The Struggle to Diminish Inequities in the U.S. Healthcare System

An STS Research Paper
presented to the faculty of the
School of Engineering and Applied Science
University of Virginia

by

Tara Tavakol
March 19, 2023

On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

Signed: _____

Approved: _____ Date _____
Peter Norton, Department of Engineering and Society

The Struggle to Diminish Inequities in the U.S. Healthcare System

In the United States, the legacy of centuries of racism includes marked health disparities by race. According to the U.S. Centers for Disease Control and Prevention (CDC), "Racism—both interpersonal and structural—negatively affects the mental and physical health of millions of people, preventing them from attaining their highest level of health, and consequently, affecting the health of our nation" (CDC, 2021).

Social determinants of health include place of residence, housing conditions, educational opportunities, employment status, and wealth, all of which are subject to inequities by race. To CDC, these are "key drivers of health inequities within communities of color, placing those within these populations at greater risk for poor health outcomes" (CDC, 2021). Among racial and ethnic minority groups in the U.S., rates of illness and death are higher; life expectancy is four years less than that of white Americans (CDC, 2021).

Inequities in U.S. healthcare are also associated with other interdependent variables, including socioeconomic status, which in turn are often attributable to differences in intergenerational transfer of wealth, access to insurance, and residential conditions (Kirby et al., 2006). Among Black Americans, 12 percent are uninsured, in comparison to 9 percent of white Americans (ASPE 2022). Many advocates strive to reduce the consequent inequities in healthcare.

While social justice advocacies, public health professionals, and medical professionals generally agree that racial and other inequities pervade the U.S. healthcare system, they disagree about the best means of redressing them. Some maintain that incremental reform can make the current system sufficiently equitable; others, however, contend that the system in itself perpetuates historical inequities, and must be reconstructed.

Review of Research

Among Black Americans, distrust of the healthcare system is due in part to a history of abuse, best exemplified by the Tuskegee syphilis study. In this study of untreated syphilis, conducted by the U.S. Public Health Service from 1932 to 1972, 600 Black men, 399 infected with syphilis plus 201 uninfected men as a control group, were study subjects without informed consent. Although the researchers told the men that they were being treated in return for their participation, and although penicillin was generally available by 1947, the researchers withheld penicillin treatment (CDC, 2022).

Scharff et al. (2010) attribute lasting distrust of the healthcare system among Black Americans to abuses such as this. “Mistrust of medical research and health care infrastructure is extensive and persistent among African Americans,” they note. “More than four centuries of a biomedical enterprise designed to exploit African Americans is a principal contributor to current mistrust.” Federal mandates now ensure that women and nonwhite people are included as study subjects in clinical research trials, but such mistrust can limit the pool of such subjects. According to Scharff et al. (2010): “mistrust of clinical investigators is strongly influenced by sustained racial disparities in health, limited access to health care, and negative encounters with health care providers.” Relative to all patients, African American patients receive, in the aggregate, less information, empathy, and attention from their physicians, and are less likely to receive medical services (Care et al., 2003).

This repeated cycle of mistrust and lack of resources hinders biomedical research in communities of color. “Black and Latinos make up 30% of the U.S. population but account for just 6% of all participants in federally funded clinical trials… fewer than 5% of federally funded

lung disease studies in the last 20 years have focused on people of color, even though black Americans are one-third more likely than whites to have asthma and over three times more likely to die from it" (Konkel, 2015). Financial constraints and cultural differences deter nonwhite participation; Konkel (2015) adds that "fear of exploitation" due to a history of abuses make many "distrustful of the biomedical establishment and reluctant to participate."

Lack of research is detrimental, as people of color are at higher risks of diseases. "Higher mortality rates have been observed in the Black population for both all-cause mortality and specific causes of death… after adjustment for income, Blacks still have higher death rates from cardiovascular disease, cancer, and other causes" (Richardus & Kunst, 2001).

Brown and Hargrove (2013) found that women of color, specifically Mexican American women and Black women, have worse functional health and that, "multidimensional approaches as well as examination of various potential mediators of health disparities provide a better understanding of how health is shaped by multiple social locations." Daw (2015) found that for healthcare such as transplants, racial disparities "directly influence post-transplant success."

Kogut (2021) found that "many health disparities involve medications, including antidepressants, anticoagulants, diabetes medications, drugs for dementia and statins, to name a few." Managed Care Pharmacy perpetuates racial disparities in medication use. For example, "pharmacy benefit designs are increasingly shifting cost of expensive medications to patients, creating affordability crises for lower income workers, who are disproportionally persons of color… the quest to maximize rebates serves to inflate list prices paid by the uninsured, among which Black and Hispanic people are over-represented" (Kogut, 2020). "Even when cost-sharing is minimal or zero, the medication adherence rates have been documented to be lower among Blacks as compared with Whites. Deeper understandings are needed about how racial disparities

in medication use are influenced by factors such as culture, provider bias, and patient trust in medical advice" (Kogut, 2020). Kogut demands Managed Care Pharmacy should address racial disparities in medication use and amplify voices of community members and their advocates. "We must not believe that entrenched health-system, societal and political structures are impermeable to change" (Kogut, 2020). Improvement needs to be made in healthcare for people of color, as it is detrimental to quality of life.

Advocacy

The American Public Health Association (APHA) acknowledges racial inequities embedded in the system, perpetuating inequities in healthcare. While APHA claims it "works to advance the health of all people and all communities," they attribute public health inequities in the U.S. in part to structural racism (APHA 2022). An APHA internal policy proposal calls on the association to "support and fund research focused on addressing structural racism and help develop solutions to mitigate racism within the institutions in the U.S." (APHA, 2020). APHA's executive director called upon Congress to take action to curtail racial profiling in law enforcement and thereby to relieve the "brutality and violence" that "continue to harm the health of individuals and communities of color, especially Black communities" (Benjamin 2021). To APHA, structural racism is a public health threat: "APHA recommends the following actions by federal, state, tribal, and local authorities… increase investment in promoting racial and economic equity to address social determinants of health… work with public health officials to comprehensively document law enforcement contact, violence and injuries" (APHA 2022). APHA also focuses on prescription medication equity to improve the current system. APHA demands, "increasing drug market competition, enhancing clinical research and drug

development centered on patients and population health outcome improvements, streamlining public and private drug pricing and reimbursement systems, and expanding affordable drug insurance to all Americans" (APHA 2022).

One advocacy, The California Black Health Network (CBHN), recognizes inequities, but favors incremental reforms only, satisfied that such reforms are sufficient to redress them. CBHN seeks to "ensure that all Black Californians, regardless of their education, socio-economic class, zip code, sexual orientation, gender identity, homelessness, or immigration status have access to high quality and equitable primary and behavioral healthcare, and avoid unnecessarily succumbing to disease" (CBHN 2022). It calls for "cost-effective coverage and value-based care" prioritizing "value, quality of care and patient outcomes" (CBHN 2022). To diminish inequities in infant and maternal mortality, CBHN demands "policies that would increase access midwifery care and birthing centers ... to increase access to group prenatal and postpartum care" (CBHN 2022).

The National Patient Advocate Foundation (NPAF) demands equal access to healthcare. NPAF "strives to shape the health care system into one that meets all patients and caregivers where they are and lessens health disparities overall" (NPAF, 2020). One advocacy, the Berkeley Media Studies Group, amplifies health inequity issues to promote reform. They do this by "helping advocates and community groups develop and fine-tune their strategies so that they can make better use of the media to advance policies that improve the social determinants of health" (Berkeley Media Studies Group, n.d.). The California Pan-Ethnic Health Network focuses on reform and policy implementation, while recognizing the present health care system issues. They state that "California must require health plans, systems, and providers to track, report, and improve health outcomes over time for key chronic conditions such as diabetes, asthma,

hypertension, and depression. Holding health plans accountable for the quality of care provided to communities of color will create the incentives needed to ensure plans invest with broader stakeholders in appropriate strategies to address barriers to community health and reduce disparities" (California Pan-Ethnic Health Network, n.d.).

The National REACH Coalition (NRC) uses health equity programs. "NRC is a national network of community-based organizations that promotes develops and implements health equity programs in both urban and rural communities" (NRC, n.d.). NRC "provides assistance with local program development by empowering and mobilizing community members to seek better health, encouraging utilization of appropriate care and consumer directed practices, implementing evidence-based practices and public health programs that fit the unique social, economic, and cultural needs of multi-ethnic communities, and moving beyond interventions that address individual behavior to a broader assessment of systemic change" (NRC, n.d.). Local and national advocacies collaborate to promote issues with the public and organize policies, focusing on surface-level reform, structural reform, or both.

Health Care Professionals' Efforts

The National Hispanic Medical Association (NHMA) seeks to reduce racial health inequalities among U.S. Hispanics, tackling reforms to address inequities. "The mission of the organization is to empower Hispanic physicians to lead efforts to improve the health of Hispanic and other underserved populations" (NHMA 2022). In October, the NHMA "submitted the Office of Civil Rights Comments to strengthen Section 1557 of the Affordable Care Act with data on race, ethnicity, language, and gender identity" (NHMA 2022).

The American Academy of Family Physicians (AAFP) advocates for health equity through public policy. AAFP launched The EveryONE Project to "empower family physicians to

advance health equity." It provides information on policies and health equity including developing policies to protect indoor air quality in housing near congested roads and increasing access to nutritious food options for all people (AAFP, n.d.).

The American Medical Association (AMA) "encourages physicians to examine their own practices to ensure equality in medical care mitigating disparity factors in the patient population." The AMA "works to increase the number of minority physicians to reflect the diversity of the U.S. population through its policies and advocacy work." They spread awareness on bias and stereotyping in medicine that impact minority populations (AMA, n.d.).

The College of American Pathologists (CAP) explores "policy development on standardized public health data, diversifying the health care workforce, diversifying clinical trials, and promoting independence in medicolegal death investigations." CAP promotes healthcare diversity. (CAP, n.d.)

The Council of Medical Specialty Societies (CMSS) "was created to provide an independent forum for the discussion by medical specialists of issues of national interest and mutual concern" (CMSS, n.d.). CMSS focuses on systemic and structural racism and its role in healthcare inequities. CMSS includes more than 800,000 physicians across 45 specialties, all protesting "the negative impact of racism in our nation and of racial inequities in our healthcare system. Racism in our society cannot be ignored as it undermines public health" (CMSS, n.d.). CMSS "supports its member specialty societies working to promote equity and reduce the adverse impact of racism" (CMSS, n.d.). They are "committed to using our platform to improve the health of every patient we serve" (CMSS, n.d.).

The Oncology Nursing Society (ONS) believes "systemic racism persists throughout today's society, presenting barriers to basic human rights and services, including quality health

care for millions of people. Overcoming those disparities and achieving social justice requires advocacy from all – but especially nurses." ONS states nurses have an ethical responsibility to advocate for equity. Nursing has been the most trusted and ethical profession for 20 years, requiring them to "speak truth to power, stand up, and call out injustice" (ONS, 2022). The American Nurses Association's code of ethics states, "the nurse collaborates with other health professionals and the public to protect human rights, promote health diplomacy, and reduce health disparities. The profession of nursing, collectively through its professional organization, must articulate nursing values, maintain the integrity of the profession, and integrate principles of social justice into nursing and health policy" (ONS, 2022). To ONS, racial inequity is a public health crisis, and through national policy, "decision-makers must confront the issue directly" (ONS). ONS condemns racism, particularly in cancer care. "Nurses and other healthcare providers must join ONS in leading the way for society to recognize the structural and systemic barriers affecting many populations, especially populations of color" (ONS, 2022).

Health care professionals are crucial in combating healthcare inequities through their efforts in promoting policy and educating one another on biases present in medicine.

Philanthropies

Non-profit philanthropies promote and fund health equity change. The Commonwealth Fund, a philanthropic foundation, recognizes pervasive inequities, stating that the system itself perpetuates historical inequities, leading to a continued cycle of racial disparities in healthcare. They sponsor efforts to improve disadvantaged groups' healthcare access by "tracking health insurance coverage, affordability, and health outcomes for Black, Latino, Asian, Pacific Islander and Native Americans" (Commonwealth Fund, 2022). It acknowledges the embedded racism in the U.S. healthcare system and its consequences, promoting "policies and practices needed to

achieve an antiracist health system that helps people of color to thrive" (Commonwealth Fund 2022).

To promote healthcare equity, the Fund has drawn attention to the stories of people who have endured inequities. Daphne, a young Black woman from a segregated, low-income neighborhood in New York said "I feel like sometimes the system, it's made for us to stay down." The Fund maintains that "racial and class marginalization" limit marginalized people's "control over outcomes that profoundly shape their lives." It brings "voice into policy" by "including the perspectives and experiences of oppressed groups most affected." According to the Fund, "policy processes are more equitable when marginalized voices guide them" (Commonwealth Fund 2022).

The Praxis Project works on national, regional, state, and local levels "to build healthy communities by transforming the power relationships and structures that affect our lives and communities." They implement "policy advocacy and local organizing as part of a comprehensive strategy for change," as a means of reforming health disparities, leveraging financial resources to disadvantaged communities (The Praxis Project, n.d.). Similarly, The Robert Wood Johnson Foundation funds research and initiatives focused on achieving health equity. They target health systems, supporting "projects that create the conditions for communities to thrive and give residents the ability to reach their greatest health potential," and supporting healthy families (RWJF, n.d.). One philanthropy, the Colorado Trust, while acknowledging health inequities, "believes advocacy for policy change is a cornerstone to achieving health equity." Their funding strategy culminates a strong field of advocates. This foundation, however, does believe that there lies a deeper issue within the system, but changing it takes time (Colorado Trust, n.d.).

The Kaiser Family Foundation (KFF) is a philanthropic organization that believes healthcare disparities are "intertwined with a contentious history of race relations in America" (KFF, 2023). KFF's demands changes to the current system. "KFF is the independent source for health policy research, polling, and journalism. Our mission is to serve as a nonpartisan source of information for policymakers, the media, the health policy community, and the public" (KFF, 2023). KFF has four major program areas: KFF Policy, KFF Polling, KFF Health News, and KFF Social Impact Media, "which conducts specialized public health information campaigns" (KFF, 2023). "We're unique in the way we bring together these different areas to create and communicate information about health policy to a variety of audiences, including policymakers, the media, and the public. This combination allows us to leverage our combined expertise and assets to play a national role on health policy" (KFF, 2023). Philanthropic organizations raise funds to assist in disparities, whether by aiding research or promoting policy and change in disadvantaged neighborhoods.

Conclusion

There are implementations needed to diminish racial inequities in healthcare. Williams and Cooper (2019) advocate that in order to reduce racial inequities in healthcare, three main steps need to be taken. First, "reducing inequities in health requires dismantling the systems that initiate and sustain inequities in a broad range of societal institutions that are the drivers of inequities in health" (Williams & Cooper, 2019). This entails development of communities of opportunity, "to minimize some of the adverse impacts of systemic racism. These are communities that provide early childhood development resources, focus on policies to reduce childhood poverty, provide work and income support opportunities for adults, and ensure healthy housing and neighborhood conditions" (Williams & Cooper, 2019). We need to ensure "access

to care for all… eliminating inequities in the receipt of high-quality care, addressing patients' social risk factors and needs more effectively, and diversifying the healthcare workforce." Communicating issues is essential, "we need to raise awareness of inequities, build political support, and increase empathy for addressing social inequities in health" (Williams & Cooper, 2019).

National, state, and local advocacies as well as healthcare professionals and philanthropic foundations all strive to diminish racial inequities in healthcare. Advocacy groups diminishing healthcare inequities with policies has shown success, however deep-rooted systemic and structural racism in the healthcare system needs improvement. While some groups target reform to address disparities, others demand research and progression of the system that has been designed to put people of color at a disadvantage for hundreds of years. For successful reduction of disparities, all aspects of community development, equality of high-quality care, and raising awareness need to be implemented. The majority of advocacies use policy and awareness, however structural change is needed, and disadvantaged community development is required to help prevent disparities in health conditions seen in these communities. There is still much to be done, but these groups are heading in the right direction in reducing healthcare inequities in the U.S.

References

AAFP (n.d.). The American Academy of Family Physicians. Advocacy for Health Equity.

AMA (n.d.). American Medical Association. Reducing Disparities in Health Care.

APHA (2022). American Public Health Association. Advocacy for Public Health.

ASPE (2022, Feb.). Office of the Assistant Secretary for Planning and Evaluation. Health Insurance Coverage and Access to Care Among Black Americans: Recent Trends and

Key Challenges. U.S. Department of Health and Human Services. Issue Brief No. HP-2022-07.

Benjamin, G. C. (2021, March 1). 117th Congress. George Floyd Justice in Policing Act of 2021. H.R. 1280.

Berkeley Media Studies Group (n.d.). Health equity.

Brown, T. H., & Hargrove, T. W. (2013). Multidimensional Approaches to Examining Gender and Racial/Ethnic Stratification in Health. *Women, Gender, and Families of Color*, *1*(2), 180–206.

CAP (n.d.). College of American Pathologists. Advocacy.

Care, I. of M. (US) C. on U. and E. R. and E. D. in H., Smedley, B. D., Stith, A. Y., & Nelson, A. R. (2003). Racial disparities in Health Care: Highlights From Focus Group Findings. In *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. National Academies Press (US).

CBHN (2022). California Black Health Network. Policy and Advocacy.

CDC (2021, Nov. 24). U.S. Centers for Disease Control and Prevention. Racism and Health.

CDC (2022, Dec. 24). U.S. Centers for Disease Control and Prevention. Tuskegee Study: Timeline.

Colorado Trust (n.d.). Health Equity Advocacy.

Commonwealth Fund (2022). About Us.

CPEHN (n.d.). California Pan-Ethnic Health Network. What We Do.

Daw, J. (2015). Explaining the Persistence of Health Disparities: Social Stratification and the Efficiency-Equity Trade-off in the Kidney Transplantation System. *American Journal of Sociology*, *120*(6), 1595–1640.

KFF (2023). Kaiser Family Foundation. About Us.

ONS (n.d.). Oncology Nursing Society. Diverse Healthcare Equity Requires Providers and Policymakers to Unite for Change.

Kirby, J. B., Taliaferro, G., & Zuvekas, S. H. (2006). Explaining Racial and Ethnic Disparities in Health Care. *Medical Care*, *44*(5), I64–I72.

Kogut, S. J. (2020). Racial Disparities in Medication Use: Imperatives for Managed Care Pharmacy. *Journal of Managed Care & Specialty Pharmacy*, *26*(11), 1468–1474.

Konkel, L. (2015). Racial and Ethnic Disparities in Research Studies: The Challenge of Creating More Diverse Cohorts. *Environmental Health Perspectives*, *123*(12), A297–A302.

NHMA (2022). National Hispanic Medical Association. About NHMA.

NPAF (2020, Nov. 18). National Patient Advocate Foundation. Health Equity.

NRC (n.d.). National REACH Coalition. About Health Disparities.

ONS (n.d.). Oncology Nursing Society. Diverse Healthcare Equity Requires Providers and Policymakers to Unite for Change.

Phelan, J. C., & Link, B. G. (2015). Is Racism a Fundamental Cause of Inequalities in Health? *Annual Review of Sociology*, *41*, 311–330.

Richardus, J. H., & Kunst, A. E. (2001). Black–White Differences in Infectious Disease Mortality in the United States. *American Journal of Public Health*, *91*(8), 1251–1253.

RWJF (n.d.). Robert Wood Johnson Foundation. Our Four Strategic Focus Areas.

Scharff, D. P., Mathews, K. J., Jackson, P., Hoffsuemmer, J., Martin, E., & Edwards, D. (2010). More than Tuskegee: Understanding Mistrust about Research Participation. *Journal of Health Care for the Poor and Underserved*, *21*(3), 879–897.

The Praxis Project (n.d.). Our History.

Williams, D. R., & Cooper, L. A. (2019). Reducing Racial Inequities in Health: Using What We Already Know to Take Action. *International Journal of Environmental Research and Public Health*, *16*(4), 606.

.