Undergraduate Thesis Research Paper

Addressing Inequality in American Healthcare: How Agencies Have Advocated for Reducing Healthcare Disparities

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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

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In the United States, nonwhites suffer much higher rates of chronic disease and premature death than whites (NAS, 2017). Such health disparities begin at birth; the mortality rate of African American infants is more than twice that of whites. African Americans die during pregnancy and childbirth at more than twice the rate of white Americans (Ely et al., 2022).

Heart disease is a leading cause of mortality among Americans generally, but African Americans are three times more likely to be diagnosed with cardiovascular diseases. Among those diagnosed, they are more than twice as likely to die of the disease. In 2010, African Americans' mortality relative to that of white Americans was 10 percent greater for lung cancer, 40 percent greater for breast cancer, and 140 percent greater for prostate cancer (O'Keefe et al., 2015). At the height of the COVID-19 pandemic, Black Americans were six to eight times more likely to be infected and die from the virus than whites (Zelner et al., 2020).

Health disparities are explained by a variety of factors, including genetics, environmental risk factors, socioeconomic status, and healthcare access (Fincher et al., 2004). Profound health disparities in the United States by race were not officially recognized by a federal agency until 1985, when Margaret Heckler, Secretary of Health and Human Services, acknowledged "a continuing disparity in the burden of death and illness experiences by Blacks and other minority Americans as compared with our nation's population as a whole." Heckler (1985) also added "that disparity has existed ever since accurate federal record keeping began more than a generation ago." Heckler's Health and Human Services Department recognized health disparities and promoted the use of this term; debates about achieving "health equity" later joined. For decades, social groups have sought ways to bridge healthcare gaps to diminish racial and ethnic disparities in health.

Important participant groups include advocacies, research foundations, hospital associations, community health centers, medical schools, large employers, and state and local public health agencies. These groups have advocated for reducing healthcare disparities in the United States by promoting the diversification of medical data and better health education to both affected and unaffected communities. Although all participant social groups agree that substantial health disparities by race are intolerable and must be reduced, they disagree on how to reduce them. Large, mainstream organizations tend to characterize the problem as one demanding incremental improvement of the United States healthcare system, through shifting research agendas, better resource allocation, and educational outreach. Many advocacies, however, frame the disparities as injustices requiring transformative, structural change in the United States healthcare system.

Review of Research

To understand how the advocacy done by social groups has had an impact on reducing something as widespread as disparities in United States healthcare, one must understand the causes of healthcare disparities and how these are targeted by group initiatives. In a causal attribution study, Taylor-Clarke et al. (2007) classified three common explanations of racial health disparities: patient attribution (assigning responsibility to the patient); physician attribution (such as biases among health professionals); or systemic attribution (such as structural racism). According to researchers, in research published from 1994 to 2003, systemic attribution rose in frequency from 11 percent to 29 percent while patient attribution declined. Because neglect of healthcare disparities contributes to their persistence, advocacies seek to raise awareness of them. In the Center for Disease Control's Healthy People 2010 interim report, there was an expressed concern that 80% of healthcare disparity reduction objectives were ineffective, and 13% of objectives worsened disparities (CDC, 2010). The greatest achievement, they noted, was the progression of models able to quantify disparities; with this better data came an emergence of more targeted advocacy initiatives in the 2010s.

Mitchell et al. (2022) contend that biases in healthcare data perpetuate health disparities. In clinical trials, for example, African Americans are often underrepresented, with implications for drug and treatment development. Roberts (2012) argues that demands for greater diversity in clinical research legitimizes misattribution of health disparities to supposed cultural and biological differences among races. Roberts claims that the lack of diverse data is merely a byproduct of the larger systemic problem of social inequality and not necessarily a cause of disparities. Bigby (2007) examines inequalities in access to quality of healthcare as a factor in health disparities. As seen by current research, professionals in the field disagree on a single attributor to healthcare disparities, thus underscoring the complexity of the issue and its deeply interwoven causes.

Other researchers have studied efforts to mitigate healthcare disparities in America. For example, Ozaki et al. (2022) found that intervention by pharmacists can reduce health disparities, while Arrieta et al. (2008) argue that a multidisciplinary approach is necessary to reduce inequalities, with support from economics, policy making, education, and social work. Major et al. (2013) propose that interactions among diverse social groups may contribute to group health differences and recommend education to reduce disparities. Despite broad consensus on the extent and gravity of health disparities by race, recommendations by researchers vary. Some contend that educational efforts to promote awareness can reduce disparities; others, however, contend that systemic change is necessary.

How Have Organizations Advocated for Reducing Healthcare Disparities?

Diversifying Healthcare Data

Prior to the turn of the twenty-first century, much of healthcare research was done on white male participants (FDA, 2017). Research on disease pathology, treatment clinical trials, and symptom classification guidelines were developed around the white male subjects and disregarded the unique experiences of all other groups of people. As a consequence, healthcare tended to assume women and racial minorities to have the same physiology and disease presentation as white men; a misconception that has directly contributed to the systemic misdiagnosis and mistreatment of African Americans in the United States healthcare system (Bell et al., 2015). As the population in the United States continues to diversify, research and awareness about healthcare disparities has become more widespread, and with it an increased call for representative healthcare data.

In a review exploring the current state of medical research, Sharma and Palaniappan (2021), from the Stanford University School of Medicine, believe “representative and diverse research participation is necessary to establish fair standards of care, minimize outcome disparities between populations, and achieve and uphold social equity.” Meharry Medical School, a historically Black medical school located in Nashville, Tennessee, endorses that “data diversity is an important step to improving health equity as data science applications continue to drive health care decisions” (Anderson, 2021). Anne Klibanki, president and CEO Mass General Brigham hospital located in Boston, conversely argues that the need for data diversification is “not about the numbers. It’s about what you are missing now.” Kilbanki (2022) contends that underrepresented groups “want to know that the perspectives that they bring are the perspectives that are known, shared, visible, and have a voice. Those are incredibly important goals within healthcare and incredibly important goals in many organizations.” Motivations for a diverse pool of patient data differ, but the consensus across initiatives is that it is a necessary step to healthcare equality.

The voices of these smaller advocacy groups have catalyzed healthcare data initiatives in larger mainstream organizations. National Institutes of Health (NIH) launched the All of Us Research Program to gather health-related data from diverse American volunteers to “help build one of the most diverse health databases in history.” Through this initiative they hope to “accelerate health research and medial breakthroughs, enable individualized prevention, treatment, and care for all of us” (AOURP, 2022). In the program’s first year, it gathered healthcare data from more than 175,000 participants, 80% of which are members of groups historically underrepresented in healthcare research (MMS, 2019). The Center for Health Equity Research and Promotion helps to fund university healthcare research focused on diverse participants, with the hope to “reduce disparities in health and health care in vulnerable populations” (CHERP, 2022). In 2016, the Penn Medicine Program partnered with the Center for Health Equity Advancement at University of Pennsylvania to launch the Race, Ethnicity, and Language demographic data collection initiative, which “modified existing and introduced new fields within the electronic health records to better capture demographic data across Penn Medicine” (CHEA, 2020).

Gathering diverse healthcare data is only half of the battle. What is done with this data and how it is used is equally important; misuse of data can be as detrimental as its lack. Nicole Richie (2019), Global Head of Health Equity and Population Science at Roche asserts that “to achieve health equity among all patient populations, we need to broadly understand genetic variations across individuals of different ancestries and establish potential links between variation and health outcomes across all communities.” The Robert Wood Johnson Foundation launched the National Commission to Transform Public Health Data Systems to “reimagine how health data are collected, shared, and used and identify what public and private investments are needed to advance health equity” (NCHE, 2021). Healthcare consulting firms, like the Research Triangle Institute Health Advance, have begun using “data analytics, qualitative and quantitative methods, (…) proprietary artificial intelligence and machine learning platforms” to “identify the countless ways social, economic, and political systems expose populations to risks and vulnerabilities” (RTIHA, 2023).

A more diverse pool of healthcare data can help physicians to better understand how disease presentation varies across individuals based on sex, race, and ethnicity. Standard of care treatments may not be equally effective across racial groups, and more personalized treatments may be necessary. These treatments can be developed by effectively utilizing diverse public health records. Currently, smaller advocacies work to raise awareness of healthcare data disparities, while larger organizations ultimately hold the power in moving initiatives forward.

Community Outreach & Education

Greater communication between communities and healthcare systems are important in addressing the unique needs of underrepresented communities. An important aspect of social group advocacies is bridging this gap between individuals and larger institutions through community outreach and education.

Many advocacies help to foster trust and communication between communities and larger institutions. The National Patient Advocate Foundation (NPAF) Trust and Equity Project contends that "patients, caregivers and their providers consistently identify trust as an essential component of good communications and shared decision making." NPAF (2023) focuses on "build(ing) awareness of the importance of trust" between individuals and healthcare institutions. The Mayo Clinic's Center for Health Equity and Community Engagement Research engages with local communities to "develop and execute innovative solutions that address most pressing health issues in the communities." In addition to community-based research, Mayo Clinic (2023) provides outreach education for "disease prevention related to health disparities, rural health and social determinants of health." The Veteran Affairs Office of Health Equity (VAOHE) aims to share "data, tools, research, and other resources to help eliminate racial and ethnic disparities experienced by Veterans." VAOHE (2020) uses an intersectional approach, communicating with local community-based organizations, local governments, advisory committees, and stakeholders to ensure that local needs are heard and considered in healthcare-related policies.

Many academic institutions have turned to community outreach as a means of addressing disparities. Community-Campus Partnerships for Health (CCPH) aims to connect communities and academic institutions to "emphasize partnership approaches to health." CCPH (2022) argues that health equity can only be achieved through collaborative efforts between communities, academic institutions, health organizations, and policymakers. CCPH provides training sessions to teach smaller advocacies how to effectively engage their members and broader communities. The Community-Based Health Equity Research Program through the University of Virginia conducts research in partnership with "numerous rural healthcare, education and community-based organizations" with the primary focus of reducing rural health disparities and promoting "health literacy" in disadvantaged communities (UVA, 2023). Georgetown University's Medical Center and School of Medicine have a similar Community-Based Health Research initiative that "facilitate(s) research to reduce cancer and related health disparities among underserved and ethnic minority populations" in the District of Columbia (GU, 2023). Academic institutions primarily work closely with surrounding communities to promote health equity.

Smaller advocacies have created health forums that allow for open communication between community members and larger institutions. The Health Equity Leadership and Exchange Network (HELEN) introduced a collaborative health forum between hospitals, academic institutions, local health departments, community health clinics, and other advocacies. Their goal is to create a "national network designed to bolster leadership and the exchange of ideas and information among communities of color" (HELEN, 2022). HELEN includes a health forum where members can post information about pressing policy issues regarding health equity, and the network is committed to monitoring the development and implementation of health laws on the local, state, and national level. The Black Health Network, based in California, hosts Health Equity Forums that feature speakers from healthcare, advocacies, research, and policy. These panels are open discussions to inform members of the current state of healthcare disparities and what can be done (BHN, 2022). Similarly, The National Center for Bioethics in Research and Health Care at Tuskegee University, in partnership with the Centers for Disease Control and Prevention's Office of Health Equity, hold annual Public Health Ethics Forums that feature diverse speakers educating listeners about the ethical concerns of healthcare disparities in rural America (CDC, 2020).

Outreach and education initiatives currently focus largely on connecting small, underrepresented communities to larger institutions. By building trust between these groups, the needs and concerns of previously disadvantaged communities can be heard and considered in healthcare, policy, and resource allocation. Education programs work to bring awareness to the urgency of disparities and teach communities how to better advocate for their needs. Smaller advocacies work to bring together members of diverse communities under a common goal that can then be taken to larger agencies capable of initiating systemic reform.

Promoting Access to Resources

Unifying communities through outreach is only the start of bringing about change; cohesive networks cannot transform the United States healthcare system without proper resources. This can be done through funding, education initiatives, and other workshops.

The National Quality Forum (NQF) argue that "measures that address healthcare disparities and culturally competent care are needed to create a long-term agenda for improving healthcare quality." NQF (2023) contend that this information must be used in "promoting the health of populations adversely affected by disparities and ensuring equitable allocation of healthcare resources." This idea emphasizes the intersectionality of healthcare equality advocacy; NQF argue that healthcare data must be used to inform resource allocation. The Health Equity Guide, founded by the Human Impact Partners, believes that "budgeting priorities and decisions are an important opportunity to align resources across multiple funding systems to advance equity, both within the health department and across government," further illustrating the collaboration required for productive resource reallocation (HEG, 2019).

Many initiatives focus on connecting smaller advocacies to larger institutions that can provide necessary resources. Allies for Reaching Community Health Equity (ARCHE) aims to bring together community leaders, medical practitioners, and policymakers together through leadership workshops and resource promotion. ARCHE (2022) Health Equity Design Labs bring together individuals and healthcare workers to address disparities and methods for mitigation; the organization "promotes resources, learning, thought leadership, collaboration, and innovative solutions that advance health equity." These labs aim to address all perspectives of health inequity to create innovative and collaborative solutions that are facilitated through synthesized reports that adopt recommendations from all parties. ARCHE also has a Health Equity Experts Network that connects local journalists to academic leaders, government officials, corporations, and nonprofit sectors to amplify the voices of health equity experts. The Prevention Institute, similarly, works to unify community-based organizations and public health departments, providing them with "tools and frameworks to inform and build capacity toward effective prevention, racial justice, and health equity strategy development" (PI, 2023). The Paxis Project, a national nonprofit that works closely with local and state organizations, "has raised more than $20 million for advocacy and community base building organizations nationwide" (TPP, 2019). This funding allows local organizations to afford more advocacy and connect community members to higher quality healthcare.

Some advocacies take a more focused approach, promoting resources to members of specific racial and ethnic groups. The Asian and Pacific Islander American Health Forum (APIAHF) provides grants, training, consulting, and technical assistance to Asian Americans who want to work in healthcare policy. APIAHF (2022) is heavily involved in health politics and informs community members of healthcare related legislation, emphasizing that "health equity must be the overarching goal against which any policy is benchmarked." APIAHF holds nine month long "Accelerator Labs" that allow community-based organizations serving Asian Americans, Native Hawaiians, and Pacific Islanders to "build capacity in full in scope of advocacy and strategic communications on issues of health and health equity." The organization also hosts a "Health Rising Leadership Institute" that allows Asian American health justice leaders to "deepen their skills in both transformational leadership and storytelling for advocacy." The National Alliance for Hispanic Health (NAHH) brings together community organizations throughout the country. The alliance invests in community-based organizations, works with national partners, and improves available resources. NAHH (2023) has "community-based members provide services to more than 15 million Hispanics throughout the U.S. every year and national organization members provide services to more than 100 million people annually." Similarly, The Indian Health Service (IHC) serves Native American and Native Alaskan communities with the hope of ensuring "comprehensive, culturally appropriate personal and public health services." Through purposeful resource allocation, the IHC (2023) has provided a "health service delivery system for approximately 2.6 million American Indians and Alaska Natives who belong to 574 federally recognized tribes in 37 states."

The advocacies of healthcare equality are profoundly interwoven; resource allocation is promoted through community outreach and informed by disparity data. Resource allocation initiatives currently take two forms; widespread, in which mainstream organizations promote to general populations, or focused, in which smaller advocacies prioritize members of specific racial and ethnic groups.

Conclusion

Though they are all unified by the same goal, large mainstream organizations and smaller advocacies tend to approach the issue of reducing racial health disparities differently. Advocacies have a more community-based approach, using their resources to unify diverse groups and amplify voices of the previously underrepresented. Mainstream organizations use these voices to guide wider-scale initiatives, illustrating that though systemic reform is typically carried out by larger and more powerful institutions, it is ultimately the desires of smaller agencies that direct these changes. The current climate of participant group advocacy places a strong emphasis on opening communication between small, disadvantaged communities and large institutions; two groups that remained largely separate prior to the turn of the century.

As knowledge about healthcare disparities in the United States becomes more widespread, social groups aimed at achieving health equality will continue to emerge and agendas will continue to shift. Healthcare disparities are a deeply rooted systemic issue in United States healthcare that will likely not be resolved without widespread change, so the success of participant group advocacy initiatives is hard to quantify short-term. Rather than exploring success in terms of disease prevalence reduction or lowered mortality rates in racial minority groups, advocacy success can be better measured short-term by an increase in public awareness of the presence of health disparities and its potential implications. Perhaps the greatest prescription for reducing health disparities is an increase in public awareness of the issue; only then can widespread systemic changes in the United States healthcare system come about.

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