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Authors

Lopez, Keila N
Baker-Smith, Carissa
Flores, Glenn
et al.

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AHA SCIENTIFIC STATEMENT

Addressing Social Determinants of Health and Mitigating Health Disparities Across the Lifespan in Congenital Heart Disease: A Scientific Statement From the American Heart Association

Keila N. Lopez, MD, MPH, Chair; Carissa Baker-Smith, MD, MPH, FAHA; Glenn Flores, MD; Michelle Gurvitz, MD, MS; Tara Karamlou, MD, MSc; Flora Nunez Gallegos, MD, MPH; Sara Pasquali, MD, MHS, FAHA; Angira Patel, MD, MPH; Jennifer K. Peterson, PhD, APRN-CNS; Jason L. Salemi, PhD, MPH; Clyde Yancy, MD, MSc, FAHA; Shabnam Peyvandi, MD, MAS, FAHA, Vice Chair; on behalf of the American Heart Association Congenital Cardiac Defects Committee of the Council on Lifelong Congenital Heart Disease and Heart Health in the Young; Council on Epidemiology and Prevention; and Council on Lifestyle and Cardiometabolic Health

ABSTRACT: Despite the overall improvement in life expectancy of patients living with congenital heart disease (congenital HD), disparities in morbidity and mortality remain throughout the lifespan. Longstanding systemic inequities, disparities in the social determinants of health, and the inability to obtain quality lifelong care contribute to poorer outcomes. To work toward health equity in populations with congenital HD, we must recognize the existence and strategize the elimination of inequities in overall congenital HD morbidity and mortality, disparate health care access, and overall quality of health services in the context of varying social determinants of health, systemic inequities, and structural racism. This requires critically examining multilevel contributions that continue to facilitate health inequities in the natural history and consequences of congenital HD. In this scientific statement, we focus on population, systemic, institutional, and individual-level contributions to health inequities from prenatal to adult congenital HD care. We review opportunities and strategies for improvement in lifelong congenital HD care based on current public health and scientific evidence, surgical data, experiences from other patient populations, and recognition of implicit bias and microaggressions. Furthermore, we review directions and goals for both quantitative and qualitative research approaches to understanding and mitigating health inequities in congenital HD care. Finally, we assess ways to improve the diversity of the congenital HD workforce as well as ethical guidance on addressing social determinants of health in the context of clinical care and research.

Key Words: AHA Scientific Statements ■ health inequities ■ heart defects, congenital ■ social determinants of health

Congenital heart disease (congenital HD) has evolved from a set of diagnoses with most deaths occurring in the first year of life to a set of conditions where, because of medical and surgical advances, >97% of children with congenital HD are expected to reach adulthood.¹ Mortality for congenital HD has steadily declined, and the number of adults living with congenital HD has surpassed the number of children with congenital HD in the United States

and other developed countries.² Recent epidemiological studies³⁻⁵ suggest that these advancements are impacted by the continued presence of disparate outcomes based on systemic inequities and structural barriers differentially impacting patients because of systemic racism (systems in which public policies, institutional practices, cultural representations, and other norms work in various, often reinforcing ways, to perpetuate racial and ethnic inequity),⁶ differences in

economic and social determinants of health, as well as inequitable treatment because of implicit bias based on an individual's race or ethnicity. Although there is more to learn about the exact interactions between medical care and social factors, data to date are clear that these disparities exist in the field of congenital cardiology.

Despite the overall improvement in life expectancy of Americans increasing nearly 10 years from 1950 to 2015, substantial sex, geographic, and racial and ethnic disparities remain.⁷ Life expectancy is notably lower in rural populations and Black populations.⁷ Racial and ethnic, socioeconomic, and geographic disparities are particularly marked in mortality and morbidity from cardiovascular disease, cancer, diabetes, hypertension, smoking, obesity, and access to quality health care. These disparities are attributable in large part to longstanding systemic racism resulting in systemic inequities. It is important to note here that the terms equality and equity are not synonymous. Equality is the idea of people experiencing or receiving the exact same amount of something regardless of what they need, whereas equity occurs when people experience or receive something based on what is needed in an impartial and fair way.⁸ Disparities also result from differences in the social determinants of health (SDOH), which are those conditions affecting the life and living circumstances of people defined by education, employment, housing, income, and specific features of the built environment including access to fresh food and safety.⁹ The historical context is explained in this statement as the background to the origins of these disparities. Common definitions are listed in Table 1.⁸ Data have demonstrated that SDOH are associated with a wide range of adverse outcomes for fetuses, children, and adults with congenital HD.³ To work toward health equity, we must examine the existence of and reduction of inequities in health, health care access, and use of quality health services according to major SDOH, systemic inequities, and individual and institutional biases toward particular racial and ethnic groups over time.

The purpose of this statement is to critically examine multilevel contributions that continue to facilitate health inequities in the natural history and consequences of congenital cardiac disease. In particular, we focus on population, systemic, institutional, and individual-level contributions to health inequities in congenital HD from prenatal to adult congenital HD care. Given the changing epidemiology of congenital HD in the United States, we examine these areas across the lifespan, with an emphasis on challenges and barriers to care in the adult congenital heart disease (ACHD) population as they transition to independently navigating a complex health care system. Importantly, we review opportunities and strategies for improvement based

on experiences from other patient populations, as well as future directions and goals for both quantitative and qualitative research approaches to understanding and mitigating health inequities in congenital HD care. These concepts are summarized in Figures 1 and 2.

POPULATION-LEVEL APPROACH

Population-level disparities in access to care are highly complex and multifaceted, with several opportunities for improvement, particularly in the US health care system. Understanding the population-level factors that impact access to care among children and adults with congenital HD can influence health policy initiatives and advocacy campaigns for the congenital HD community. For patients with congenital HD, population-level disparities often center around equitable access to centers with specialized care, availability of health care professionals to accommodate complex patients, and affordability of specialized congenital HD care (Table 2).¹⁰ The focus of

Table 1. Common Terms and Definitions Used in This Statement as Provided by the American Heart Association

Term	Definition
Race	Social construct not rooted in biology (eg, White, Black, Asian)
Ethnicity	Social characteristics people may have in common such as language, religion, regional background, traditions, and culture not rooted in biology (eg, Hispanic)
Racial inequity	When a racial group is not standing on approximately equal footing
Racism	Discrimination against individuals or groups based on beliefs of racial superiority or the belief that race reflects inherent differences in attributes and capabilities
Structural racism	A system in which public policies, institutional practices, cultural representations, and other norms work in various, often reinforcing, ways to perpetuate racial group inequity
Implicit bias	Negative associations people unknowingly hold and are expressed without conscious awareness
Health care disparities	Differences between groups in health insurance coverage, access to and use of care, and quality of care
Health disparities	When one population experiences a higher prevalence of adverse health outcomes than others
Microaggressions	Everyday and often subtle verbal, nonverbal, and environmental slights, snubs, or insults that are intentional or unintentional
Social determinants of health	The conditions in which people are born and live and are shaped by the distribution of money, power, and resources, and are mostly responsible for avoidable differences in health status

Adapted with permission from the American Heart Association *Structural Racism and Health Equity Language Guide*. Copyright 2021 American Heart Association, Inc.⁸

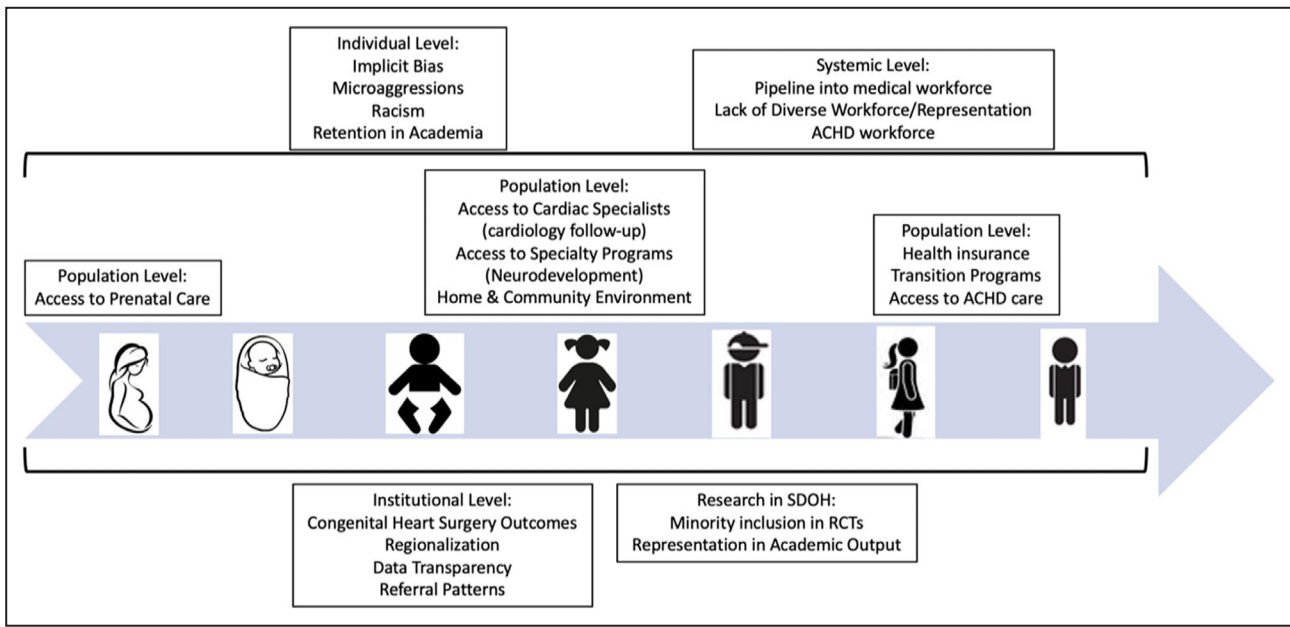


Figure 1. Contributions to health inequities in congenital heart disease across the lifespan.

Population-, systemic-, and individual-level factors contributing to health inequities at specific time points as well as broadly across the lifespan. ACHD indicates adult congenital heart disease; RCTs, randomized controlled trials; and SDOH, social determinants of health.

this section is to review how these population-level disparities (SDOH, referral patterns, and access to quality care and insurance) impact an individual with congenital HD throughout the lifespan. The National Academy of Medicine (formerly the Institute of Medicine) and the Healthy People 2030 initiative define access to care as “the timely use of personal health services to achieve the best possible health outcomes.”¹¹ Children and adults with chronic medical conditions represent a particularly at-risk group with regard to accessing care because of challenges in obtaining adequate health insurance coverage. Uninsured and underinsured individuals are more likely to forgo necessary testing, doctor visits, and preventive care visits often citing cost barriers.¹²

Accessibility of Quality Care

The ability for one to successfully access quality health care ties closely with a longstanding history of systemic inequities resulting in unequal SDOH, and the impact of implicit bias as experienced based on one’s racial and ethnic background. Important components of obtaining quality care include an individual’s ability to identify the existence of a health care need early, access to needed health care services, and recognition of the potential impact on immediate and longer-term health outcomes. In the congenital HD landscape, the importance of access to quality care stretches from prenatal care through to adulthood.

Prenatal detection of complex congenital HD is associated with better outcomes after birth (compared

with postnatal detection), and requires referral to a pediatric cardiology specialist.^{13,14} Despite the benefits of prenatal detection of congenital HD, only 50% to 70% of patients with complex congenital HD are diagnosed before birth in the United States with significant regional variability.¹⁵ Studies have shown that families with a lower socioeconomic status (SES) are associated with lower rates of prenatal detection of congenital HD, which results in gaps in appropriate referrals (ie, access to care).^{16,17}

Access to care remains an issue throughout the lifespan, as a significant proportion of people with ACHD experience a gap in cardiology care, especially during the time of transferring between pediatric and adult congenital specialty care.¹⁸ Thus, although parents may understand the importance of cardiology follow-up in childhood, this information is frequently not recognized by young adult patients transitioning to adult congenital care.¹⁸ In a study of adult patients new to ACHD specialty care, 40% of patients experienced a gap in cardiology care, with the most common reason being that they “felt well” and an overall lack of knowledge surrounding the importance of long-term follow-up.¹⁸

Strategies for Improvement

Use of community-based participatory research (CBPR) with qualitative methods is necessary to understand why certain populations are less likely to undergo prenatal detection of congenital anomalies. CBPR is also

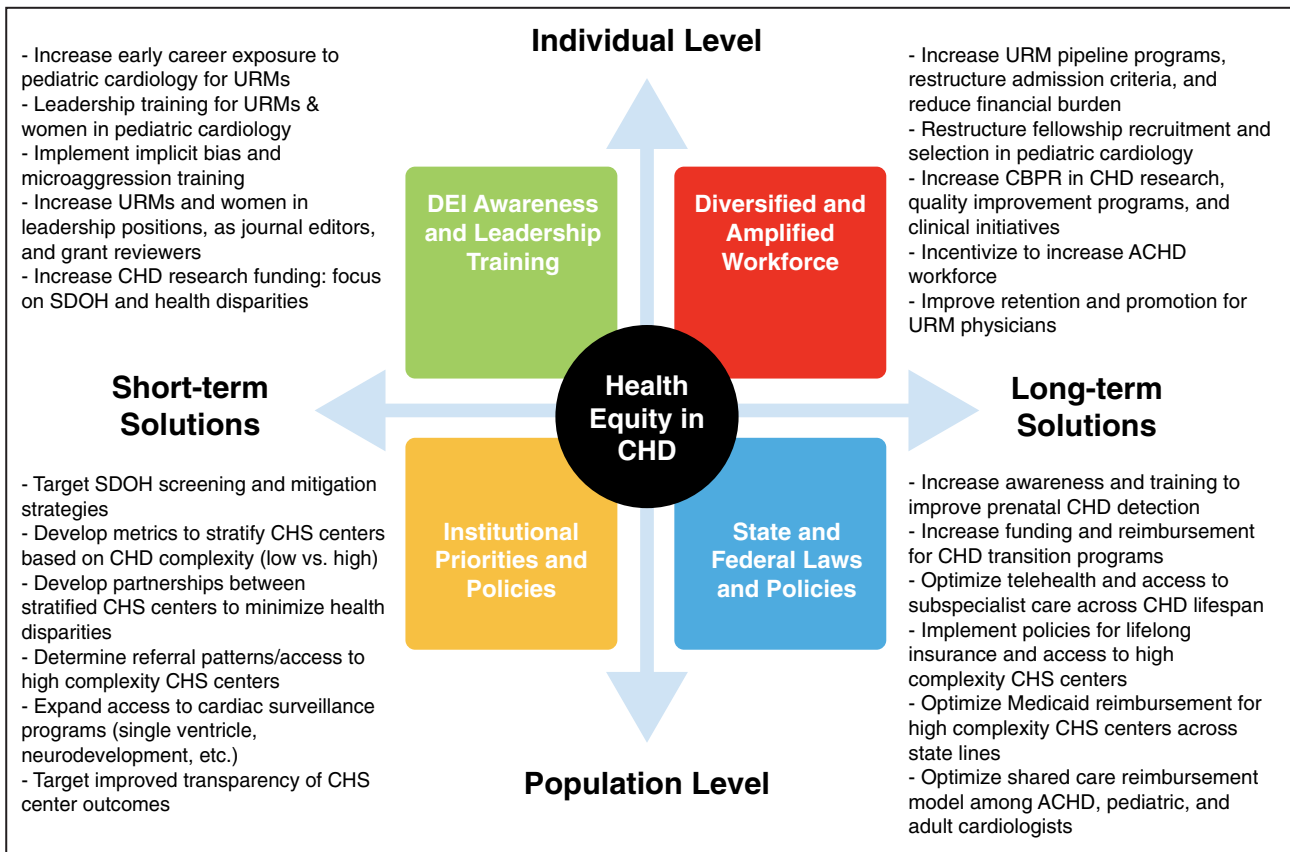


Figure 2. Solutions to mitigate health inequities in congenital heart disease from the individual to the systemic level and from short- to long-term strategies.

ACHD indicates adult congenital heart disease; CBPR, community-based participatory research; CHD, congenital heart disease; CHS, congenital heart surgery; DEI, diversity, equity and inclusion; SDOH, social determinants of health; and URMs, underrepresented minorities.

needed to understand why certain populations are less likely to recognize the need for or have less capacity or opportunity to adhere to maintenance of lifelong cardiology care. Creating CBPR partnerships with patient organizations can help address and mitigate issues of knowledge and access to quality care. Intervening on aspects of care that impact access and affect health outcomes is also critically important. Training obstetric sonographers in the detection of congenital HD, providing information on the need for lifelong care in all arenas (eg, in-person, online) at a lower health-literacy level, and providing and reimbursing for transition education services are several potential solutions.

Availability of Quality Care

Geographic availability of subspecialty services for congenital cardiac care is challenging and limited, particularly for patients whose socioeconomic and insurance status precludes them from accessing quality care, despite being an at-risk population. Availability to access care also refers to an individual’s mobility,

including access to reliable transportation and occupational flexibility, all of which tend to be more challenging with populations from lower socioeconomic backgrounds. These patterns and associations are not novel and have been identified in older publications from the 1990s¹⁹ and early 2000s,²⁰ suggesting minimal improvements of access to care among patients with congenital HD despite an overall improvement in outcomes related to advancement in surgical and medical care.

Disparities in access to care continue to exist even in contemporary cohorts, with uneven geographic distribution of specialty health care professionals and centers around the country. In the United States, most specialty congenital cardiac centers are concentrated in large urban regions leading to limited access to those living in rural or smaller communities. As such, among pediatric patients with congenital HD, several studies have identified a direct relationship between one’s geographic location and impact on outcomes, including mortality and morbidity. For example, among neonates with hypoplastic left heart syndrome in the

Table 2. Factors Associated With Access to Health Care

Term	Definition
Acceptability	Care that meets varying cultural and social factors related to an individual's ability to seek and accept medical attention
Affordability	The economic capacity of an individual, encompassing time and resources, to use appropriate health-related services
Approachability	Ability of an individual to recognize a health care need, identify service providers and how to reach them, and understand the potential for treatment options
Appropriateness	Measure of the quality of services and care being provided to meet the specific needs of a patient; encompasses timeliness, a system's ability to provide the correct care for the individual, and the effectiveness of providing continuous and coordinated attention
Availability/ accommodation	Factors pertaining to the physical space and individual capacity within a health care system to provide necessary services
Health care access	Opportunity and ease with which a patient is able to use a specific service, reach an individual health care provider, and navigate a health system to obtain appropriate services

Each factor influences health inequities at a population level.

state of Texas, a greater distance between birth location and cardiac surgical center (>90 minutes) was associated with an almost 20% increase in neonatal mortality compared with those born in locations <10 minutes away, regardless of whether the neonate was prenatally diagnosed.²¹ This same trend was found in a national population-based study with 1-year infant mortality being 28% higher among those who did not live proximal to a specialized cardiac center.²² Distance to care has also been associated with SES, because mothers of hypoplastic left heart syndrome infants traveling from a farther distance resided in communities with >20% poverty and were less likely to have obtained >12 years of education.²¹ The same issue exists when patients with congenital cardiac issues seek high-level care for noncardiac issues. Challenges exist in access to centers with adequate experience in congenital cardiology to provide safe and effective care for noncardiac issues.²³

Adults are the fastest growing patient group with congenital HD,²⁴ and access to specialized care from health care professionals with expertise in both adult medicine and congenital HD (ie, ACHD) is imperative to meet the needs of this unique population.^{25,26} Access to ACHD specialists is even more limited than access to pediatric cardiologists because of small numbers of formally trained ACHD specialists, with a total of only 447 health care professionals officially board certified as of May 2021.²⁷⁻²⁹ Furthermore, it is estimated that almost half of the US population lives >1 hour away

from an ACHD specialist,³⁰ and the population furthest away tends to disproportionately represent Latino ethnicity, lack health insurance, have a lower level of education, and live below the federal poverty level.³⁰ Adult patients in rural states with fewer ACHD specialty centers are at an even higher risk for gaps in care, with ~50% of patients in Colorado, Washington, and Oregon experiencing a 3-year or greater gap in cardiology care.¹⁸

Strategies for Improvement

It is imperative to identify strategies that optimize availability of congenital HD health care professionals and services beginning in utero and spanning across the lifespan. Strategies to mitigate lack of geographic availability include using satellite clinics to serve nonurban areas and increasing telehealth capabilities including coordinating care with general adult cardiologists, which can assist in improving access to care, particularly for rural populations. Providing vital information both to patients as well as adult cardiologists on where to access ACHD health care professionals and centers is critically important. For example, conducting research that links patients with ACHD with the directory of ACHD centers and health care professionals through the Adult Congenital Heart Association, a patient-centered advocacy organization, could mitigate lack of knowledge surrounding how to access this specialized care.³¹ Future studies and quality initiative programs are necessary to assess whether these measures will improve availability of specialty congenital cardiac care to all patients across the lifespan.

Affordability of Specialized Congenital HD Care

Assessment of the impact of health insurance on access to quality health care has been explored in large, population-based data sets. Lack of or inadequate health care coverage has been shown to be one of the most impactful SDOH and the largest barriers to access to a health care system contributing to disparities in health care outcomes.³² Where patients are referred for their congenital HD care also is impacted by insurance acceptance at each center, as well as where the patients are born. Starting with prenatal care and throughout the lifespan, there are inequalities in the referral center's quality as well as who has "the right" insurance to receive congenital HD care, particularly those from minority and lower SES communities.³³ For example, beginning before birth, prenatal diagnosis of congenital HD is less likely among women with public insurance compared with those with private insurance.¹⁶ Delays in diagnoses and subsequent referral to appropriate cardiology subspecialty care are

potentiated by differences in health insurance type. Of note, cost of insurance and overall health care is also a barrier to access to quality care, and there is likely a link between health care costs and SDOH.

A 2003 study found that children with Medicaid insurance had a higher mortality rate than those with commercial insurance within the same institutions, suggesting that patients with different insurance types have different outcomes even when referred to similar centers.³⁴ Although this study and other similar studies do not prove causality in the relationship between insurance type and outcomes, it does demonstrate an association and suggests a link between the them. Multiple studies have explored referral patterns to congenital cardiac centers by insurance status, revealing a higher proportion of those with private insurance being referred to lower-mortality hospitals compared with those with public insurance.³⁵ The intersectionality (interconnected relationship of social categorizations that result in overlapping and thus magnified disadvantage) of insurance status and race and ethnicity appears to be linked to worse outcomes as well. In a population-based study in California, public insurance status explained almost 30% of the relationship between Latino ethnicity and poor outcomes in infants with severe congenital HD.³⁶ Persistent inequities as related to insurance type are likely reflective of differential referral patterns in addition to other differences in the SDOH that impact various aspects of health outcomes in patients even when treated at similar institutions. This is particularly true when one considers differences in state-to-state Medicaid coverage (particularly those that have expanded Medicaid) and the changes in insurance that occur as one ages.

Strategies for Improvement

Investigating how insurance status is associated with population-level disparities can allow for actionable health policy changes that have the potential to impact large groups of patients with congenital HD. Investigating policies for public insurance accessibility within each state and across state lines to access quality congenital HD care, insurance coverage during the critical transition period for those on public insurance, as well as insurance acceptance at quality congenital HD centers will be critical to understanding some of these differences. This becomes particularly important as increased numbers of children and adults with special health care needs, including congenital HD, rely on government-sponsored health insurance.³⁷ Finally, other aspects of care impacting quality care and outcomes in patients with congenital HD, including insurance coverage for neurodevelopmental services (physical, occupational, and speech therapies), medications, outpatient studies (echocardiograms, electrocardiograms), as well

as opportunity costs for accessing quality care (cost of parking, gas, childcare, missed work days), are all areas that require further investigation and interventions to improve congenital HD access.

INSTITUTIONAL-LEVEL APPROACH

Institutional factors are likely to be highly relevant to the disparity equation, yet few studies have focused or addressed this area specifically. Data surrounding variation in congenital heart surgery (CHS) outcomes because of traditional patient factors (prematurity, obesity), procedural factors, and the impact of socioeconomic and racial and ethnic factors have all been described.^{36,38–46} The intersection between these factors and access to high-quality and experienced cardiac care centers may serve to mitigate or amplify health disparities, particularly among highly complex patients. If the intersection results in suboptimal delivery of and access to care, this can lead to higher mortality, morbidity, length of stay, and cost.^{36,39–42,47–49} Understanding interactions between socioeconomic factors, race and ethnicity, SDOH, and institutional factors that mitigate or potentiate adverse outcomes among patients with congenital HD are critical to informing future policy decisions.³⁶ Currently, it remains unclear whether hospital-level factors make a greater contribution to the variation in outcome among disadvantaged socioeconomic groups, or whether patient factors and SDOH play the greatest role. In this section we will examine the intersection and impact of institutional volume, access to high-quality CHS centers, regionalization of care, and patient income with SDOH and racial and ethnic disparities.

Intersection of Institutional Volume, SDOH, and Racial and Ethnic Disparities

Several studies have investigated the impact of race and income level on patients undergoing surgery for congenital HD. Previous investigations have demonstrated associations between race and ethnicity, lower SES, and worse outcomes after CHS on pediatric patients; however, the underlying reasons for the discrepancies in outcomes are unclear.^{36,39–42,46,47} SES and race have also been associated with increased mortality after a wide range of interventions in patients with ACHD.^{50–53} Of concern, it is not known the degree to which institutional-level factors contribute to the variation in CHS outcomes, and which factors play the most impactful role among disadvantaged socioeconomic and racial and ethnic groups.

Disparities specific to institutional factors have often been described in regard to hospital volume. Larger-volume hospitals may perform better relative to smaller hospital systems because of more surgical experience and improved postoperative intensive care.

Alternatively, volume may be less important if specific hospitals in geographically enriched regions have more evolved processes or safety nets to resolve health care disparities because of SDOH.

The degree to which race and ethnicity and socioeconomic factors influence access to high-quality hospitals for CHS pediatric patients is unknown. Data show that patients with congenital HD who are Black or publicly insured tend to receive care at hospitals with worse patient outcomes.^{54,55} This may be attributable to proximity to these centers versus referral patterns to these centers. Data have also shown that Black neonates from the lowest SES quintiles undergoing highly complex cardiac surgery have equivalent survival outcomes to White neonates, but longer length of postoperative hospital stay. This difference in hospital stay may be related to time to surgical intervention, surgical technique, or the quality of postoperative care, and may make its impact once patients are discharged from the hospital, because those who have been in the intensive care unit longer have likely had a more complicated course.

It is unknown whether SES and race and ethnicity influence the type of care provided or the degree to which these factors complicate discharge planning for adults with congenital HD. The systems of care for congenital cardiac patients differ from care for adults because of the relatively lower volume of CHS and the resource intensity needed to care for this population. However, there remains a wide variation in mortality and other outcomes across hospitals even with the same volume, and the intersection between institutions and SDOH in impacting outcomes remains less clear.

Strategies for Improvement

There needs to be investment in understanding the best metrics to determine quality CHS centers within and between institutions that perform CHS both for pediatric and adult populations. Conducting studies that assess the impact of the intersectionality between quality of CHS and patient SDOH, as well as mediating factors, is critically important to understand if we want to improve outcomes for all communities. Additional consideration to modify timing of and preparation for discharge to address all patient needs and take note of their neighborhood SDOH before discharge from the hospital is necessary to mitigate potential risk factors for patients who have reduced safety nets or access at home.⁴¹

Intersection of Access to High-Quality CHS Institutions, SDOH, and Racial and Ethnic Disparities

National distribution of CHS centers is known from studies of both administrative data and clinical registry

data. Welke and colleagues showed 153 centers providing CHS care across the continental United States using 2012 Healthcare Cost and Utilization Project data.⁵⁶ These authors show inherent inefficiencies in the contemporary system of CHS care in the United States. Many hospitals are small volume and located near others. High-risk operations are performed infrequently at numerous hospitals and at low-volume hospitals (those performing <25 cases per year), despite many of these institutions being near high-volume centers. Currently, de facto regionalization already occurs in children with congenital HD, with over 53% of patients bypassing their nearest hospital, preferring more experienced centers (which parenthetically contribute CHS outcome data to the Society of Thoracic Surgeons Congenital Heart Surgery Database).³⁸

Overall, the congenital HD population has a variable racial and ethnic and geographic distribution, which may impact access to high-quality medical services and the equitable provision of state and federal services. In a recent study, Karamlou et al used geocoding to define the socioeconomic and racial and ethnic landscape for the congenital HD population using national data from 52 Pediatric Health Information System hospitals. These authors found that although Latino patients were primarily located in California and Texas, Native American patients were primarily located in the Southwest, and Black and White patients were fairly scattered, with more Black individuals concentrated in the Southeast.⁵⁷ The proportion of patients living below the poverty level was highest in the South (20%) and New Mexico (20%), where Black and Native American patients, respectively, predominantly reside. The data also showed that median income was \$41 082 (interquartile range, \$20 456) for the entire population, and that income varied by hospital location, with 28 hospitals located in communities having lower than median income and 22 hospitals in communities having higher than median income. Median income was generally substantially lower among American Indian (\$35 912) and Black (\$36 479) patient populations.

There are nonsurgical factors that additionally distinguish high-quality from low-quality institutions, including surveillance and neurodevelopmental programs. Variations of home monitoring, including virtual interfaces (Cardiac High Acuity Monitoring Program application) and structured home visitation, address the excessive attrition and mortality in the interstage surgical period.^{58,59} Unfortunately, these programs may disproportionately be available to certain SES and racial and ethnic groups, and therefore the effect of these programs on reducing socioeconomic and racial and ethnic disparities is not known, particularly because access to technology may limit the effectiveness of these programs in economically disadvantaged families. Additionally, the application of culturally

competent congenital HD surveillance programs may translate into mechanisms that increase parent and community engagement by increasing the visibility of health care services, as demonstrated among other chronic disease populations.⁶⁰ Furthermore, institutional programs that target nutrition and growth may be interventions that further reduce disparate outcomes in cardiac surgical mortality.⁴⁸ Finally, enrollment and participation in neurodevelopmental programs, as well as school-based neurodevelopmental outreach, such as the First-Five California initiative,⁶¹ may also help identify at-risk children and facilitate access to resources.

Specific health care delivery modifications that could prove useful among underresourced, limited-English-proficient, or socially challenged parents faced with caring for a critically ill infant remain largely unknown. This important gap for at-risk infants and families, and the solutions to narrow or close the gap warrant further investigation. Proactive solicitation and incorporation of family-perceived needs could facilitate successful programmatic development and improve parent/caregiver adherence. Preoperative risk factors, such as prematurity or malnutrition, may be relevant targets for interventions to reduce these disparities in cardiac surgery mortality.⁴⁸

Strategies for Improvement

Future efforts should be focused on obtaining data and understanding referral patterns of various racial and ethnic and sociodemographic groups to various CHS centers based in part on volume and transparency. Beyond that, detailing which communities are able to access further distance high-quality CHS centers, and the resources, income, and insurance needed to access these institutions is of critical importance. Research is needed to understand how nonsurgical specific health care delivery seen in high-quality institutions could be the key to mitigating disparities in the SDOH, particularly in underresourced, limited-English-proficient, or socially challenged parents faced with caring for a critically ill infant.

Intersection of Institutional Regionalization of Care, SDOH, and Racial and Ethnic Disparities

Given the differences in patient outcome based in part on institutional location and volume, available data demonstrating the impact of regionalization of CHS, suggest that 1000 lives could be saved over 10 years if all patients undergoing CHS in the United States were cared for at high-volume, low-mortality hospitals.⁵⁶ However, it remains unclear whether regionalization may be associated with reduced access to high-quality institutions for some patients,

particularly for lower socioeconomic groups who are disproportionately Black and Latino individuals, or whether travel to these institutions may be challenging for patients living in rural areas or in states without a CHS hospital.⁶² Reimbursement policies that impact the ability to receive care across state lines, particularly for government-sponsored health care (Medicaid services) could further marginalize high-quality care to at-risk populations in remote areas.⁶³ Furthermore, other surgical specialties have noted unintended consequences upon regionalization, including a decline in the proportion of non-White Medicare patients receiving surgery.⁶⁴ Thus, the degree to which access to high-quality centers upon regionalization may change for CHS patients of different socioeconomic, geographic, and racial and ethnic backgrounds after regionalization is unknown but critical to understand.

Strategies for Improvement

Research is needed to understand referral patterns to specific institutions and the degree to which those patterns disproportionately impact lower socioeconomic communities and specific racial and ethnic populations. Research is needed to inform paradigms for regionalization that minimize health care disparities among CHS patients and provide the largest survival advantage while minimizing imposed hardships. One potential strategy is determining if instead of complete regionalization of care, whether stratifying centers between high and low surgical volumes (which may have other defining aspects of complex care delivery including availability of rapid extracorporeal membrane oxygenation, cardiac MRI, and 3D modeling for complex lesions) and partnering lower with higher volume centers for more complex lesions may improve congenital HD outcomes across the lifespan. Research is also needed to strategize optimal reimbursement strategies between institutions and across state lines, particularly for those populations that have public insurance.

Intersection Between Income, Institutional Geography, SDOH, and Health Disparities

The burden of care for pediatric patients with congenital HD is associated with the highest cost, complications, readmissions to hospital, and mortalities among all other chronic conditions in pediatrics,³⁸ making the benefit of identifying feasible solutions to current health inequities substantial. The relationship between median income and mortality is parabolic rather than linear. Patients with congenital HD from both lower median income and higher median income fare worse compared with patients with median income between \$72 000 and \$80 000 (Figure 3).⁵⁷ Although the relative disadvantage imparted by higher income may seem

counterintuitive, it seems plausible that higher-income patients, who are financially equipped to travel, might access more complex care that is delivered only at regionalized centers (ie, the highest surgical expertise in Ebstein's anomaly or unifocalization of major aortopulmonary collateral arteries). Prior work has shown that most patients with congenital HD often bypass their regional centers to receive care at perceived centers of excellence.³⁸ These data demonstrate that one cannot look at low income as the sole barometer for worse congenital HD outcomes. Important data from Winkleby et al⁵³ demonstrated the challenges in viewing individual factors (such as income or zip code as a proxy for income) in isolation; an analysis of income level combined with neighborhood factors demonstrated that lower-income families living in high-income neighborhoods still had higher mortality. It may be that comparatively lower-income families in affluent neighborhoods have less disposable income after accounting for higher cost of living, or that these families may have reduced access to free social services and health care often concentrated in lower-income neighborhoods. Furthermore, the impact of adverse SDOH exposure may persist despite relocation to higher-income neighborhoods.

Strategies for Improvement

Research is needed to determine how lack of equity in access to high-quality, protocol-driven, multidisciplinary care institutions drive better or worse surgical outcomes, particularly in racial and ethnic minorities and lower-SES communities as was argued by Karamlou and colleagues⁴² and others.^{21,36,53} Data on the timeliness of access to these highly specialized surgical interventions, coupled with adequate surveillance, are needed to understand institutional inequities. Further investigation on the most complex congenital HD conditions and their intersection with income and the SDOH, particularly in the ability to access high-quality institutional surveillance, neurodevelopmental, and complicated pharmacologic therapies is critical to understand, because they are likely to magnify the impact of socioeconomic and racial and ethnic disparities over the lifetime of patients with congenital HD.

SYSTEMIC WORKFORCE LEVEL APPROACH

In this section, we address race, medicine, and the diversity of the medical workforce; lessons learned from workforce disparities in adult cardiology and implications for ACHD populations; and successful strategies for enhancing health care workforce diversity.

Race, Medicine, and the Diversity of the Medical Workforce: A Painful History

The first Black physicians emerged in the post-Civil War era, yet they were denied entry into the American Medical Association, and as such, were refused medical licensing in many states. The Jim Crow/ Reconstruction era by law promoted race exclusion from all social experiences, including health, health care, and medical education. At the beginning of the 20th century, many minority-serving medical schools were operational, several with tenures longer than 10 years and a track record of graduates not dissimilar to those attending other medical schools. The *Flexner Report* appropriately called for more rigor in medical education and initiated the pivot to today's sophisticated academic medical centers and potent research enterprises. Yet the report preferentially led to the closing of all but 2 minority-serving medical schools. A conservative extrapolation analysis indicates the closing of just 6 of those schools resulted in a deficit of nearly 35 000 underrepresented minority physicians in medicine over the 20th century.⁶⁵

Four minority-serving medical schools remain: Charles Drew, Howard, Meharry, and Morehouse. These 4 schools represent 2.6% of all US medical schools, but contribute 15% of all physicians of color. Data from the American Association of Medical Colleges 2019 to 2020 academic year detail the demographics of all first-year medical students, and the numbers are staggering. This includes only 4.6% Black women and only 2.8% Black men, a number unchanged since 1978.⁶⁶ Additionally, Latina (3.4%) and Latino (3.4%) make up only 6.8% of all first-year medical students, despite their growing representation in the United States.

Despite a demographic surge in America's minority children, pediatric workforce diversity has clearly failed to keep pace, particularly in academia. Minorities comprise 49.9% of US children,⁶⁷ which is more than twice the proportion of minorities among all US pediatricians (24%).⁶⁸ Underrepresented minorities (URMs) (classified as Latino, Black, American Indian/Alaska Native, and Native Hawaiian, as per the Association of American Medical Colleges) account for 41% of American children, but only 11% of pediatricians, 10% of all faculty at US medical schools, and 6% of all full professors at US medical schools.⁶⁹ Beyond this, URM nurses make up only 16.8% of the registered nurse workforce, with the lack of diversity even more apparent in nursing faculty.⁷⁰

These stark disparities between the US population and America's health care workforce are particularly troubling, given that, even after adjusting for income, communities with high proportions of minorities have over 4 times the likelihood of other communities to

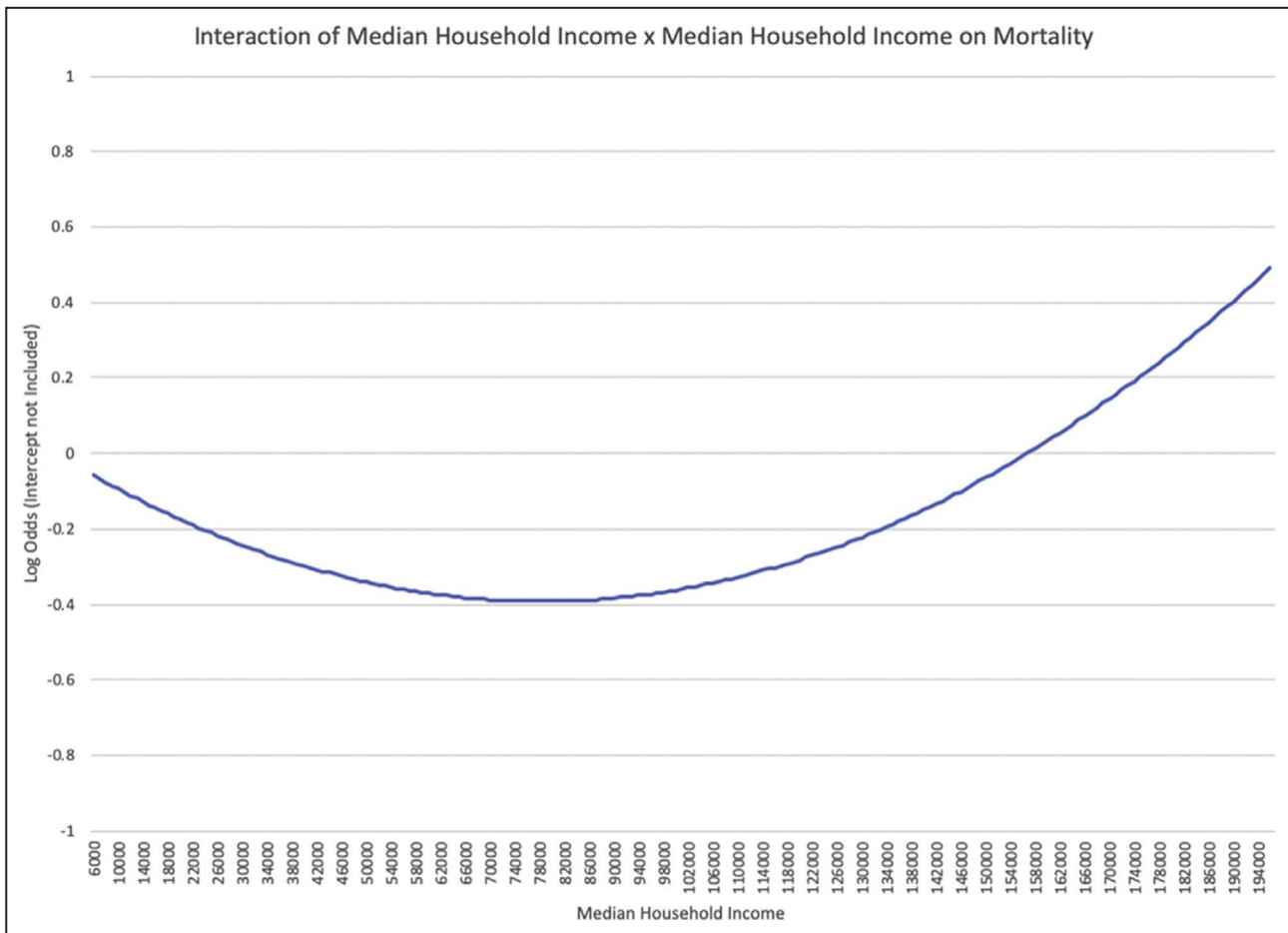


Figure 3. The relationship between income and mortality among children with congenital heart disease.

Relationship between median neighborhood household income (horizontal axis) and the probability of death (vertical axis) over the range of available data was nonlinear, with higher risk at lower and higher income levels. The risk of death nadirs between annual neighborhood household income of \$72 000 and \$80 000. Reprinted from Karamlou et al.⁵⁷ Copyright 2021, with permission from the Society of Thoracic Surgeons.

suffer from physician shortages, whereas URM pediatricians and other physicians are significantly more likely than their non-URM counterparts to care for minority, publicly insured, and uninsured patients.⁷¹ A recent study also revealed that Black men seen by Black physicians are much more likely to select every preventive service, particularly invasive services, once meeting with a racially concordant physician, and suggested that Black physicians could reduce the Black-White male gap in cardiovascular mortality by 19%.⁷²

The adverse effects of a nondiverse workforce on patients and families extend beyond the physician and include the entire interprofessional health care team. It is hugely beneficial for parents of patients with limited English proficiency to have a competent bedside nurse who speaks their language, both in terms of quality care and parent satisfaction.⁷⁰ It is important to consider that the entire health care staff be diverse, and that efforts be made to encourage and support those from URMs who want to further their education in other health care areas.

In the field of cardiology, data from the American Association of Medical Colleges, American Medical Association, and American Board of Internal Medicine address URM physicians pursuing pediatric cardiology. From 2006 to 2016, the percent of URM physicians in pediatric cardiology fellowships grew slightly, from 7.7% to 9.9%, whereas URM physicians account for <8% of practicing pediatric cardiologists.⁷³

Strategies for Improvement

The painful history outlined above and the challenging residual consequences require thoughtful interventions. The call for more diversity in the medical workforce, including more minority-serving physicians, more diversity of thought, and greater advocacy for health equity, is no longer sufficient. Addressing the pipeline of physicians entering the medical workforce requires moving beyond diversity, or representativeness, because it alone is insufficient to guarantee change. Real change is required for any effect other

than nominal to address the workforce providing care for those with congenital HD. What is ultimately necessary is an upstream approach and a culture change within the medical education process. This comes from policy and commitment and requires strident leadership with the will and authority to acknowledge the presence of systemic racism within medicine and within society, and to develop programs and strategies allowing for equitable training and access. Several strategies are plausible:

1. High school and undergraduate pipeline programs generating a positive bias, (seeing “someone who looks like me”), are encouraging young students in science, technology, engineering, and math to remain true to a path for admission to medical school or other health care professional educational pathways.
2. A recalibrated medical school admission process that holds performance on the Medical College Admission Test as the de minimis criterion for admission and includes an increasingly valuable holistic assessment of the skills necessary for success in medicine is a worthy experiment.
3. Substantial cost reduction, or even tuition-free medical or graduate school, removes an especially onerous barrier for the URMs wishing to become health care professionals.
4. Provocatively, establishing and funding new minority-serving medical schools might quickly and more adroitly correct the undersupply of URM physicians.
5. Placing a greater focus on retention and promotion of URM academic physicians and recognizing the daily biases that many URMs encounter can assist in maintaining URMs in mentorship and leadership roles within the medical workforce. Failure to fully commit to this change will only perpetuate the maldistribution of URM physicians in the medical workforce and likely the persistence of unwelcome and unacceptable health care disparities.

Lessons Learned From Workforce Disparities in Adult Cardiology and Implications for Congenital HD Workforce and Populations

As seen in the other areas of health care, the field of cardiology is not immune to the lack of diversity. This includes the training pathway to both private practice and academic faculty positions for both pediatric and adult cardiology, which have minimally improved over the past decade despite targeted efforts.⁷⁴ URMs comprise approximately one-third of the US population, but only 8% of the overall adult cardiology workforce.^{75,76} In 2016, URMs accounted for 13% of adult cardiology

fellows, and 10% of pediatric cardiology fellows, with increases of only 1.3% and 2.2%, respectively, over the prior decade; after training, the percentages decrease, and URMs comprise only 8.6% of adult cardiology academic faculty and 7.8% of pediatric cardiologists.⁷³ In addition, a study of the perceptions of adult cardiology fellowship directors about diversity in their training programs showed that 84% believed that women and minorities were underrepresented among faculty, and over 69% believed diversity is important for excellence in health care; however, only 6% of program directors listed diversity as a top priority in rank lists and almost 2 out of 3 felt their training programs were diverse enough already. Among those who did want to increase URMs in their training programs, only half had ideas of how to accomplish it.⁷⁷ Finally, only 55% of programs reported that women or URMs were present at their fellowship rank meetings.

The actual percentage of URM cardiologists entering cardiac subspecialties is likely lower than those for general cardiology, but this information is frequently missing in available data sets. ACHD is a relatively new subspecialty in cardiology, with the first board certification exam administered in 2015. Thus, race and ethnicity data on practicing ACHD cardiologists with or without certification are currently unavailable. Because ACHD cardiologists must complete either a pediatric or adult cardiology training pathway, we can assume that the proportion of URM practitioners is at least as low as those 2 groups, and possibly lower, given the additional 2 years of training required beyond either cardiology pathway. The need for health care professionals for patients with ACHD has grown over many decades as congenital HD survival has improved.^{2,24} In the past decade, studies have addressed ACHD professional training, and workforce size and geographic distribution, but have not provided or addressed specific information on gender or race and ethnicity.^{27,28}

Lack of information on diversity in other areas of congenital HD is also striking. There are no complete data on diversity among pediatric cardiology professional subspecialties, because even recent articles on the workforce pipeline in pediatrics address proportions of women and men in the pediatric subspecialty workforce, but not URMs.⁷⁸ There also are no general population data available on the race and ethnicity of the pediatric or patients with congenital HD populations. Multiple studies show differential outcomes for patients with congenital HD from different racial and ethnic groups, but these are based on specific procedures or administrative data, and do not reflect the whole population.^{79,80} The birth prevalence of congenital HD overall has not been shown to differ by race and ethnicity, although certain types of congenital HD may have relative differences⁸¹; survival differences, however, may change the expectations for the ACHD population.

It is clear that numbers of URM among congenital HD and ACHD health care professionals are lower than desired. The causes are likely multifactorial and include the cost of education, insufficient academic preparation for admissions requirements, lack of concordant mentors, implicit bias in the admissions process and stereotype threats, limited exposure to health careers, and poor advising.⁸² General adult cardiology is trying to address workforce disparities in multiple ways, including efforts from the American College of Cardiology that include establishing health equity and antiracism resource centers⁸³ and other activities of the Diversity and Inclusion Task Force. The American Academy of Pediatrics also has an active Diversity and Inclusion Task Force and has created an Equity Agenda⁸⁴ that includes a plan to strengthen and diversify the pipeline to practice and leadership in pediatrics.

Strategies for Improvement

Targeted programs are needed to advance diversity in the congenital HD workforce. Three national programs have demonstrated that successful strategies exist for increasing workforce diversity, and could be applied to the pediatric and adult congenital HD space. The first is the Meyerhoff Scholars Program at the University of Maryland, Baltimore County, which provides a promising model for increasing retention and academic performance of URM undergraduates in science, technology, engineering, and mathematics and for preparing those undergraduates to pursue and succeed in graduate and professional programs.⁸⁵ The Meyerhoff Scholars Program is nearly 30 years old, with proven improved outcomes for Black science, technology, engineering, and mathematics majors and the potential to be replicated at several other institutions. A more diverse pipeline entering medical school and other health-related fields has the potential to diversify the primary care and subspecialty workforce as a whole.

The second is the Robert Wood Johnson Foundation Harold Amos Medical Faculty Development Program (AMFDP), established in 1983 to increase the number of faculty from historically disadvantaged backgrounds who can achieve senior ranks in academic medicine and who will encourage and foster the development of succeeding classes of such physicians.⁸⁶ AMFDP is considered to be the most successful diversity program in American medicine.⁸⁷ Each AMFDP scholar receives an annual stipend and annual grant supporting research activities, and conducts research in association with a senior faculty member located at an academic medical center, dental school, or school of nursing. In partnership with the American Heart Association, 2 AMFDP slots annually are reserved for

scholars conducting cardiology research. More than 80% of AMFDP alumni remain in academic medicine, and about 1 out of 3 have been promoted to associate professor and another third to full professor. Many of them hold other academic titles, including associate dean, chair, and division chief. Four are deans or presidents of medical schools, 3 are National Institutes of Health Directors, and many have been elected members of the National Academy of Medicine.

Another successful workforce diversity program is the Academic Pediatric Association's Research in Academic Pediatrics Initiative on Diversity (RAPID) program, which is sponsored by the National Institute of Diabetes and Digestive and Kidney Disorders.⁸⁸ RAPID is a research education program aimed at recruiting, retaining, and professionally advancing diverse early-career faculty in general pediatrics who are pursuing research careers. It includes small research grants, mentoring by nationally renowned senior investigators, monthly mentoring conference calls, and an annual career-development conference. Outcomes data from the first 5 years²⁹ reveal that among the first 10 RAPID scholars, mean scores were 4.5 (5=strongly agree) for RAPID fostering mentoring, developing research skills, and helping scholars feel more comfortable as URM faculty; 78% delivered platform or poster presentations, and a total of 56 articles were written along with a mean of 2.5 subsequent grants. RAPID also was associated with a significant increase in representation of URM members in the Academic Pediatric Association (Figure 4). Thus, RAPID was associated with career advancement and increased professional society diversity, and could serve as a national model for enhancing URM career development and professional society diversity.

INDIVIDUAL LEVEL APPROACH

As noted in this statement, for years research has demonstrated that there are racial and ethnic disparities in outcomes for children and adults with congenital HDs. Although it is key to investigate population, systemic, and institutional causes for these disparities, it is critical and equally important to take the next step and understand the drivers behind individually experienced health disparities. At the forefront of individual-level discrimination and health system inequities lie the socially constructed entities of race and ethnicity. An individual's race and ethnicity are often described as a predisposing risk factor for poor outcomes, but understanding how they are closely tied with structural inequities as well as SDOH is of utmost importance (social, structural, financial, and environmental factors).^{89,90} Only by more deeply understanding how these variables tie in with race and ethnicity and acknowledging the impact

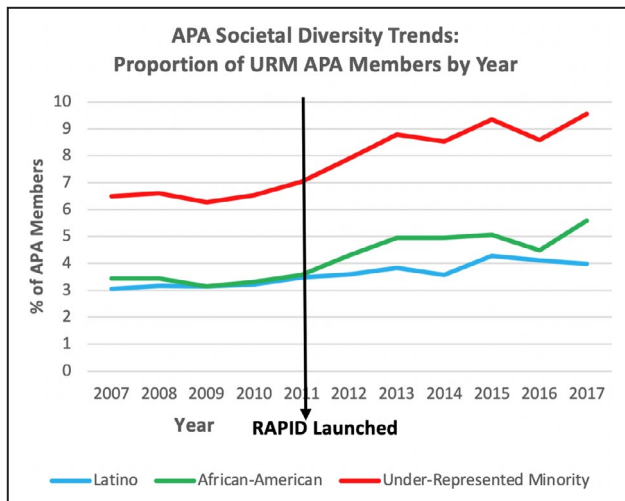


Figure 4. Proportion of underrepresented minority (URM) members in the Academic Pediatric Association (APA).

After initiation of the Research in Academic Pediatrics Initiative on Diversity (RAPID) program, there has been a steady increase in the percent of APA members from underrepresented groups including Black and Latino members.

of racial and ethnic divides within this country can we move toward addressing the observed disparities within congenital HD from multiple angles.

Implicit Bias, Microaggressions, and Racism

Personal testimonies from racial and ethnic minority patients often touch on the theme of experienced discrimination and the negative impact this has on access to care, health care processes, and health outcomes. In an effort to overcome these health inequities, individual patients have often had to serve as their own advocates fighting to combat the biases and racism within our health care systems. Discriminatory practices including implicit bias are part of the institutionalized racism that must be addressed to tackle differences in patient-level outcomes.

Implicit bias describes the individually held attitudes or stereotypes that impact our understanding, actions, and decisions without one being aware or conscious of its occurrence.⁹¹ The role of implicit bias and its impact on health outcomes was examined in *Unequal Treatment*, the 2003 National Academy of Medicine report that recognized implicit bias as a contributor to racial and ethnic health disparities.⁹² The authors described the impact of socially conditioned prejudices and experienced discrimination as significant contributors to poor health outcomes. Individual perceptions of discrimination or stereotyping within a health care system have been linked with delays in obtaining care, decreased access to subspecialty health care professionals, and noncompliance with treatment.^{93–95}

Furthermore, interventions aimed at increasing health care professional cultural competency through multi-cultural training demonstrated a 9% reduction in implicit biases when compared with a control group.⁹⁶

Unlike macroaggressions (racism and misogyny) that occur at systematic and structural levels, microaggressions happen at a more interpersonal and private level. Microaggressions are subtle verbal, behavioral, or environmental snubs, slights, and insults directed at individuals or groups based on their social characteristics (eg, race, class, sexuality, gender) that implicitly communicate or engender a hostile, derogatory, or negative sentiment.⁹⁷ Microaggressions occur daily and are commonly delivered automatically with dismissive body language and tone of voice, and generate stresses equal to or worse than overt discrimination for URMs.^{98,99} Microaggressions extract a psychological and physical toll on those who experience them, with a societal price of harming the already fragile pipeline of women and minority physicians in academia.⁹⁸

Microaggressions may be intentional or unintentional and come in 4 different forms: (1) microassaults (verbal or nonverbal acts aiming to attack a person's group or identity or harm them through name calling, avoidance, or discriminatory actions); (2) microinvalidations (comments or actions that disregard, exclude, or dismiss the thoughts, feelings, or experiential reality of an individual or a group); (3) microinsults (subtle snubs or humiliations that convey a stereotype, insensitivity, or a demeaning message about a person's group identity); and (4) environmental microaggressions (microassaults, microinsults, and microinvalidations reflected in the policies, culture, and climate of the workplace).

A review of the impact of racism on child health by the American Academy of Pediatrics highlights the state of the knowledge and proposes strategies to reduce the health effects of racism and biases.¹⁰⁰ It challenges health care professionals to recognize racism as a core determinant of child health, increase discourse surrounding implicit and explicit biases, and to become agents of change in an effort to improve equity and optimize outcomes.

Strategies for Improvement

To combat these disparities, the solution is not to provide individual equal care, because that would not move the needle in overcoming the differences in SDOH, systemic inequities, and implicit bias for racial and ethnic minorities. Research should be focused on interventions that assist in the goal of achieving equity, and that target mitigation of the SDOH factors that put a patient at an unfair disadvantage for achieving optimal congenital HD outcomes. Additionally, conducting studies that identify and target interventions to reduce variation in care that may result from health care professional, structural, and

system-level biases and racist practices are critical to reducing health disparities in congenital HD. This includes assessments of implicit bias and microaggressions in individual health care professionals to establish an awareness and accountability of our biases, as well as reexamining the diversity of leadership in our clinics and hospitals to optimize health care delivery systems and policies based on equitable, inclusive, and antiracist practices.¹⁰¹ Training in reducing microaggressions using the microaggression triangle model, the Open the Front Door model, the A.C.T.I.O.N (Ask, Come, Tell, Impact, Own, Next step) model, or the XYZ (I feel X when Y because Z) model, help to enhance recognition of microaggressions, rebuild relationships, and restore justice.^{97,98} Finally, funding research and scholarly work focused on investigations that prioritize historically marginalized and vulnerable populations, involving them in the research planning and execution to ensure community trust to reduce health disparities are critically important.

Representation and Retention of URM Faculty

Shared racial and ethnic backgrounds between health care professionals and the patients they serve has been associated with increased patient satisfaction, improved adherence, and a greater likelihood to participate in preventative care.^{92,102} Although women now make up nearly 50% of pediatric cardiology trainees, a 2019 *JAMA Cardiology* review found that URM trainees and cardiologists accounted for <8% of practicing adult and pediatric health care professionals.⁷³ This is an improvement from prior decades; however, there are woefully low proportions of women and URMs in leadership positions in academic institutions, journal editorial boards, and cardiology associations, as well as among those who are full professors in medical schools.^{69,73} The American College of Cardiology has set forth a multipronged approach to engage diverse health care professionals and improve the diversity in the adult and pediatric workforce. Data have shown that the impact of a health care professional that reflects the community they serve should not be underestimated.^{66,71} Additionally, inclusion and representation go beyond an individual's race and ethnicity. Ensuring a diverse workforce should encompass a broad definition of diversity, including gender identity, members of the LGBTQ (lesbian, gay, bisexual, transgender, and queer or questioning) community, individuals with disabilities, individuals from various geographical backgrounds, and those with varying life experiences.

Strategies for Improvement

Efforts to enhance diversity and inclusion should target strategies that engage medical students and residents

early on to the field of cardiology as well as diversifying the leadership within the field of pediatric cardiology. There should be leadership training prioritization for URMs, women, individuals with disabilities, and LGBTQ individuals in the congenital HD field to enhance their success at the highest academic levels, as well as increase their likelihood of obtaining leadership positions in academic journals and institutions.

RESEARCH CONSIDERATIONS WHEN ADDRESSING SDOH

Health disparities exist. Research is needed to design interventions that target modifiable risk factors at patient, health care professional, system, and policy levels,¹⁰³ and evaluate the effectiveness of those interventions in minimizing health disparities in the congenital HD population. Research on SDOH factors that influence outcomes in congenital HD are key to guide health policy conversations and initiatives. In this section we will discuss (1) inclusion of a diverse population in congenital HD research and community-engaged research principles to mobilize and build trust in underrepresented communities; (2) overarching approaches to analysis and causal inference, particularly for observational studies on SDOH; and (3) strategies to ensure diversity of researchers and investigators in dissemination of research in scientific journals.

A recent analysis of nearly 255 000 publications on randomized clinical trials in the United States reported that the total percentage of minority inclusion in randomized clinical trials during the past 25 years was ≈4%.¹⁰⁴ Although National Institutes of Health–funded studies (n=59 577) had a 4-fold higher minority inclusion rate in 2018 (11.1%) compared with 1993 (2.8%), and non-National Institutes of Health–funded studies (n=194 958) had a 2-fold increase during the same timeframe (from 1.2% to 2.8%), racial and ethnic minorities remain underrepresented in randomized clinical trials and biomedical research.¹⁰⁴ The inadequate representation of Black, Latino, and indigenous people is even apparent in recent SARS-CoV-2 vaccine trials.¹⁰⁵

Health disparities research can take many forms. Increased access to high-speed technology and availability of large administrative and clinical databases have increased the share of disparities research emerging from secondary analyses of observational data. The advantages to this approach include larger sample sizes but also adequate representation of different racial and ethnic groups and socioeconomic backgrounds, particularly when using population-based data sets. It is critical that “substantial causal theorizing in relation to critical substantive knowledge”¹⁰⁶ guide hypotheses, study design, selection and operationalization of variables, and analytic plan. Moreover, tools like directed acyclic

diagrams that reflect the complex relationships/interactions/pathways involving race and ethnicity and SDOH can help to avoid common analytic errors such as inappropriately controlling for mediators or colliders.^{107,108} Instead, analyses that capture complex and dynamic relationships (eg, structural equation modeling) can go beyond simple identification of disparities and reveal modifiable causal mechanisms (ie, SDOH) that can be targeted for intervention. For example, in a population-based study in California studying 1-year outcomes in children with complex forms of congenital HD, a formal mediation analysis was performed and found that insurance status and maternal education levels (as proxies for SES) explained 60% of the relationship between Latino ethnicity and poor outcome, whereas traditional risk factors such as birth weight and prematurity explained little of the relationship.³⁶ Collaborations between cardiologists, epidemiologists, and statisticians with expertise in these complex analytic frameworks are key to make meaningful discoveries using large data sets.

Qualitative research methodologies are also powerful tools that allow researchers to hear from populations themselves about problems and potential solutions. These methodologies may be particularly useful in the assessment of implicit bias or microaggressions that may be difficult to quantitatively measure. In general, this may take the form of in-depth interviews with individuals or focus groups to discuss sensitive topics important to a particular community.¹⁰⁹

Community-engaged research, of which CBPR is the most well-known approach, has emerged as an effective strategy to design research more easily translated into real-world health settings. Other advantages include that this methodology can encourage recruitment, enrollment, and retention through community interactions; build greater trust that is likely to improve uptake of proposed interventions; and establish an ongoing academic–community partnership for sustainable reduction of health disparities and underlying inequities. In the general pediatric population, roadmaps have been suggested to address and mitigate health disparities while engaging the communities we are working with.¹¹⁰ Additionally, increasing representation of URM researchers to conduct CBPR and other diversity-related research as well as funding for this type of research can increase participation and trust by minority communities to participate in congenital HD research.

As this statement reviews, the vast majority of health disparity research in the congenital HD population has focused on identification of racial and ethnic and socioeconomic disparities using measured variables. These studies were essential to identify the fact that congenital HD care is not immune to health disparities. Although mortality from congenital HD has steadily declined overall, racial and ethnic disparity in mortality has remained the same even in the current era.⁷⁹ The

future of health disparities research in the congenital HD population will include both qualitative research methods to identify implicit and explicit bias as well as CBPR to begin interventions that can minimize health disparities with community engagement.

Equally important are strategies to ensure adequate dissemination of research identifying and addressing health inequities in congenital HD. Unfortunately, underrepresentation of minorities on editorial boards has at times resulted in deprioritization of health equity research and worse yet, the publication of peer-reviewed articles that propagate implicit and explicit biases. Similar to the call to action to increase representation of women on editorial boards to ameliorate gender disparities, there should be equal focus on leveling the playing field with minority representation as well.¹¹¹ To best serve all stakeholders in society in the advancement of science and medicine, all journals should be committed to assess and change existing editorial culture such that they may serve as champions of diversity, equity, and inclusiveness.¹¹²

ETHICAL GUIDANCE ON ADDRESSING SDOH

Health care ethics are often focused on the therapeutic relationship that balances the needs of the individual patient and the recommendations of the health care professional. When determining what actions are just, the most commonly known ethical framework called principlism considers 4 principles: (1) autonomy (respect for decision-making capacities of autonomous people), (2) beneficence (provide benefits and balance benefits against risks and costs), (3) nonmaleficence (not cause harm to others), and (4) justice (appropriate distribution of benefits, risks, and costs fairly).¹¹³ However, medical literature shows that health is influenced by more than individual patient-level factors.⁷ Absolute health outcomes and differences in outcomes between groups are a result of long-standing systemic inequities and structural racism, often accounting for differences in socioeconomic position and “the high burden of illness responsible for appalling premature loss of life arising in large part because of the conditions in which people are born, grow, live, work, and age.”^{114,115} The justification for addressing these conditions, the SDOH, shifts medical ethics from an individual patient–physician-level focus to a systemic-level focus where the principle of justice takes prominence. The ethical obligation of recognizing the impact of SDOH on health is grounded in multiple theories of justice beyond the scope of this article.^{116–118} Briefly, however, John Rawls argued that justice requires fair and equitable distribution of goods. Norman Daniels connects justice to SDOH by stating that health inequities are unjust when SDOH (such as basic education, affordable housing, income security, and other forms

of antipoverty policy) are not distributed according to Rawls's principles of justice.¹¹⁹

When grounded in the principle of justice, examining SDOH to decrease health inequities in fetal, pediatric, and ACHD becomes an ethical imperative and a moral obligation. This obligation falls both on institutions and individual physicians to support clinical practice and policy choices that address the health inequities themselves to especially improve overall health of those most at risk. A holistic approach to improve health for patients with congenital HD should incorporate the viewpoint that institutions and physicians have an ethical obligation to acknowledge and work toward mitigating SDOH factors. Beyond this, we also have a moral imperative to recognize the role implicit bias and systemic inequities play in the health of patients with congenital HD. Acknowledging the importance of these factors on health are important first steps. In a recent systematic review, SDOH (poverty, lack of insurance, housing instability, parental educational attainment, immigration status, food insecurity, and transportation barriers) were significantly associated with a lower likelihood of fetal congenital HD diagnosis, higher congenital HD incidence and prevalence, increased infant mortality, adverse postsurgical outcomes (including hospital readmission and death), decreased health care access (including missed appointments, no shows, and loss to follow-up), impaired neurodevelopmental outcomes (including intelligence quotient and school performance) and quality of life, and adverse outcomes for adults with congenital HD (including endocarditis, hospitalization, and death).³ Practically, in the care of patients with congenital HD, holistic, ethically oriented care would address health care inequities and SDOH by identifying, investigating, and proposing concrete solutions to improve outcomes and create equitable policies.¹²⁰ Areas to improve health care equity in congenital HD can include: prenatal diagnosis of congenital HD, access to high-quality congenital HD surgery and postsurgical outcomes, access to neurodevelopmental clinics and interventions, communication (language barriers, poor health literacy), access to lifelong congenital HD care (and insurance), recognition and treatment of poorer mental health in patients with congenital HD, access to transition education and skill-building programs, and training all health care professionals and staff in implicit bias while increasing the ACHD workforce and diversity of the pediatric and adult cardiology spaces. Factors to address SDOH can include screening for SDOH so needs may be more quickly addressed (transportation challenges for clinical care and medications, food insecurity, food deserts), identifying deficiencies in educational attainment (proposing a 504 plan or screening for attention deficit hyperactivity disorder), and finding strategies for families to live a heart-healthy lifestyle (exercise) when their neighborhood safety and the build environment negatively impact their ability to do so.

Finally, when conducting research, race should be understood to be a social construct and not used as a sole predictor of outcomes.¹²¹ The social and political means for racial classification do not adequately represent medically relevant biological information.¹²² Differences observed in research among races likely results from longstanding systemic racism. SDOH, and in particular, health care disparities and implicit bias, fail to associate with sufficient precision when race is used as the surrogate.

Contextualizing SDOH and health care disparities within an ethical framework compels us to imagine diagnosis, treatment, and management for patients with congenital HD, not only by surgical procedures or medications, but considering these important holistic factors allows for providing actual best care and improve outcomes of these populations.

CONCLUSIONS

There are multilevel contributors that continue to facilitate health inequities in the care of the patient with congenital HD in the United States. To mitigate these inequities, we must take a multipronged approach and examine contributors at the population, systemic, institutional, and individual levels. Importantly, these areas must be examined across the lifespan beginning before birth and extending into adulthood.

ARTICLE INFORMATION

The American Heart Association makes every effort to avoid any actual or potential conflicts of interest that may arise as a result of an outside relationship or a personal, professional, or business interest of a member of the writing panel. Specifically, all members of the writing group are required to complete and submit a disclosure questionnaire showing all such relationships that might be perceived as real or potential conflicts of interest.

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Writing Group Disclosures

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Keila N. Lopez	Baylor College of Medicine	NIH/NHLBI (K23HL127164, Early Career Grant for improving transition from pediatric to adult care)*	None	None	None	None	None	None
Shabnam Peyvandi	UCSF	NIH/NINDS (K23 Fetal Markers of Neurodevelopment Outcome in congenital heart disease)†	None	None	None	None	None	None
Carissa Baker-Smith	Nemours-Alfred I. DuPont Hospital for Children	None	None	None	None	None	None	None
Glenn Flores	Connecticut Children's Medical Center, University of Connecticut	None	None	None	None	None	None	None
Michelle Gurvitz	Boston Children's Hospital	None	None	None	None	None	None	None
Tara Karamlou	Cleveland Clinic Foundation	None	None	None	None	None	None	None
Flora Nunez Gallegos	Stanford University School of Medicine	None	None	None	None	None	None	None
Sara Pasquali	University of Michigan	None	None	None	None	None	None	None
Angira Patel	Lurie Children's Hospital of Chicago	None	None	None	None	None	None	None
Jennifer K. Peterson	Johns Hopkins University	None	None	None	None	None	None	None
Jason L. Salemi	University of South Florida	None	None	None	None	None	None	None
Clyde Yancy	Northwestern University	None	None	None	None	None	None	None

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Reviewer Disclosures

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Emile Bacha	New York Presbyterian Hospital—Columbia University College of Physicians and Surgeons	None	None	None	None	None	None	None
Susan M. Fernandes	Stanford University School of Medicine	None	None	None	None	None	None	None
Steven A. Fisher	University of Maryland School of Medicine	None	None	None	None	None	None	None

This table represents the relationships of reviewers who may be perceived as having actual or reasonably perceived conflicts of interest as reported on the disclosure questionnaire, which all reviewers are required to complete and submit. A relationship is considered to be significant if (1) the person receives \$10 000 or more during any 12-month period, or 5% or more of the person's gross income; or (2) the person owns 5% or more of the voting stock or share of the entity, or owns \$10 000 or more of the fair market value of the entity. A relationship is considered to be modest if it is less than significant under the preceding definition.

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