## Societal responsibility and action

Addressing and eliminating structural racism will require a sea change. It will need to involve those who would be affected by the changes, and this demands potential interventions to be first pretested in real-life settings. It should not be transactional, nor require building a new bureaucracy, assigning the task to experts, nor first requiring litigation or major legislation.

Defining "burden" by specific diseases reinforces the current situation in which, on average, systems are deemed sufficient. However, the range and extremes of the current situation are not sufficient, and the current situation divides groups, each believing theirs is the greater burden and in greater need for special attention. Allying with other advocacy groups for health equity may enlarge ownership and political power for change. In a study of 323 violent and nonviolent

**Table 3.** Individual actions ensuring health care as a basic human right

| Actions | Comment | Reference(s) |
|---|---|---|
| Continued learning | Evidence on toxicity of adverse social determinants on mortality and morbidity rates. | Gravity Project[76] |
| Self-awareness | Gain insight into personal biases and assumptions concerning race, religions, etc, with Implicit Association Tests. | Project Implicit[77] |
| Overcome biases | – | Myers[78] |
| Be a visible leader and educator and call out microaggression and bias | Silence is complicity and assent. | Farmer[35] |
| Routine check on social determinants of health in patients | Social determinants of health are as or more important clinically than the usual vital signs. | Daltroy[75] |
| Reach out, befriend, and mentor at-risk persons | One supportive caring individual in a person's life is an essential ingredient in successful navigation of life's challenges and opportunities, resistance, resilience, and recovery. | Werner[79]; Brooks[80] |
| Proactively assist at-risk persons to seek or maintain Medicaid eligibility | A March 31, 2023, law starts the unwinding of Medicaid continuous coverage for 8–24 million people. | Clarke[71] |
| Collaborate with advocacy groups for universal health care | Enlarge political power with groups such as retirees (Generation X, etc) and veterans. | Chenoweth[109] |
| Implement and support self-help, navigator, psychosocial, and practice guidelines | Narrows gap between what is known and what is practiced in the continuous challenge of insuring a population's health. | Robb-Nicholson et al[18]; Daltroy;[19] Karlson;[20] Williams;[21,23–25] Fortin[22] White[26] |
| Exchange visits to higher-performing groups | Without consultants, visits to higher-performing units predictably improve outcomes and process of lesser performing units. | Blooml[81]; Hoffenberg[82] |

**Table 4.** Begin again: social activism*

| Conceptual goal | Comment | Reference(s) |
|---|---|---|
| Universal health care | Not an expense but a moral imperative. | Zieff[83] |
| Evaluate diversity, equity, and inclusion efforts | – | – |
| Implement Best Practices and practice guidelines and system improvements in management of patients with SLE | – | American College of Rheumatology Ad Hoc Committee on Systemic Lupus Erythematosus Guidelines[84] |
| Enable building of power infrastructure and wealth accumulation in African American people | Grassroots organization grows critical mass and enduring and effective social movements. | South;[85] Black Futures Lab[86] |
| Limit private equity incursions into the public health system | Every new venture has had an unintended, adverse effect on patients. | Cai[87,88] |
| Resist Medicare Advantage | This has grown to encompass 30 million people. | Cunningham-Cook[89] |
| Partner with experts in the provision of health services in resource-limited populations | Lessons are bidirectional. | Flower[90]; Suzon[91]; Tikly[92] |
| Create a broadband, secure, universal "society internet" without commerce or ads | If one is not counted or acknowledged, one will never be heard, counted, or part of the solution. It would be the vital infrastructure for universal ID and participation in the democratic process, telehealth, tele-triage, self-care, basic critical skills, and health literacy. | De Wit[93]; Arendt[94] |
| Eliminate child poverty | Disparities begin at birth. | South[85]; Whiteford[87]; Pantell[95]; Hamilton and Darity[96] |
| Model tolerance, continuous learning, critical appraisal, appreciation of diversity, resourcefulness, and resilience | "People must learn to hate, and if they can learn to hate, they can be taught to love…" (Nelson Mandela)<br>The Kauai Longitudinal Study demonstrated the effectiveness of having just one person's support and attention in prevention, resilience, and recovery from adversity. | Werner[79] |
| Universal baby bonds | Trust accounts for every child born that can only be accessed in adulthood. Government would top up accounts annually, depositing more for poorer families. | Cassidy[97] |
| "Pay for time" in health care vs pay for services emphasizing procedures, tests etc | Concierge-styled practices and slow medicine increase satisfaction of providers and patients and incentivizes meaningful relations rather than procedures and diagnostic studies. | Sweet[98] |
| Integrate horizontally and siloed efforts in the identification and management of mental health conditions and chronic ailments starting in the youth of the disadvantaged | Mental and chronic illnesses and social deprivation often begin in youth. They appear and are dealt with as truancy, crime, school lunch, homelessness, educational achievement, and mental health. Costs, adverse outcomes, and progression to chronic illnesses are less when managed by systems of care across silos. | Collins et al[99] |
| Establish registry of systemic rheumatic illnesses | Linked to rheumatic disease treatments and outcomes, they are a means of postmarketing surveillance, an active process for improving the processes of care in real time. | Flower et al[100] |
| Implement demonstrably effective at-home programs | Applicable to homebound, rural, and Medicare-/Medicaid-eligible patients. | Levine et al[101]; Master et al[102] |
| Endow competitive scholarships for educational and postgraduate training for historically underrepresented minorities to expand dissemination, mentoring, and related expenses to enable completion | Incentivizes and supports culturally appropriate health care providers and those already on the fast track. Expand Pell Grants and modify selection modeled after the Mitchell Institute Scholars Program. | National Association of Student Financial and Administrators[103]; The Mitchell Institute[104] |
| Disseminate small-loan programs for startup businesses in communities at risk | This is an effective intervention to build commerce. | US Small Business Administration[105] |
| Forgive medical debt | The proven means to financial security is to carry no debt and save. | Holpuch[106] |

(Continued)

**Table 4.** (*Cont'd*)

| Conceptual goal | Comment | Reference(s) |
|---|---|---|
| Establish public endowment and tax relief for safety-net institutions | Safety-net institutions are essential in marginalized communities. | – |
| Disseminate public apprenticeship programs for all trades and professions | Earning while learning is a win–win and builds human resources and financial security. | US Department of Labor[107] |
| Curate narratives of heroic, courageous, humanitarian achievements of African American people, past and present | Observing behavior is more powerful than lectures. Celebrating success resilience and innovation is communicable. | The HistoryMakers[108] |

* SLE, systemic lupus erythematosus.

protests between 1900 and 2006 worldwide, whenever 3.5% of the population engaged in nonviolent demonstrations, leaders enacted the systemic reforms called out by the protestors ("3.5% rule").[109] The rule presumably is also relevant to opposing points of view gaining political traction.

For the United States, that would mean if approximately 9 million US people publicly and nonviolently called out for universal health care, our leaders would enact it. This hasn't happened and seems remote, but Obama's leadership to enact the ACA was tremendous progress. Rudolf Virchow put it as, "Medicine is a social science, and politics is nothing more than medicine on a large scale."[110]

**Racism, poverty and health.** South et al make the case for targeting wealth and, we add, starting with the youth of the country, in improving population health:

> *"Focusing on income as a social determinant of health would mitigate the systemic factors that enable continued health outcomes discrepancies … real wealth drives health in enabling choice and stability in education, nutrition, and housing, … Wealth provides cushion for dealing with social disadvantages like single parenting, unexpected emergencies, such as unanticipated medical expenses, involvement in the criminal justice system, or job loss. Wealth also provides a level of security that buffers against the weathering effects of chronic stressors."*[85]

Wealth results from the accumulation of savings over generations. The persistent racial gap in wealth can be almost entirely accounted for by the racial gap in income.[111] Decades after the landmark civil rights legislation and the Great Society of the 1960s, the average wealth of White households is still seven times greater than that of Black households. Poverty is a permissive factor, but we believe that the more important factor is that a group is viewed with contempt or fear by those around them. The robust governmental economic responses under President Biden during the COVID-19 pandemic resulted in historic gains against poverty and reducing hardship, and this illustrates the power of government to change or improve what appears to be an inherent part of the human condition.[112]

## Continued vigilance for and opposition to threats to health equality

The monetization and corporatization of US health care forecasted by Paul Starr in 1982 is nearly complete.[113] The market approach to supporting health care has spawned virtual monopolies of health care delivery systems, and private equity efforts are creating a shadow profit-driven health care system, privatizing Medicare and Medicaid,[114] luring physicians, especially primary care physicians,[115] away from their practices to become employees. Health care workers feel morally injured, burned out, powerless, and voiceless in their medical organizations to act humanely and professionally. They witness unsafe staffing levels, predatory drug prices, mercenary and exploitative executive–worker salary ratios, etc. Retirement and unionization are seen as their recourse. Private equity has carved out profitable diagnostics and procedures such as kidney dialysis, diabetic retinopathy monitoring, etc, with promises of increasing efficiency of procedures or processes of care or economies of scale but with little convincing information on patient outcomes or even overall cost savings once administrative costs and profits margins are counted in.

## Reparations

Cash compensation for the effects of slavery are being debated and especially by nations involved with the slave trade. In the United States, two federal reparations bills have stalled. Other places and institutions have taken steps, started research, and have met opposition and delay.

One exception may be unfolding in the Barbados. British settlers came to Barbados in 1627. By 1807, an estimated 387,000 enslaved Africans had been illegally trafficked and provided the labor that made sugarcane an extremely profitable crop. British Barbadian Slave Codes justified and legalized slavery. As many as 30,000 enslaved people are believed to have died on Drax family plantations in the Barbados and Jamaica alone. A 14 × 21–mile island with 285,000 individuals, 92% Black, once the most "notoriously racist" place in the region, it is now completely independent of British rule since 2021. Its Gini coefficient, a measure of income distribution, indicates an income gap of almost seven points higher than that of the United States. It is now leading the world in the reparations effort.[116]

The Caribbean intergovernmental organization will ask 10 European countries to begin negotiations for reparations. Their request is not focused on reparations to individuals. Instead, their goals are to have careful accounting of what occurred during the enslavement, the psychological and cultural toll from centuries of oppression, formal apologies, and, most importantly, viewing reparations as a public investment to improve infrastructure and human conditions: education, health care, and sovereign debt forgiveness.

Failing this, the Caribbean nations are prepared to go to international court. Legal experts argue that the over 400 years of enslavement in the Americas was a crime committed against humanity and violated international laws, and reparations are due. Whether reparations in the Barbados or anywhere else would the outcomes of patients with SLE is uncertain but not likely to make them worse.

## Conclusions

We have labored since the 1960s to understand African American health disparities in lupus. Multiple risk factors and the importance of the social determinants of health have been recognized. Under our watch, contempt and fear of a racial group, intentionally and unintentionally, became entrenched and grew. It was and is man made. In that, it is men and women who can change it. There are choices and opportunities that take us (Table 3) and our country (Table 4) forward. The mitigation and solution of the problem begins with reformulating the challenge as a moral one, of universal health care as a basic human right. Using one's network and resources can create opportunities for racism's victims to "take up their space" and to search for their dreams. Equally important will be acknowledging the historical facts, giving the aggrieved a voice to tell their story. Continued vigilance and calling out racial bias in medical education and medical practices and resisting unjust private equity incursions into Medicare and Medicaid, primary care practices, and other components of health care will also help. SLE in patients in the context of all the health care and other societal challenges our nation faces is, by the numbers, a relatively small problem, but its resolution will benefit many other disparities and will come when there is universal health equality. We owe it to one another.[117]

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## AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be published.

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