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Comprehensive Review

Health Care Disparities in Congenital Cardiology: Considerations Through the Lens of an Interventional Cardiologist

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ABSTRACT

When resources in a society are dispersed unevenly, generally through allocation standards, distinct patterns emerge along lines of socially defined categories of people. Power, religion, kinship, prestige, race, ethnicity, gender, age, sexual orientation, and class all play a role in determining who has access to social goods in society. In most cases, social inequality refers to a lack of equality of outcome, but it can also refer to a lack of equality of access to opportunity. Unfortunately, health care is not immune to these social disparities and/or inequalities. These health care disparities in interventional cardiology were recently brought to the forefront by the Society for Cardiovascular Angiography and Interventions (SCAI) as a major focus of 2020-2021. In a recent publication, unique factors leading to disparities were reported to exist among the subsections of interventional cardiology. The congenital heart disease council of SCAI created a task force to further investigate the unique challenges and disparities impacting the practice of congenital heart disease and pediatric cardiology.

When resources in a society are dispersed unevenly, generally through allocation standards, distinct patterns emerge along lines of socially defined categories of people. Power, religion, kinship, prestige, race, ethnicity, gender, age, sexual orientation, and class all play a role in determining who has access to social goods in society. In most cases, social inequality refers to a lack of equality of outcome, but it can also refer to a lack of equality of access to opportunity. Unfortunately, health care is not immune to these social disparities and/or inequalities. These health care disparities in interventional cardiology were recently brought to the forefront by the Society for Cardiovascular Angiography and Interventions (SCAI) as a major focus of 2020-2021. In a recent publication,[1] unique factors leading to disparities were reported to exist among the subsections of interventional cardiology (Figure 1). The congenital heart disease (CHD) council of SCAI created a task force to further investigate the unique challenges and disparities impacting the practice of CHD and pediatric cardiology.

Health care disparity in congenital heart surgical mortality

For the last decade, there have been persistent differences in the mortality of non-White patients with CHD, and this was reported in a recent SCAI article by Grines et al.[1] Several studies have shown mounting evidence that even after adjustment for gender, surgical risk type (Society of Thoracic Surgeons [STS] category), genetic syndrome, and age, these differences persist.[2-7] There remains an unequal distribution of severe heart disease, with an increased burden of CHD in non-Hispanic Blacks and Asians.[8,9] The unequal distribution of severe cases is based on that of live births; therefore, considerations of access to prenatal diagnosis and, consequently, potential differences in rates of termination must be taken into account. It is unknown whether termination rates are higher for patients with earlier access to care, such as those with higher socioeconomic status. As these populations experience more severe types of CHD at live birth, naturally, the morbidity and mortality rates are increased as well. Trends in right-sided lesions have also been noted, with a higher prevalence of less severe types in Whites.[10] These altered expression patterns not only suggest a potential genetic component but also raise questions regarding environmental factors .[11] Perhaps the most troubling finding is that while the mortality continues to trend downward, we continue to see disparate mortality rates in non-Hispanic Blacks.[2,3] Although multiple factors have been suggested to play a role in these continued and troubling findings,

Abbreviation: CHD, congenital heart disease.

Keywords: congenital heart disease; congenital interventional cardiology; disparities; diversity, equity, and inclusion.

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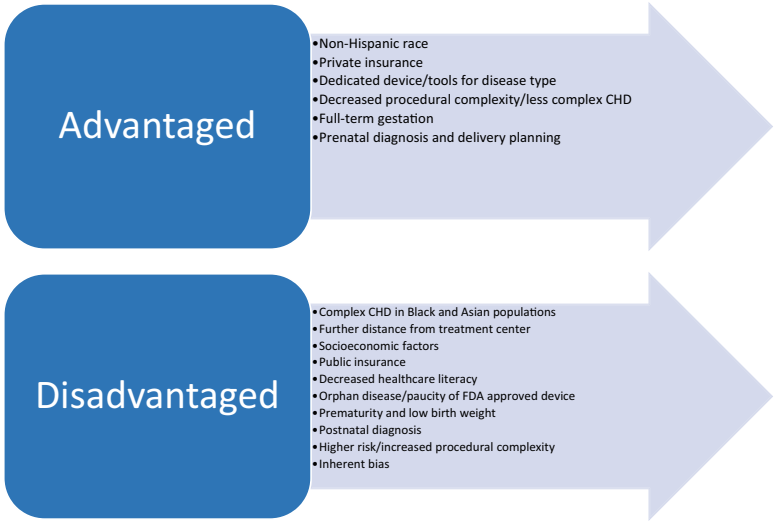


Figure 1. Comparison of the advantaged versus disadvantaged groups. CHD, congenital heart disease; US FDA, United States Food and Drug Administration.

several studies attempting to identify factors (ie, prematurity) have not demonstrated an association with neonatal mortality. The overall rate of disparate mortality of a patient with CHD persists into adulthood.[9,12]

With these disparities in consideration, the CHD council of SCAI has undertaken this systematic review to investigate potential modifiable factors in the population with CHD as possible targets for improvement.

Patient distance from the interventional center

There has been a remarkable advance in the spectrum of congenital cardiac defects that can be palliated or repaired using transcatheter or surgical interventions. Although some of these conditions can be treated electively, others require urgent or emergent intervention. The provision of lifesaving congenital interventional procedures to vulnerable children and adults with CHD by trained congenital interventional cardiologists seems to be a simple task based on established guidelines.[13] However, the accomplishment of this goal can be arduous because of the lack of widespread availability of appropriate congenital diagnostic services, congenital interventional cardiologists with a well-equipped catheterization laboratory with appropriate support from an experienced congenital cardiac surgeon, and the infrastructure for appropriate preprocedural and postprocedural care. All these may not be available in many free-standing community hospitals or even state-of-the-art adult cardiac catheterization laboratories. Thus, many of these therapies can be safely performed only at distant specialized children's hospitals with appropriate resources as aforementioned.

Although there exists a plethora of adult cardiac catheterization laboratories throughout the United States, with more than 1 million catheterizations performed annually in adults, pediatric facilities are much sparser, with only approximately 125 pediatric cardiology programs in the nation.[14] Undoubtedly, some of these programs likely have limited interventional capabilities that may not be able to offer the most contemporary transcatheter treatment options for varied congenital cardiac lesions. Furthermore, many of these pediatric programs are in heavily populated urban areas. In fact, 8 US states lack a pediatric cardiology program and 14 states have only a single program. As a result (especially in the larger predominantly rural states), patients may need to travel hundreds of miles to a program that can provide state-of-the-art congenital interventional services as well as appropriate follow-up evaluations and/or treatment. This can be a major barrier to the care and outcomes for these patients because distance from a cardiac care center has been shown to be associated with worse survival for pediatric patients with all types of CHD.[15] Similar geographic challenges have been shown to exist for similar patient groups that require unique care with highly specialized resources. For example, adult patients with CHD pose an analogous challenge for whom there may be large geographic areas lacking the ability to provide comprehensive and contemporary care owing to the unique aspects of their care. In fact, Gurvitz et al[16] have shown that patients from certain rural areas are more likely to have significant lapses in care.

A recent study assessing geographic access to care for adults with CHD in the United States estimated that nearly half of the adult patients with CHD reside in an area that is at least 1 hour driving time away from a specialized center for adults with CHD, and 5.4% of patients reside >4 hours away, thus potentially necessitating an unnecessary overnight hospital stay.[17]

The clinical impact of this disparity is potentially profound, as certain interventional procedures are necessary to prevent devastating or fatal outcomes. For example, infants born with D-transposition of the great arteries or those with single ventricle anatomy and obstructed pulmonary venous return (ie, hypoplastic left heart syndrome with restrictive atrial septum) present profoundly cyanotic and may not survive without intervention within the first few hours of life. Furthermore, postoperative patients with shunt-dependent pulmonary blood flow can present acutely with shunt obstruction, necessitating very rapid assessment and/or intervention. Less acutely, patients with severe valve stenoses or conduit obstruction may benefit from urgent intervention but may have limited geographic access for routine follow-up, thus delaying assessment and treatment in the catheterization laboratory.

There is a paucity of access to health care for the pediatric patient with CHD compared with the adult patient with coronary artery disease, especially in rural areas.[2,18,19] There are data indicating that access to specialized pediatric cardiac centers is associated with improved survival.[19] Similar improvements in mortality were also found for adults with CHD when surgery was performed at a specialized center for adults with CHD.[20] Decreased mortality has also been shown in pediatric leukemia treated at specialized cancer centers.[21] Adult echocardiograms and fetal ultrasounds are more likely to be readily accessible than a fetal echocardiogram.

Given the potential disparities described above with the clinical implications that may significantly affect patient health and outcome, further evaluation is necessary to determine whether increased distance from interventional pediatric cardiac services results in disparate procedural outcomes and/or inadequate procedural follow-up. It should also be mentioned that discussions continue surrounding the centralization of tertiary care and dilution of experience at each individual cardiac center. There are current models of outreach clinics operated by a large center to address this distance from center concern and require further exploration.

Prematurity

Advancements in perinatal medicine have resulted in significant improvements in the survival of premature and low-birth-weight infants. This has resulted in an increased number of low-birth-weight infants with CHD including patent ductus arteriosus, which may also lead to pulmonary hypertension. Thus, there is an increasing number of premature and low-birth-weight infants who may require diagnostic and interventional procedures in the catheterization laboratory. However, because of their size, fragility, and associated comorbidities, these patients pose significant challenges and are at greater risk of adverse events during invasive procedures.

Prematurity occurs disproportionately in non-Hispanic Blacks and is a complex and multifactorial issue. In past studies, it has been shown that Black infants are 4 times more likely to have significant morbidity and die of complications compared with White infants.[22] In addition, the rates of prematurity are higher in lower socioeconomic classes among both Blacks and Whites, as is low birth weight.[22] Racial disparities are consistently seen in premature births in the United States, with non-Hispanic Black women found to have a 2- to 2.5-fold increased risk compared with non-Hispanic White women.[23-25] This finding is multifactorial, and it has been suggested that even increased stress plays a significant role in prematurity disparity.[26] Given these facts, we, as an interventional community, must be aware of the disparate risks that Black patients have for interventional procedures.

A study from the Congenital Cardiac Catheterization Project on Outcomes registry demonstrated that low weight was an independent risk factor for major adverse events during cardiac catheterization.[27] Patients weighing <2 kg at the time of procedure had a significantly greater risk of death from cardiac perforation or cardiac arrest due to bradycardia, hypotension, and complete atrioventricular block. The need for blood transfusion was also significantly greater in the patients weighing <2 kg who made up 1% of the overall case volume. The risk of acute arterial injury from vascular access is also increased in smaller patients. Glatz et al[28] reported that patients weighing <4 kg at the time of catheterization had a greater risk of acute arterial occlusion after arterial access for cardiac catheterization. Backes et al[29] reported a 19% incidence rate of acute arterial occlusion following percutaneous device closure of patent ductus arteriosus in premature infants weighing <4 kg. Complications remain high in very small patent ductus arteriosus closures. In a recent meta-analysis, the overall complication rate for this procedure in patients weighing ≤1.5 kg was 26%, with a major adverse event rate of 8%.[30] These patients are at higher risk of complications related to hypothermia, hypoglycemia, respiratory distress, and fluid overload during transport to the catheterization laboratory and during the procedure itself. Thus, warming blankets and heat lamps, use of an esophageal temperature probe for continuous patient temperature monitoring, minimization of fluid and contrast administration, avoidance of arterial access, and use of transthoracic echocardiography for imaging during the procedure are undertaken to minimize risks to the patient. A multidisciplinary team may be used for transport of the patient to the catheterization laboratory, and some centers have recommended intubation of patients weighing <2 kg before transport to the catheterization laboratory.[31]

Differences in case complexity and difficulty in determining risk—procedural-type risk categories for pediatric and congenital cardiac catheterization

One of the unique opportunities within the field of CHD is the breadth and spectrum of disease that is treated. Cardiac catheterization in pediatric and adult patients with CHD encompasses a broad range of procedures, some of which occur infrequently. Two separate patients may possess the same CHD diagnosis but necessitate completely different individualized approaches to catheterization—a well-known challenge to any congenital cardiac interventionalist. It is known that patients with CHD at live birth have disparate levels of severe CHD types, as much as 50% higher in non-Hispanic Blacks and Asians, putting these patients at a higher risk of morbidity for interventional procedures.[8-11]

Given the heterogeneity of the patient population, attempts to stratify patients and determine procedural risk have proven difficult. To allow equitable comparisons of procedural adverse event rates, the Catheterization for Congenital Heart Disease Adjustment for Risk Method tool sought to develop a method to adjust for case-mix complexity.[32] This approach emphasized the procedure risk category, number of hemodynamic indicators, and patient age. Subsequently, a multi-institutional initiative in 2016 generated a scoring system to predict the risk of serious adverse events for individual pediatric patients undergoing cardiac catheterizations—Catheterization Risk Score for Pediatrics.[33] A subsequent publication provided minor modifications for a revised version of Catheterization Risk Score for Pediatrics to increase clinical utility as a preprocedural risk model.[34] These scoring systems stratify patients on the basis of baseline characteristics using a 21-point scale that estimates the risk of a procedurally related serious adverse event.

All the abovementioned publications outline the limited amount of data encompassing adult patients with CHD and the challenges unique to this fragile patient population with its own subset of disparities.[35] The Catheterization Risk in Adult Patients score in 2019 proposed a pre-catheterization risk scoring system.[36] However, external validation studies for the aforementioned models/scoring systems remain limited at this time, and their clinical efficacy remains in question. The heterogeneous patient spectrum within pediatric and adult CHD portends the difficulty in categorizing diagnoses and patient characteristics to extrapolate concise scoring systems. Further research is needed with an emphasis on the classification of CHD diagnoses and the inherent risks that they bring into the catheterization laboratory. Risk stratification and adjustment are crucial to study for possible disparities as more severe CHD lesions may have a higher interventional risk, with that risk weighing more toward the non-White patients.

Prenatal diagnosis

CHD is the most common congenital malformation and, although mortality from congenital heart defects has improved over time, it remains a significant cause of death in infants and children and the most important cause of infant mortality due to congenital anomalies.[37,38] Mortality trends of CHD in the United States reveal significant racial disparities, with persistently higher mortality in Black patients than in White patients over time. Critical CHD in neonates refers to cardiac malformations requiring intervention within the first 30 days of life, and advances in ultrasound technology over time have led to improvements in prenatal diagnosis of such infants.[18,39] Indications to refer to fetal echocardiography are based on established maternal and fetal risk factors; however, most cases of CHD occur in low-risk pregnancies and therefore rely on routine obstetric ultrasound to detect cardiac malformations and subsequently refer for a detailed fetal echocardiogram.[39] Fetal echocardiography allows for the precise diagnosis of CHD, detailed prenatal counseling, planning for perinatal management, and selection of fetuses who are at risk of hemodynamic instability after delivery that would require a specialized delivery plan and need to be delivered at a tertiary surgical center. Protocols using fetal echocardiography have been created to risk stratify fetuses diagnosed with CHD/hypoplastic left heart syndrome, and the management of newborns who are at high risk often requires a multidisciplinary team made up of pediatric cardiologists, obstetricians, surgeons, and neonatologists.[39-41] Although there have been conflicting data on the impact of prenatal diagnosis of all types of CHD on overall mortality, prenatal diagnosis has been shown to improve outcomes and mortality in select populations with critical CHD, such as hypoplastic left heart syndrome and transposition of the great arteries.[42-46]

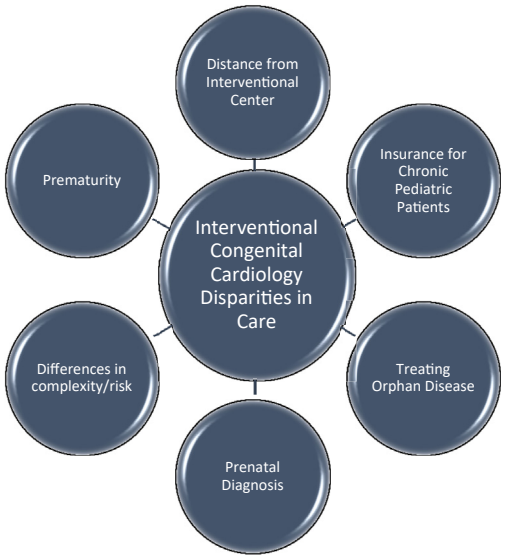
Although technology and techniques for fetal echocardiogram have improved significantly over time, disparities in the prenatal diagnosis of CHD exist. Studies have consistently shown low rates of prenatal diagnosis of CHD, ranging from 28% to 61% in various studies, but with trends showing improvement over time.[18,47-50] A study from the STS database in 2015 reported a wide variation in the prenatal diagnosis of CHD across regions and states,[47] and a few studies have investigated the relationship of socioeconomic factors to prenatal diagnosis, consistently showing that patients with lower socioeconomic status are less likely to have a prenatal diagnosis of CHD.[18,49,50] A study from Boston Children's Hospital demonstrated that lower socioeconomic status and public insurance were independently associated with a lower likelihood of having a prenatal diagnosis of CHD, although no racial disparities were seen.[50] Living in poverty or in a rural community were independent factors associated with a decreased likelihood of having a prenatal diagnosis in a separate study from Children's Hospital of Wisconsin.[18] The Fetal Heart Society was established in 2014, with one of its goals being to foster and support multicenter research and create a research collaborative. There are ongoing projects assessing the socioeconomic and geographic factors in the prenatal diagnosis of critical heart disease.[51] Although the rate of prenatal diagnosis of CHD is improving over time, it is clear that patients living in impoverished and/or rural communities are less likely to have a prenatal diagnosis. As there is strong evidence that fetal diagnosis and prenatal risk stratification of infants born with critical CHD are associated with improved outcomes, further studies on racial and socioeconomic disparities are needed to develop solutions that would allow an improved rate of prenatal diagnosis in the most susceptible patient populations.

Insurance affecting congenital cardiac health outcomes

In 2002, having compiled data from numerous studies, the Institute of Medicine reported that "the uninsured have poorer health and shortened lives" and that having insurance decreased all-cause mortality.[52] Pediatric-specific studies investigating the effect of insurance on health have demonstrated similar findings.[53,54]

Although research regarding how insurance status affects outcomes in patients with CHD is relatively sparse, studies have demonstrated a clear association with outcomes. As a social determinant of health, insurance status is often intimately linked with race, ethnicity, and socioeconomic status. Peyvandi et al[55,56] conducted a population-based cohort study using the California Office of Statewide Health Planning and Development database to determine the effects of racial/ethnic and socioeconomic factors on the outcome of CHD. A composite outcome of mortality and readmissions in the first year of life was studied for Hispanic and non-Hispanic White ethnicities. Overall, Hispanic ethnicity was associated with a poor outcome, with an odds ratio of 1.7. It should be noted that 75% of the Hispanic patients had public or no insurance versus 30% of the non-Hispanic White patients. In mediation analysis, the total effect of race/ethnicity was 37.8% and that of maternal education represented 33.2%, and insurance status (categorized as public, private, or self-pay/other) explained 27.6% of the poor outcome. Another study found that children from the lowest-income neighborhoods had 1.18 times the odds of mortality, 7% longer stays, and 7% higher costs than the children from the highest-income neighborhoods, and those with public insurance had a mortality rate 1.15 times those with private insurance.[57] In addition, Kucik et al[58] found that a lack of insurance resulted in 3 times the mortality risk compared with privately insured infants with critical CHDs.

Suboptimal access to quality care appears to be a recurring driver of poor outcomes because underinsured infants with CHD have been shown to be referred to pediatric cardiologists later than those with insurance[59] and have increased rates of readmission following surgery for CHD.[60] Furthermore, the influence of insurance and access to care remains constant across the continuum of CHD, with studies showing that government insurance (vs private) is associated with increased morbidity during adult CHD surgery admissions.[61] Although there remains a paucity of data specific to access to catheterization and subsequent outcomes in patients with CHD with regard to insurance status, it is reasonable to assume that disparities exist. Further studies are necessary to understand the full scope of this disparity.



Central Illustration. Complexities and factors of disparities in the congenital interventional population. Several factors contribute to disparities in interventional congenital heart disease. Each factor is unique and complex but lead to disparities in care of disadvantaged populations.

Suggestions for improved patient outcomes

Tracking outcomes with factors associated with inequities (eg, distance from center, differences in race, intervention in parent education as it relates to medical literacy) is the first step to decreasing disparities in the congenital interventional community (Central Illustration). In addition, the diversity of providers in congenital interventional cardiology needs to concomitantly be addressed. Our group continues to have significant underrepresentation of minority groups and as we acknowledge the importance of diversity in our workforce, we must begin to address this at the early stages of education and recruit talented colleagues with diverse backgrounds. This will only improve our parent–provider relationship and ultimately begin to improve patient care. Advocacy for improved insurance coverage of our pediatric population must continue to be fostered by our congenital interventional community. Possible solutions for access to care would be for tertiary large cardiac centers to operate satellite clinics with outreach to more underserved areas, providing quality care within a more reasonable distance.

Summary

We have identified several factors that may lead to disparities in care and poor outcomes for pediatric and adult patients with CHD who require diagnostic and interventional catheterization. By increasing awareness of these concepts, we can begin to enact changes that may lead to improved access to high-quality care for all our patients. Going forward, we hope to leverage existing data and registries such as IMPACT to continue to gain a better understanding of how these factors directly impact our patients with CHD who require care in the cardiac catheterization laboratory.

Declaration of competing interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Ethics statement

This research is adherent to relevant ethical guidelines.

Peer review statement

Given his role as Associate Editor, Frank F. Ing had no involvement in the peer review of this article and has no access to information regarding its peer review. Full responsibility for the editorial process for this article was delegated to Alexandra J. Lansky.

References

1. Grines CL, Klein AJ, Bauser-Heaton H, et al. Racial and ethnic disparities in coronary, vascular, structural, and congenital heart disease. *Catheter Cardiovasc Interv*. 2021; 98(2):277–294.
2. Lopez KN, Morris SA, Sexson Tejtel SK, Espaillat A, Salemi JL. US mortality attributable to congenital heart disease across the lifespan from 1999 through 2017 exposes persistent racial/ethnic disparities. *Circulation*. 2020;142(12):1132–1147.
3. Oster ME, Strickland MJ, Mahle WT. Racial and ethnic disparities in post-operative mortality following congenital heart surgery. *J Pediatr*. 2011;159(2):222–226.
4. Nembhard WN, Pathak EB, Schocken DD. Racial/ethnic disparities in mortality related to congenital heart defects among children and adults in the United States. *Ethn Dis*. 2008;18(4):442–449.
5. Nembhard WN, Salemi JL, Ethen MK, Fixler DE, Canfield MA. Mortality among infants with birth defects: joint effects of size at birth, gestational age, and maternal race/ethnicity. *Birth Defects Res A Clin Mol Teratol*. 2010;88(9):728–736.
6. Nembhard WN, Salemi JL, Ethen MK, Fixler DE, Dimaggio A, Canfield MA. Racial/ethnic disparities in risk of early childhood mortality among children with congenital heart defects. *Pediatrics*. 2011;127(5):e1128–e1138.
7. Nembhard WN, Xu P, Ethen MK, Fixler DE, Salemi JL, Canfield MA. Racial/ethnic disparities in timing of death during childhood among children with congenital heart defects. *Birth Defects Res A Clin Mol Teratol*. 2013;97(10):628–640.
8. Knowles RL, Ridout D, Crowe S, et al. Ethnic and socioeconomic variation in incidence of congenital heart defects. *Arch Dis Child*. 2017;102(6):496–502.
9. Gilboa SM, Salemi JL, Nembhard WN, Fixler DE, Correa A. Mortality resulting from congenital heart disease among children and adults in the United States, 1999 to 2006. *Circulation*. 2010;122(22):2254–2263.
10. van der Linde D, Konings EE, Slager MA, et al. Birth prevalence of congenital heart disease worldwide: a systematic review and meta-analysis. *J Am Coll Cardiol*. 2011; 58(21):2241–2247.
11. Broussard CS, Gilboa SM, Lee KA, Oster M, Petrini JR, Honein MA. Racial/ethnic differences in infant mortality attributable to birth defects by gestational age. *Pediatrics*. 2012;130(3):e518–e527.
12. Gilboa SM, Devine OJ, Kucik JE, et al. Congenital heart defects in the United States: estimating the magnitude of the affected population in 2010. *Circulation*. 2016; 134(2):101–109.
13. Feltes TF, Bacha E, Beekman III RH, et al. Indications for cardiac catheterization and intervention in pediatric cardiac disease: a scientific statement from the American Heart Association. *Circulation*. 2011;123(22):2607–2652.
14. Mozaffarian D, Benjamin EJ, Go AS, et al. Heart disease and stroke statistics—2015 update: a report from the American Heart Association. *Circulation*. 2015;131(4): e29–e322.
15. Fixler DE, Nembhard WN, Xu P, Ethen MK, Canfield MA. Effect of acculturation and distance from cardiac center on congenital heart disease mortality. *Pediatrics*. 2012; 129(6):1118–1124.
16. Gurvitz M, Valente AM, Broberg C, et al. Prevalence and predictors of gaps in care among adult congenital heart disease patients: HEART-ACHD (The Health, Education, and Access Research Trial). *J Am Coll Cardiol*. 2013;61(21):2180–2184.
17. Salciccioli KB, Oluyomi A, Lupo PJ, Ermis PR, Lopez KN. A model for geographic and sociodemographic access to care disparities for adults with congenital heart disease. *Congenit Heart Dis*. 2019;14(5):752–759.
18. Hill GD, Block JR, Tanem JB, Frommelt MA. Disparities in the prenatal detection of critical congenital heart disease. *Prenat Diagn*. 2015;35(9):859–863.
19. Kaltman JR, Burns KM, Pearson GD, Goff DC, Evans F. Disparities in congenital heart disease mortality based on proximity to a specialized pediatric cardiac center. *Circulation*. 2020;141(12):1034–1036.
20. Mylotte D, Pilote L, Ionescu-Ittu R, et al. Specialized adult congenital heart disease care: the impact of policy on mortality. *Circulation*. 2014;129(18):1804–1812.
21. Alvarez EM, Malogolowkin M, Hoch JS, et al. Treatment complications and survival among children and young adults with acute lymphoblastic leukemia. *JCO Oncol Pract*. 2020;16(10):e1120–e1133.
22. Parker JD, Schoendorf KC, Kiely JL. Associations between measures of socioeconomic status and low birth weight, small for gestational age, and premature delivery in the United States. *Ann Epidemiol*. 1994;4(4):271–278.
23. Manuck TA. Racial and ethnic differences in preterm birth: a complex, multifactorial problem. *Semin Perinatol*. 2017;41(8):511–518.
24. Schaaf JM, Liem SM, Mol BW, Abu-Hanna A, Ravelli AC. Ethnic and racial disparities in the risk of preterm birth: a systematic review and meta-analysis. *Am J Perinatol*. 2013;30(6):433–450.
25. Menon R, Dunlop AL, Kramer MR, Fortunato SJ, Hogue CJ. An overview of racial disparities in preterm birth rates: caused by infection or inflammatory response? *Acta Obstet Gynecol Scand*. 2011;90(12):1325–1331.
26. Kramer MR, Hogue CJ, Dunlop AL, Menon R. Preconceptional stress and racial disparities in preterm birth: an overview. *Acta Obstet Gynecol Scand*. 2011;90(12): 1307–1316.
27. Backes CH, Cua C, Kreutzer J, et al. Low weight as an independent risk factor for adverse events during cardiac catheterization of infants. *Catheter Cardiovasc Interv*. 2013;82(5):786–794.
28. Glatz AC, Shah SS, McCarthy AL, et al. Prevalence of and risk factors for acute occlusive arterial injury following pediatric cardiac catheterization: a large single-center cohort study. *Catheter Cardiovasc Interv*. 2013;82(3):454–462.
29. Backes CH, Cheatham SL, Deyo GM, et al. Percutaneous patent ductus arteriosus (PDA) closure in very preterm infants: feasibility and complications. *J Am Heart Assoc*. 2016;5(2):e002923.
30. Bischoff AR, Jasani B, Sathanandam SK, Backes C, Weisz DE, McNamara PJ. Percutaneous closure of patent ductus arteriosus in infants 1.5 kg or less: a meta-analysis. *J Pediatr*. 2021;230:84–92.e14.
31. Hubbard R, Edmonds K, Rydalch E, Pawelek O, Griffin E, Gautam N. Anesthetic management of catheter-based patent ductus arteriosus closure in neonates weighing <3 kg: a retrospective observational study. *Paediatr Anaesth*. 2020;30(4):506–510.
32. Bergersen L, Gauvreau K, Foerster SR, et al. Catheterization for congenital heart disease adjustment for risk method (CHARM). *JACC Cardiovasc Interv*. 2011;4(9): 1037–1046.
33. Nykanen DG, Forbes TJ, Du W, et al. CRISP: catheterization risk score for pediatrics: a report from the Congenital Cardiac Interventional Study Consortium (CCISC). *Catheter Cardiovasc Interv*. 2016;87(2):302–309.
34. Hill KD, Du W, Fleming GA, et al. Validation and refinement of the catheterization risk score for pediatrics (CRISP score): an analysis from the congenital cardiac interventional study consortium. *Catheter Cardiovasc Interv*. 2019;93(1):97–104.
35. Oliver JM, Gallego P, Gonzalez AE, et al. Risk factors for excess mortality in adults with congenital heart diseases. *Eur Heart J*. 2017;38(16):1233–1241.
36. Taggart NW, Du W, Forbes TJ, et al. A model for assessment of catheterization risk in adults with congenital heart disease. *Am J Cardiol*. 2019;123(9):1527–1531.
37. Boneva RS, Botto LD, Moore CA, Yang Q, Correa A, Erickson JD. Mortality associated with congenital heart defects in the United States: trends and racial disparities, 1979-1997. *Circulation*. 2001;103(19):2376–2381.
38. Lee K, Khoshnood B, Chen L, Wall SN, Cromie WJ, Mittendorf RL. Infant mortality from congenital malformations in the United States, 1970-1997. *Obstet Gynecol*. 2001;98(4):620–627.
39. Donofrio MT, Moon-Grady AJ, Hornberger LK, et al. Diagnosis and treatment of fetal cardiac disease: a scientific statement from the American Heart Association. *Circulation*. 2014;129(21):2183–2242.
40. Donofrio MT. Predicting the future: delivery room planning of congenital heart disease diagnosed by fetal echocardiography. *Am J Perinatol*. 2018;35(6):549–552.
41. Sanapo L, Moon-Grady AJ, Donofrio MT. Perinatal and delivery management of infants with congenital heart disease. *Clin Perinatol*. 2016;43(1):55–71.
42. Holland BJ, Myers JA, Woods Jr CR. Prenatal diagnosis of critical congenital heart disease reduces risk of death from cardiovascular compromise prior to planned neonatal cardiac surgery: a meta-analysis. *Ultrasound Obstet Gynecol*. 2015;45(6):631–638.
43. Verheijen PM, Lisowski LA, Stoutenbeek P, et al. Prenatal diagnosis of congenital heart disease affects preoperative acidosis in the newborn patient. *J Thorac Cardiovasc Surg*. 2001;121(4):798–803.
44. Tworetzky W, McElhinney DB, Reddy VM, Brook MM, Hanley FL, Silverman NH. Improved surgical outcome after fetal diagnosis of hypoplastic left heart syndrome. *Circulation*. 2001;103(9):1269–1273.
45. Bonnet D, Coltri A, Butera G, et al. Detection of transposition of the great arteries in fetuses reduces neonatal morbidity and mortality. *Circulation*. 1999;99(7):916–918.
46. Kumar RK, Newburger JW, Gauvreau K, Kamenir SA, Hornberger LK. Comparison of outcome when hypoplastic left heart syndrome and transposition of the great arteries are diagnosed prenatally versus when diagnosis of these two conditions is made only postnatally. *Am J Cardiol*. 1999;83(12):1649–1653.
47. Quartermain MD, Pasquali SK, Hill KD, et al. Variation in prenatal diagnosis of congenital heart disease in infants. *Pediatrics*. 2015;136(2):e378–e385.
48. Pinto NM, Keenan HT, Minich LL, Puchalski MD, Heywood M, Botto LD. Barriers to prenatal detection of congenital heart disease: a population-based study. *Ultrasound Obstet Gynecol*. 2012;40(4):418–425.
49. Friedberg MK, Silverman NH, Moon-Grady AJ, et al. Prenatal detection of congenital heart disease. *J Pediatr*. 2009;155(1):26–31.e1.
50. Peiris V, Singh TP, Tworetzky W, Chong EC, Gauvreau K, Brown DW. Association of socioeconomic position and medical insurance with fetal diagnosis of critical congenital heart disease. *Circ Cardiovasc Qual Outcomes*. 2009;2(4):354–360.

51. Pinto NM, Morris SA, Moon-Grady AJ, Donofrio MT. Prenatal cardiac care: goals, priorities and gaps in knowledge in fetal cardiovascular disease: perspectives of the Fetal Heart Society. *Prog Pediatr Cardiol*. 2020;59:101312.
52. Institute of Medicine (US) Committee on the Consequences of Uninsurance. *Care Without Coverage: Too Little, Too Late*. National Academy Press; 2002.
53. Stone ML, LaPar DJ, Mulloy DP, et al. Primary payer status is significantly associated with postoperative mortality, morbidity, and hospital resource utilization in pediatric surgical patients within the United States. *J Pediatr Surg*. 2013;48(1):81–87.
54. Todd J, Armon C, Griggs A, Poole S, Berman S. Increased rates of morbidity, mortality, and charges for hospitalized children with public or no health insurance as compared with children with private insurance in Colorado and the United States. *Pediatrics*. 2006;118(2):577–585.
55. Peyvandi S, Baer RJ, Chambers CD, et al. Environmental and socioeconomic factors influence the live-born incidence of congenital heart disease: a population-based study in California. *J Am Heart Assoc*. 2020;9(8):e015255.
56. Peyvandi S, Baer RJ, Moon-Grady AJ, et al. Socioeconomic mediators of racial and ethnic disparities in congenital heart disease outcomes: a population-based study in California. *J Am Heart Assoc*. 2018;7(20):e010342.
57. Anderson BR, Fieldston ES, Newburger JW, Bacha EA, Glied SA. Disparities in outcomes and resource use after hospitalization for cardiac surgery by neighborhood income. *Pediatrics*. 2018;141(3):e20172432.
58. Kucik JE, Cassell CH, Alverson CJ, et al. Role of health insurance on the survival of infants with congenital heart defects. *Am J Public Health*. 2014;104(9):e62–e70.
59. Perlstein MA, Goldberg SJ, Meaney FJ, Davis MF, Zwerdling Kluger C. Factors influencing age at referral of children with congenital heart disease. *Arch Pediatr Adolesc Med*. 1997;151(9):892–897.
60. Setton M, He W, Benavidez OJ. Morbidity during adult congenital heart surgery admissions. *Pediatr Cardiol*. 2019;40(5):987–993.
61. Benavidez OJ, He W, Lahoud-Rahme M. Readmissions following congenital heart surgery in infants and children. *Pediatr Cardiol*. 2019;40(5):994–1000.