Pediatric RESEARCH

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SYSTEMATIC REVIEW

Social determinants of health and outcomes for children and adults with congenital heart disease: a systematic review

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BACKGROUND: Social determinants of health (SDH) can substantially impact health outcomes. A systematic review, however, has never been conducted on associations of SDH with congenital heart disease (CHD) outcomes. The aim, therefore, was to conduct such a systematic review.

METHODS: Seven databases were searched through May 2020 to identify articles on SDH associations with CHD. SDH examined included poverty, uninsurance, housing instability, parental educational attainment, immigration status, food insecurity, and transportation barriers. Studies were independently selected and coded by two researchers based on the PICO statement.

RESULTS: The search generated 3992 citations; 88 were included in the final database. SDH were significantly associated with a lower likelihood of fetal CHD diagnosis, higher CHD incidence and prevalence, increased infant mortality, adverse post-surgical outcomes (including hospital readmission and death), decreased healthcare access (including missed appointments, no shows, and loss to follow-up), impaired neurodevelopmental outcomes (including IQ and school performance) and quality of life, and adverse outcomes for adults with CHD (including endocarditis, hospitalization, and death).

CONCLUSIONS: SDH are associated with a wide range of adverse outcomes for fetuses, children, and adults with CHD. SDH screening and referral to appropriate services has the potential to improve outcomes for CHD patients across the lifespan.

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IMPACT:

- Social determinants of health (SDH) are associated with a wide range of adverse outcomes for fetuses, children, and adults with congenital heart disease (CHD).
- This is the first systematic review (to our knowledge) on associations of SDH with congenital heart disease CHD outcomes.
- SDH screening and referral to appropriate services has the potential to improve outcomes for CHD patients across the lifespan.

BACKGROUND

Innovation and technical advancement have revolutionized the field of pediatric and adult congenital heart disease (CHD) over the past century. As clinical outcomes have improved dramatically over time, however, healthcare disparities have persisted for the most vulnerable populations. Structural cardiac defects are the most common birth defect, affecting approximately 0.8–1% of the population.[1–3] These birth defects range in complexity and occur across all the socioeconomic groups. With CHD mortality in infancy and childhood decreasing substantially with the evolution of advanced surgical and catheter-based interventions, >90% of children with CHD now survive into adulthood, and this large population of adults with CHD continues to grow with time.[4] As a result, there are now more adults than children living with CHD in the US. Although survival has improved, CHD patients continue to face major socioeconomic and demographic disparities in outcomes at all ages.[3]

Social determinants of health (SDH) are conditions in which people live and grow up within the wider context of systems and influences shaping daily life.[5] SDH include poverty, lack of insurance, housing instability, parental educational attainment, immigration status, food insecurity, and transportation barriers. These factors contribute to poor clinical outcomes, healthcare inequities, and escalating healthcare costs. The central importance of the association of SDH with health outcomes specifically in the context of cardiovascular diseases was underscored by the American Heart Association and American College of Cardiology in their 2019 guidelines for clinical risk assessment.[6] There are no published systematic reviews, however, of the associations of SDH with major CHD outcomes across the lifespan, including fetal diagnosis; incidence and prevalence; infant mortality; post-surgical outcomes; access to care, loss to follow-up, and hospital readmissions; neurodevelopmental outcomes and quality of life (QOL); and adult CHD. The study aim, therefore, was to conduct a systematic review of the association of SDH with CHD outcomes.

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METHODS

SDH: definitions

The following SDH were included in this analysis: poverty, uninsurance, housing instability, parental educational attainment, immigration status, food insecurity, and transportation barriers. These were chosen because they are the domains addressed in a recently published SDH screening instrument used for interventions effective in reducing social risks and improving child and caregiver health.[7] For articles in which there was no assessment of socioeconomic status (SES), Medicaid coverage was used as a proxy for low income.

Outcomes

The following CHD outcome categories across the lifespan were evaluated: fetal diagnosis; incidence and prevalence; infant mortality; post-surgical outcomes; access to care, loss to follow-up, and hospital readmissions; neurodevelopmental outcomes and QOL; and adult CHD.

Inclusion and exclusion criteria

Inclusion criteria consisted of published, original research on the associations of SDH with CHD. Exclusion criteria included: (1) letters to the editor, commentaries, editorials, viewpoints, perspectives, opinion pieces, case reports, book chapters, author or keyword indexes, and review articles; (2) publications that did not address clinical outcomes in patients with CHD; (3) articles focusing on acquired pediatric cardiac diseases, variants of normal, patent foramen ovale, primary arrhythmias, cardiovascular complications of connective tissue disorders, and pulmonary hypertension in the absence of structural CHD; (4) studies that classified SDH as race/ethnicity, maternal stress, environmental exposures, or vitamin or drug/alcohol exposures; (5) animal-only studies; (6) analyses of the association of CHD (as an independent variable) with SDH (as the dependent variable); and (7) articles on populations outside of the US or Canada (because the focus was on SDH in developed countries in North America with comparable healthcare systems).

Literature search

Using sentinel articles to harvest and test search terms, the following search strategy was developed for PubMed/MEDLINE to retrieve all records using natural language and controlled vocabulary (when available) relating to the association of SDH with CHD (Table 1). This strategy then was translated and adapted for the other databases. The following databases were searched from date of inception through May 18, 2020: PubMed MEDLINE (including Pre-MEDLINE and non-MEDLINE; 1945 to May 2020), Scopus (Elsevier; 1966 to May 2020), Cochrane Central Register of Controlled Trials (Wiley; through May 2020), CINAHL (Ebsco; 1981 to May 2020), PsycInfo (Ebsco; 1872 to May 2020), Social Interventions Research & Evaluation Network (SIREN) Evidence & Resource Library (University of California, San Francisco; through May 2020), and SocIndex (Ebsco; 1895 to May 2020). No filters were used for language or publication date. ProQuest RefWorks (Legacy version) was used to de-duplicate and manage all citations.

Once articles were identified and compiled by the search criteria described above and duplicates removed, vetting was performed by title and abstract by two authors using strict inclusion and exclusion criteria (Fig. 1). For studies for which there was lack of clarity regarding whether or not inclusion criteria were met, final decisions were made by reaching consensus among at least three authors. Once title and abstract vetting was completed, a full-text review was performed using the inclusion and exclusion criteria to determine final inclusion in the systematic review. Consensus opinion with regards to inclusion of studies was again reached when questions arose.

PROSPERO registration

This systematic review was registered in PROSPERO (CRD42020169253).

RESULTS

The initial search generated 3992 citations. A total of 88 studies met inclusion criteria (Fig. 1 and Table 2). Study designs were variable and included retrospective chart reviews, retrospective and prospective cohort studies, cross-sectional studies, and prospective case–control studies. No studies were identified that examine housing instability.

The sections that follow report the findings on SDH associations with seven major CHD outcomes across the lifespan: fetal diagnosis; incidence and prevalence; infant mortality; post-surgical outcomes; access to care, loss to follow-up, and hospital readmissions; neurodevelopmental outcomes and QOL; and adult CHD.

Fetal diagnosis of CHD

Four articles were identified that examined SDH associations with the fetal diagnosis of CHD (Table 2).[8–11] Three studies documented that poverty or low SES is associated with a significantly lower likelihood of a prenatal CHD diagnosis; one study also found that low maternal educational attainment and public insurance were SDH risk factors for no prenatal CHD diagnosis. An analysis of 444 patients presenting to Boston Children's Hospital with critical CHD (defined as surgical or catheter intervention required in infants ≤30 days old) revealed that only 35% of those in the lowest SES composite-score quartile received a prenatal CHD diagnosis, vs. 62% of those in the highest SES quartile. A retrospective study of >2.5 million infants born in California revealed that the lowest income tertile, public insurance, and low maternal educational attainment were associated with a significantly higher likelihood of CHD. In a study of 535 patients presenting to Children's Hospital of Wisconsin with CHD, residing in a higher poverty zip code was associated with a significantly lower odds of a prenatal CHD diagnosis. One study of 100 Cincinnati infants with CHD found no association of family income, parental educational attainment, or insurance coverage with prenatal CHD diagnosis, although the sample size (100) was limited and multivariable analyses were not performed.

CHD incidence and prevalence

Fifteen articles examined the association of SDH with CHD incidence and prevalence (Table 2).[12–26] Poverty generally was found to be significantly associated with CHD incidence and prevalence, but such associations were either equivocal or lacking for other SDH examined, including food insecurity, immigration, and parental educational attainment.

Eleven articles analyzed an association between low SES and an increased CHD incidence or prevalence, and most found that SES was significantly associated with CHD incidence or prevalence. SES definitions, however, varied among the studies, with low SES defined as individual poverty, low family income, neighborhood poverty, maternal educational attainment, parental employment, operator/laborer occupation, crowding, rental occupancy, or some combination thereof.[12–15,17–21,25,26] A study of 1.9 million children born in Ontario, Canada, revealed that birth in low SES areas was associated with significantly higher CHD rates (rate ratio = 1.20; 95% confidence interval [CI] = 1.15–1.24).[12] A population-based study of 2.4 million live-born infants in California documented that those residing in neighborhoods with the lowest SES composite score had a significantly higher CHD incidence vs. those from the highest SES neighborhoods (adjusted odds ratio (OR) = 1.31; 95% CI, 1.21–1.41).[25] Low SES also was found to be associated with a significantly higher CHD incidence risk in studies using cardiology clinic registries[13] and national databases.[17]

Table 1. Strategies for database searches (up to May 18, 2020).

Database	Search strategy	Hits
PubMed/Medline (including Pre-MEDLINE and non-MEDLINE)	("Heart Defects, Congenital"[Mesh] OR "congenital heart"[tw] OR "congenital cardiac"[tw] OR "cardiac anomaly"[tw] OR "cardiac anomalies"[tw] OR "conotruncal heart defects"[tw] OR dextrocardia[tw] OR "double outlet right ventricle"[tw] OR "ectopia cordis"[tw] OR "fontan procedure"[tw] OR "glenn procedure"[tw] OR "tetralogy of fallot"[tw] OR "tricuspid atresia"[tw] OR "univentricular heart"[tw]) AND ("Social Determinants of Health"[Mesh] OR "Socioeconomic Factors"[Mesh] OR socioeconomic[tw] OR socio-economic[tw] OR sociodemographic[tw] OR socio-demographic[tw] OR social[tw] OR economic[tw] OR poverty[tw] OR income[tw] OR financial[tw] OR employment[tw] OR unemployment[tw] OR "marital status"[tw] OR "education level"[tw] OR "educational level"[tw] OR "education status"[tw] OR "educational status"[tw] OR "Nutritional Status"[Mesh] OR "food insecurity"[tw] OR "Healthcare Disparities"[Mesh] OR disparit*[tw] OR insurance[tw] OR uninsured[tw] OR "Social Environment"[Mesh] OR "population density"[tw] OR "Residence Characteristics"[Mesh] OR "deprived areas"[tw] OR housing[tw] OR residential[tw] OR residence[tw] OR urban[tw] OR rural[tw] OR "Communication Barriers"[Mesh] OR "Emigrants and Immigrants"[Mesh] OR immigra*[tw] OR emigra*[tw] OR migrant[tw] OR "Prejudice"[Mesh] OR prejudic*[tw] OR "Domestic Violence"[Mesh] OR abuse[tw] OR "Substance-Related Disorders"[Mesh] OR addict[tw] OR addict*[tw] OR alcohol[tw] OR "Smoking"[Mesh] OR smok*[tw] OR "Tobacco Smoke Pollution"[Mesh]) AND ("United States"[Mesh] OR "united states"[tw] OR USA[tw] OR Alabama[tw] OR Alaska[tw] OR Arizona[tw] OR Arkansas[tw] OR California[tw] OR Colorado[tw] OR Connecticut[tw] OR Delaware[tw] OR "District of Columbia"[tw] OR Florida[tw] OR Georgia[tw] OR Hawaii[tw] OR Idaho[tw] OR Illinois[tw] OR Indiana[tw] OR Iowa[tw] OR Kansas[tw] OR Kentucky[tw] OR Louisiana[tw] OR Maine[tw] OR Maryland[tw] OR Massachusetts[tw] OR Michigan[tw] OR Minnesota[tw] OR Mississippi[tw] OR Missouri[tw] OR Montana[tw] OR Nebraska[tw] OR Nevada[tw] OR "New Hampshire"[tw] OR "New Jersey"[tw] OR "New Mexico"[tw] OR "New York"[tw] OR "North Carolina"[tw] OR "North Dakota"[tw] OR Ohio[tw] OR Oklahoma[tw] OR Oregon[tw] OR Pennsylvania[tw] OR "Rhode Island"[tw] OR "South Carolina"[tw] OR "South Dakota"[tw] OR Tennessee[tw] OR Texas[tw] OR Utah[tw] OR Vermont[tw] OR Virginia[tw] OR Washington[tw] OR "West Virginia"[tw] OR Wisconsin[tw] OR Wyoming[tw] OR "Canada"[Mesh] OR canada[tw] OR Alberta[tw] OR "British Columbia"[tw] OR Manitoba[tw] OR "New Brunswick"[tw] OR Newfoundland[tw] OR Labrador[tw] OR "Northwest Territories"[tw] OR "Nova Scotia"[tw] OR Nunavut[tw] OR Ontario[tw] OR "Prince Edward Island"[tw] OR Quebec[tw] OR Saskatchewan[tw] OR "Yukon Territory"[tw] OR "united states"[ad] OR USA[ad] OR Alabama[ad] OR Alaska[ad] OR Arizona[ad] OR Arkansas[ad] OR California[ad] OR Colorado[ad] OR Connecticut[ad] OR Delaware[ad] OR "District of Columbia"[ad] OR Florida[ad] OR Georgia[ad] OR Hawaii[ad] OR Idaho[ad] OR Illinois[ad] OR Indiana[ad] OR Iowa[ad] OR Kansas[ad] OR Kentucky[ad] OR Louisiana[ad] OR Maine[ad] OR Maryland[ad] OR Massachusetts[ad] OR Michigan[ad] OR Minnesota[ad] OR Mississippi[ad] OR Missouri[ad] OR Montana[ad] OR Nebraska[ad] OR Nevada[ad] OR "New Hampshire"[ad] OR "New Jersey"[ad] OR "New Mexico"[ad] OR "New York"[ad] OR "North Carolina"[ad] OR "North Dakota"[ad] OR Ohio[ad] OR Oklahoma[ad] OR Oregon[ad] OR Pennsylvania[ad] OR "Rhode Island"[ad] OR "South Carolina"[ad] OR "South Dakota"[ad] OR Tennessee[ad] OR Texas[ad] OR Utah[ad] OR Vermont[ad] OR Virginia[ad] OR Washington[ad] OR "West Virginia"[ad] OR Wisconsin[ad] OR Wyoming[ad] OR canada[ad] OR Alberta[ad] OR "British Columbia"[ad] OR Manitoba[ad] OR "New Brunswick"[ad] OR Newfoundland[ad] OR Labrador[ad] OR "Northwest Territories"[ad] OR "Nova Scotia"[ad] OR Nunavut[ad] OR Ontario[ad] OR "Prince Edward Island"[ad] OR Quebec[ad] OR Saskatchewan[ad] OR "Yukon Territory"[ad] OR AL[ad] OR AK[ad] OR AZ[ad] OR AR[ad] OR CA[ad] OR CO[ad] OR CT[ad] OR DE[ad] OR DC[ad] OR FL[ad] OR GA[ad] OR HI[ad] OR ID[ad] OR IL[ad] OR IN[ad] OR IA[ad] OR KS[ad] OR KY[ad] OR LA[ad] OR ME[ad] OR MD[ad] OR MA[ad] OR MI[ad] OR MN[ad] OR MS[ad] OR MO[ad] OR MT[ad] OR NE[ad] OR NV[ad] OR NH[ad] OR NJ[ad] OR NM[ad] OR NY[ad] OR NC[ad] OR ND[ad] OR OH[ad] OR OK[ad] OR Ore[ad] OR PA[ad] OR RI[ad] OR SC[ad] OR SD[ad] OR TN[ad] OR TX[ad] OR UT[ad] OR VT[ad] OR VA[ad] OR WA[ad] OR WV[ad] OR WI[ad] OR WY[ad] OR AB[ad] OR BC[ad] OR MB[ad] OR NB[ad] OR NL[ad] OR NT[ad] OR NS[ad] OR NU[ad] OR ON[ad] OR PE[ad] OR QC[ad] OR SK[ad] OR YT[ad]) NOT "Marfan Syndrome"[Mesh] NOT "Myocarditis"[Mesh] NOT ("Animals"[Mesh] NOT ("Animals"[Mesh] AND "Humans"[Mesh])) NOT ("Editorial"[pt] OR "Letter"[pt] OR "Case Reports"[pt] OR "Systematic Review"[pt] OR "Meta-Analysis"[pt] OR "Comment"[pt])	1845
Scopus (Elsevier)	TITLE-ABS-KEY(("congenital heart" OR "congenital cardiac" OR "cardiac anomaly" OR "conotruncal heart defects" OR dextrocardia OR "double outlet right ventricle" OR "ectopia cordis" OR "fontan procedure" OR "glenn procedure" OR "tetralogy of fallot" OR "tricuspid atresia" OR "univentricular heart") AND (socioeconomic OR socio-economic OR sociodemographic OR socio-demographic OR social OR economic OR poverty OR income OR financial OR employment OR unemployment OR "marital status" OR "education level" OR "educational level" OR "education status" OR "educational status" OR "food insecurity" OR disparit* OR insurance OR uninsured OR "population density" OR "deprived areas" OR impoverished OR housing OR residential OR residence OR urban OR rural OR immigra* OR emigra* OR migrant OR prejudic* OR abuse OR violence OR addict OR addict* OR alcohol OR smok*) AND ("united states" OR usa OR alabama OR alaska OR arizona OR arkansas OR california OR colorado OR connecticut OR delaware OR "District of Columbia" OR florida OR georgia OR hawaii OR idaho OR illinois OR indiana OR iowa OR kansas OR kentucky OR louisiana OR maine OR maryland OR massachusetts OR michigan OR minnesota OR mississippi OR missouri OR montana OR nebraska OR nevada OR "New Hampshire" OR "New Jersey" OR "New Mexico" OR "New York" OR "North Carolina" OR "North Dakota" OR ohio OR oklahoma OR oregon OR pennsylvania OR "Rhode Island" OR "South Carolina" OR "South Dakota" OR tennessee OR texas OR utah OR vermont OR virginia OR washington OR "West Virginia" OR wisconsin OR wyoming OR canada OR alberta OR "British Columbia" OR	687

Table 1. continued

Database	Search strategy	Hits
	manitoba OR "New Brunswick" OR newfoundland OR labrador OR "Northwest Territories" OR "Nova Scotia" OR nunavut OR ontario OR "Prince Edward Island" OR quebec OR saskatchewan OR "Yukon Territory" OR (affilcountry, "United States") OR (affilcountry, "Canada")) AND NOT marfan AND NOT myocarditis) AND (LIMIT-TO (DOCTYPE, "ar"))	
Cochrane Central Register of Controlled Trials (CENTRAL) (Wiley)	All Text: ("congenital heart" OR "congenital cardiac" OR "cardiac anomaly" OR "conotruncal heart defects" OR dextrocardia OR "double outlet right ventricle" OR "ectopia cordis" OR "fontan procedure" OR "glenn procedure" OR "tetralogy of fallot" OR "tricuspid atresia" OR "univentricular heart") AND (socioeconomic OR socio-economic OR sociodemographic OR socio-demographic OR social OR economic OR poverty OR income OR financial OR employment OR unemployment OR "marital status" OR "education level" OR "educational level" OR "education status" OR "educational status" OR "food insecurity" OR disparit* OR insurance OR uninsured OR "population density" OR "deprived areas" OR impoverished OR housing OR residential OR residence OR urban OR rural OR immigra* OR emigra* OR migrant OR prejudic* OR abuse OR violence OR addict OR addict* OR alcohol OR smok*) NOT marfan NOT myocarditis	175
CINAHL (Ebsco)	(MH "Heart Defects, Congenital+" OR TX "congenital heart" OR TX "congenital cardiac" OR TX "cardiac anomaly" OR TX "conotruncal heart defects" OR TX dextrocardia OR TX "double outlet right ventricle" OR TX "ectopia cordis" OR TX "fontan procedure" OR TX "glenn procedure" OR TX "tetralogy of fallot" OR TX "tricuspid atresia" OR TX "univentricular heart") AND (MH "Social Determinants of Health" OR MH "Socioeconomic Factors+" OR TX socioeconomic OR TX socio-economic OR TX sociodemographic OR TX socio-demographic OR TX social OR TX economic OR TX poverty OR TX income OR TX financial OR TX employment OR TX unemployment OR MH "Marital Status+" OR TX "marital status" OR TX "education level" OR TX "educational level" OR TX "education status" OR TX "educational status" OR MH "Nutritional Status" OR MH "Food Security" OR TX "food insecurity" OR MH "Healthcare Disparities" OR TX disparit* OR TX insurance OR TX uninsured OR MH "Social Environment+" OR MH "Population Density" OR TX "population density" OR TX "deprived area" OR TX "deprived areas" OR TX impoverished OR MH "Residence Characteristics+" OR TX housing OR TX residential OR TX residence OR TX urban OR TX rural OR MH "Communication Barriers" OR TX "non-English-speaking" OR MH "Immigrants+" OR TX immigra* OR TX emigra* OR TX migrant OR MH "Prejudice" OR TX prejudic* OR MH "Domestic Violence+" OR TX abuse OR TX violence OR MH "Substance Dependence+" OR TX addict OR TX addict* OR TX alcohol OR TX smok*) AND (MH "United States+" OR MH "Canada+") NOT TX marfan NOT TX myocarditis Limit to: Human Limit to Geographic Subset: Canada and USA	408
PsycInfo (Ebsco)	("congenital heart" OR "congenital cardiac" OR "cardiac anomaly" OR "conotruncal heart defects" OR dextrocardia OR "double outlet right ventricle" OR "ectopia cordis" OR "fontan procedure" OR "glenn procedure" OR "tetralogy of fallot" OR "tricuspid atresia" OR "univentricular heart") AND (socioeconomic OR socio-economic OR sociodemographic OR socio-demographic OR social OR economic OR poverty OR income OR financial OR employment OR unemployment OR "marital status" OR "education level" OR "educational level" OR "education status" OR "educational status" OR "food insecurity" OR disparit* OR insurance OR uninsured OR "population density" OR "deprived areas" OR impoverished OR housing OR residential OR residence OR urban OR rural OR immigra* OR emigra* OR migrant OR prejudic* OR abuse OR violence OR addict OR addict* OR alcohol OR smok*) NOT marfan NOT myocarditis	294
SocIndex (Ebsco)	(TX "congenital heart" OR TX "congenital cardiac" OR TX "cardiac anomaly") NOT TX marfan NOT TX myocarditis	583
Social Interventions Research & Evaluation Network (SIREN) Evidence & Resource Library (University of California, San Francisco)	Text Searches: "congenital heart", "congenital cardiac", "cardiac anomaly", "conotruncal heart defects", dextrocardia, "double outlet right ventricle", "ectopia cordis", "fontan procedure", "glenn procedure", "tetralogy of fallot", "tricuspid atresia", "univentricular heart"	0

Two articles used the Nationwide Inpatient Sample (NIS) to examine secular trends in CHD prevalence, but reached different conclusions. One study demonstrated that those in the upper income quartile experienced a significantly greater temporal decrease in the prevalence of severe CHD vs. those in the lowest income quartile,[19] whereas another found that mild CHD prevalence significantly increased only in the high SES group.[20] Another population-based study using the NIS reported that the overall CHD incidence was actually significantly lower in the lowest SES group, although the authors speculated that this may have been due to lower access to hospitals with better diagnostic tools.[21]

A study on food insecurity as a risk factor for conotruncal heart defects reported that food insecurity was associated with higher adjusted odds of D-transposition of the great arteries, but only among normal-weight and underweight mothers (and not those who were overweight or obese); no association of food insecurity, however, was found with tetralogy of Fallot.[16] An analysis of the National Birth Defects Prevention Study revealed that having immigrant parents was associated with significant lower odds of certain CHDs, with the greatest number of significantly protective adjusted ORs noted for foreign-born parents residing ≤5 years vs. >5 years in the US.[22] Another study, however, found no association of maternal birthplace with left ventricular outflow-tract malformations.[24] Two studies found no association of maternal educational attainment with CHD prevalence.[23,24]

Infant mortality

Nine articles analyzed associations between SDH and infant mortality in CHD patients (Table 2). Poverty, low parental educational attainment, uninsurance, transportation barriers, and immigration status were significantly associated with infant mortality.[1–3,27–32]

A study of 229 children with hypoplastic left heart syndrome (HLHS) identified via the Metropolitan Atlanta Congenital Defects Program documented survival rates that were almost three times

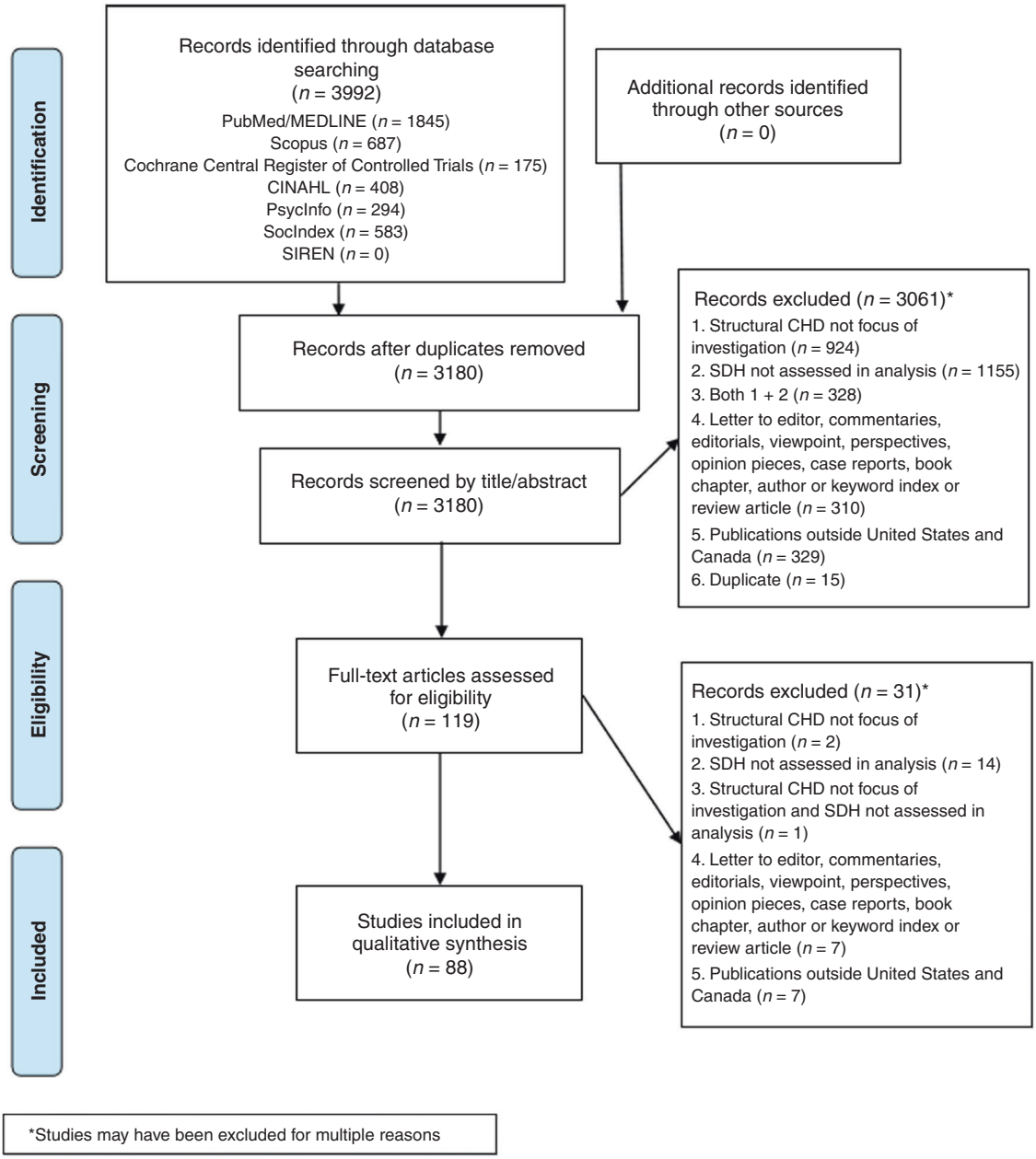

Fig. 1 Flow diagram of study selection (adapted from PRISMA), including study identification, screening, eligibility, and final inclusion procedures and numbers.

worse for those residing in high-poverty (9%) vs. low-poverty (25%; $P < 0.001$) neighborhoods.[32] An analysis of data from birth-defect surveillance programs from four states (Arizona, New York, New Jersey, and Texas) on almost 10,000 infants with CHD revealed that poverty was associated with about double the adjusted odds of infant mortality.[3]

Low maternal educational attainment was associated with a significantly higher risk of CHD infant mortality in three studies.[1,3,30] For example, one study of coarctation of the aorta revealed a mortality rates of 27% for infants of mothers who had not completed high school vs. 5% for those who at least completed high school ($P = 0.004$).[30] Research on 4390 infants with CHD also documented that lower paternal educational was associated with a 62% increased risk of infant mortality.[31]

An analysis of the Texas Birth Defects Registry revealed that uninsured infants with critical and noncritical CHDs had approximately triple and double the risk of neonatal mortality, respectively, compared with infants with private insurance.[29] Another Texas study found that residing in a county bordering Mexico was associated with higher adjusted odds of CHD infant mortality.[28]

Post-surgical outcomes

A total of 25 articles evaluated the association of SDH with post-surgical outcomes in CHD patients (Table 2). Poverty and low SES were consistently associated with adverse post-operative outcomes, including worse HLHS survival,[33] increased in-hospital mortality and resource utilization after orthotopic heart transplant for single-ventricle vs. cardiomyopathy patient cohorts,[34] higher inter-stage mortality in the Single Ventricle Reconstruction Trial,[35] higher mortality following congenital heart surgery,[36] worse 1-year transplant-free survival after the Norwood procedure (stage I palliation for single-ventricle CHD),[37] unplanned readmission in the first 90 days after congenital heart surgery,[38] longer length of

Table 2. Summary of the included studies on the association of social determinants of health with congenital heart disease (CHD).

Social determinant(s) of health (SDH)	Study design	Sample size	Notes	Reference number—first author
Fetal diagnosis of congenital heart disease—4				
Poverty/socioeconomic status (SES) —Patients with public insurance, lower SES, and living below the poverty level less likely to have a prenatal diagnosis of critical CHD	Retrospective analysis of infants presenting to the Boston Children's with critical CHD from 2003 to 2006	$N = 444$	Adjusted for 4 covariates	[9]—Peiris
Poverty/transportation barriers —Maternal educational attainment, income, and insurance type not significantly associated with prenatal diagnosis	Prospective study of 100 consecutive infants diagnosed with major CHD who received prenatal care in Cincinnati eight-county area from October 2007 to May 2009	$N = 100$	Adjusted for 7 covariates	[11]—Sekar
Poverty/transportation barriers —Those living in impoverished or rural communities were at highest risk of not having diagnosis made prenatally	Patients presenting to the Children's Hospital of Wisconsin with critical CHD from 2007 to 2013	$N = 535$	Adjusted for 9 covariates	[8]—Hill
Poverty/parental educational attainment —Infants with critical CHD were more likely to be born to mothers enrolled in WIC and have public insurance and less likely to be born to mothers with college degrees or mother at top SES tertile	Linked dataset from the Office of Statewide Health Planning and Development to access ICD-9 diagnosis codes for all infants born in California from 2008 to 2012 to compare infants with critical CHD to general population	$N = 2{,}514{,}837$	Adjusted for 12 covariates	[10]—Purkey
CHD prevalence and incidence—15				
Poverty/parental educational attainment —For whites in the lowest SES stratum, risk of aortic stenosis was five times that of blacks —Controlling for socioeconomic factors attenuated the white excess for Ebstein's anomaly and disclosed white excess for L-TGA	Population-based case-control study in Maryland, the District of Columbia, and northern Virginia between 1981 and 1987	$N = 4808$ ($n = 2087$ cases, $n = 2721$ controls)	Adjusted for 6 covariates, including maternal educational attainment, occupation of the head of the household, and family income per family member	[18]—Correa-Villaseñor
Low income —Medicaid coverage associated with CHD higher rate	The University of Arizona Pediatric Cardiology Registry between 1990 and 1994. Questionnaire to all mothers to confirm data collected from patient records and maternal demographics	$N = 831$	Chi-square test, no covariates	[13]—Baron
Poverty/parental educational attainment —Low SES associated with increased risk of D-transposition of the great arteries (dTGA), reduced risk of tetralogy of Fallot (TOF) (prevalence)	Interview data from case mothers and a population-based case–control study in Los Angeles, San Francisco, and Santa Clara from 1987 to 1989	$N = 1430$ ($n = 734$ control, $n = 207$ conotruncal cases, $n = 348$ isolated cleft lip with/without cleft palate, $n = 141$ isolated cleft lip without cleft palate)	Adjusted for 4 covariates Individual SES defined by maternal education and parental employment; neighborhood SES defined by education, poverty, unemployment, operator/laborer occupation, crowding, and rental occupancy	[15]—Carmichael
Educational attainment/immigration status —Maternal educational attainment and birthplace not significantly associated with prevalence rate ratios for left ventricular outflow tract	The Texas Birth Defect Registry database from 1999 to 2001	$N = 1{,}077{,}574$	Adjusted for 5 covariates	[24]—McBride

Table 2. continued

Social determinant(s) of health (SDH)	Study design	Sample size	Notes	Reference number—first author
Food insecurity —Food insecurity associated with higher adjusted odds of D-transposition of the great arteries but only among normal-weight and underweight mothers (and not those who were overweight or obese); no association of food insecurity, however, with tetralogy of Fallot	Population base case–control data in Los Angeles, San Francisco, and Santa Clara counties from 1999 to 2004	$N = 1884$ ($n = 1189$ cases; $n = 695$ controls)	Adjusted for 7 covariates	[16]—Carmichael
Low SES/parental educational attainment —Operator/laborer mothers at two times greater risk to have offspring with TOF and dTGA (AOR ≥ 2.2), and either parent unemployed was more likely to have dTGA cases (AOR ≥ 1.4)	Data from National Birth Defect Prevention Study in 1997–2000	$N = 4392$ ($n = 2551$ controls and $n = 1841$ cases)	Adjusted for 8 covariates SES—measured by parents' educational attainment, occupation, and household income	[26]—Yang
Poverty/parental educational attainment —Low maternal educational attainment and low income not associated with increased risk of dTGA —Low income not associated with increased risk of TOF	Population-based case–control study in California from July 1999 to June 2004	$N = 1502$ ($n = 617$ non-malformed controls, $n = 608$ with orofacial clefts, $n = 277$ with conotruncal heart defects)	Adjusted for 5 covariates SES was defined by maternal educational attainment, maternal and paternal employment, and annual household income	[14]—Carmichael
Parental educational attainment/ immigration status —Maternal residence along Texas–Mexico border associated with increase in prevalence of isolated TA —No significant association between low maternal educational attainment and increased prevalence of dTGA or TOF	Texas Birth Defects Registry from 1999 to 2004	$N = 2,208,758$	"Variables that were significantly related to the outcome of interest in the crude analyses and for which <10% of cases had missing values were included in the multivariate analyses"	[23]—Long
Low SES/parental educational attainment —Children born in low SES areas had significantly higher CHD prevalence	Healthcare data through Ontario Ministry of Health and Long-Term Care (MOHLTC)—all children born alive in hospital in Ontario, Canada, 1994–2007	$N = 1,871,760$	Adjusted for 3 covariates SES defined by neighborhood income and educational attainment	[12]—Agha
Poverty —Incidence of CHD similar for all SES classes except lowest SES class, which had significantly lower CHD incidence	The Nationwide Inpatient Sample from Jan 2008 to Dec 2008	$N = 1,204,887$	Descriptive statistics	[21]—Egbe
Poverty —Prevalence of TOF, TA, HLHS, and PA from 1999 to 2008 did not change significantly in the lowest income quartile —In contrast, significant temporal decrease in prevalence of TOF, TA, HLHS, and PA in the highest income quartile, decrease in the prevalence of PA in the third income quartile, and decrease in the prevalence of TOF, TA, and HLHS in second income quartile (authors speculate that this may be due to increased prenatal diagnosis of CHD and termination of pregnancy)	Population-based study—the Nationwide Inpatient Sample from 1999 to 2008	$N = 9,696,908$	Descriptive statistics	[19]—Egbe

Table 2. continued

Social determinant(s) of health (SDH)	Study design	Sample size	Notes	Reference number—first author
Low income —Prevalence of isolated PDA increased across all income quartiles from 1998 to 2008 —No change in prevalence of mild CHD in lowest income quartiles; increase in prevalence of mild CHD in highest income quartile (authors speculate that this may be due to access to hospitals with better diagnostic tools, although could be influenced by missing data)	The Nationwide Inpatient Sample in 1998 and in 2008	$N = 1{,}990{,}893$	Descriptive statistics	[20]—Egbe
Immigration status —Infants with both parents foreign-born had lower unadjusted rates of six CHDs —Infants with foreign-born mothers had lower crude rate of aortic stenosis —After adjustment, immigrant protective associations remained for aortic stenosis, right ventricular outflow tract obstruction, and pulmonary valve stenosis —more statistically significant protective results observed in infants with parents who had spent ≤5 years in US	National Birth Defects Prevention Study, 1997–2011	$N = 44{,}029$ ($n = 32{,}200$ cases, $n = 11{,}829$ controls)	Adjusted for 11 covariates	[22]—Hoyt
Low income —Low income associated with CHD prevalence; compared with infants of diabetic mothers born in family with highest 25th quartile family income, infants in lowest 25th quartile family income had higher odds of CHD	Nationally representative Kids' Inpatient Database (KID) for years 2003, 2006, 2009, and 2012	$N = 183{,}453$	Adjusted for 1 covariate (race/ethnicity) or unadjusted	[17]—Chou
SES/parental educational attainment —Lower SES at neighborhood level associated with incidence of live-born CHD and was most significant for those with the highest social deprivation	Population-based cohort study in California (2007–2012) Socioeconomic variables for each subject's census tract collected from US Census website	$N = 2{,}419{,}651$	Adjusted for 2 covariates Social deprivation index [SDI] determined at the neighborhood level SES defined by income, parental educational attainment, occupation at neighborhood level	[25]—Peyvandi
Infant mortality—9				
Poverty/parental educational attainment —Low paternal educational attainment associated with increased mortality of infants with CHD, whether diagnosis was made before or after death —Lower income, maternal educational attainment, and SES scores not associated with death before CHD diagnosis	Infants with CHD identified in a population-based study between 1981 and 1989 in the Baltimore Washington metropolitan area	$N = 4390$	Adjusted for 6 covariates	[30]—Kuehl
Uninsured/parental educational attainment/poverty —Death rates 33 vs. 4% for infants of uninsured vs. insured mothers for coarctation of aorta	Baltimore Washington Infant Study of infantile coarctation of aorta	$N = 105$	Adjusted for 5 covariates	[31]—Kuehl

Table 2. continued

Social determinant(s) of health (SDH)	Study design	Sample size	Notes	Reference number—first author
—27.3% mortality for infants of mothers who had not completed high school vs. 4.9% for those who at least completed high school ($P = 0.004$) —Income and paternal educational attainment not associated with survival in multivariate analysis				
Poverty/immigration status/transportation barriers —Lower first-year survival and lower referral rate in border counties (bordering Mexico) —Maternal educational attainment, distance to a major center, and foreign-born parents not associated with mortality	Infants with severe CHD, born 1996–2003, identified from Texas Birth Defects Registry	$N = 1213$	Adjusted for 12 covariates	[28]—Fixler
Low income/uninsured —Uninsured infants with critical and noncritical CHDs had approximately 3 and 2 times the increased neonatal mortality risk, respectively, vs. infants with private insurance —Publicly insured infants had 30% reduced mortality risk vs. privately insured infants during neonatal period, but 30% increased risk in the post-neonatal period	Population-based, retrospective study in a cohort of Florida resident infants born with CHDs between 1998 and 2007	$N = 43,411$	Adjusted for 8 covariates	[29]—Kucik
Poverty/parental educational attainment —Census-tract-level poverty and low parental educational attainment associated with higher adjusted odds of infant mortality	Population-based data from 4 state-based birth defect surveillance programs (Arizona, New York, New Jersey, and Texas) in retrospective cohort study of infants from 1999 to 2007 with CHD	$N = 10,578$	Adjusted for 11 covariates	[3]—Kucik
Poverty —High neighborhood poverty associated with higher death rate and lower survival probability of children with HLHS	Infants with nonsyndromic HLHS born between 1979 and 2005 identified through Metropolitan Atlanta Congenital Defects Program	$N = 212$	Adjusted for 10 covariates	[32]—Siffel
Low income —Deliveries covered by Medicaid (including for infants with CHD) associated with infant mortality attributable to birth defects	2011–2013 Linked Birth and Infant Death Data from National Vital Statistics System for infants <1 year old	$N = 9,542,603$	Adjusted for 12 covariates	[27]—Almli
Poverty/parental educational attainment —Lower maternal educational attainment not associated with increased hazard of infant mortality —Medicaid status not significantly associated with increased or decreased hazard of infant mortality, after adjustment for confounding variables	Infants with CHDs born between 2004 and 2013 ascertained by NC Birth Defects Monitoring Program	$N = 15,533$	Adjusted for 22 covariates	[2]—Pace
Poverty and educational attainment —Lower maternal educational attainment and public insurance had significantly increased odds of poor outcome (mortality or re-admission)	Population-based cohort study using California Office of Statewide Health to assess outcomes for live-born infants with HLHS and dTGA	$N = 1796$	Adjusted for 14 covariates	[1]—Peyvandi

Table 2. continued

Social determinant(s) of health (SDH)	Study design	Sample size	Notes	Reference number—first author
Post-surgical outcomes—23				
Low income/transportation barriers —Patients with Medicaid older at the time of operation vs. patients with private insurance and managed care —No association of distance between patient's home and surgical center found for ASD, VSD, TOF, or AVC	Office of Statewide Health Planning and Development database for 1995 and 1996 in California	$N = 666$	No covariates; Kruskal–Wallis one-way ANOVA, weighted linear regression	[87]—Chang
Low income —Publicly insured children significantly more likely to use higher-mortality hospitals for cardiac surgery vs. those with indemnity coverage	Retrospective cohort study using annual California state-mandated hospital discharge dataset between 1992 and 1994	$N = 5071$	Adjusted for 6 covariates	[88]—Erickson
Low income —Income not associated with treatment choices	National Inpatient Sample dataset, 1998–1997	$N = 1986$	Adjusted for 8 covariates	[87]—Chang
Low income —Medicaid coverage associated with higher risk of dying after CHD surgery	Population-based retrospective cohort study using hospital discharge abstract data from five states (CA, MA, IL, PA, and WA) in 1992 and 1996	$N = 11,636$	Adjusted for risk category (RACHS-1) and additional clinical variables	[38]—Lushaj
Low income/uninsured/transportation barrier —Zip code median family income <$30,000 and distance between home and hospital >100 miles associated with reduced likelihood of readmission after neonatal cardiac surgery —Uninsurance not significantly associated with likelihood of readmission	Single center, case–control study at Boston Children's Hospital between 1992 and 2002	Case: $N = 498$; control: $N = 254$	Adjusted for 2 covariates	[44]—Mackie
Low income —Lower family income associated with lower physical and psychosocial functioning	Pediatric Heart Network cross-sectional study (pediatric cardiac centers in US and Canada)	$N = 537$	Adjusted for 5 covariates	[89]—McCrindle
Poverty —Adjusting for median income by zip code universally increased magnitude of ORs (of death) and overall level of significance for blacks and Latinos	Kids' Inpatient Database 2000	$N = 8483$	Adjusted for 6 covariate	[90]—Benavidez
Poverty —Income not associated with post-discharge death	Statewide hospital discharge data from California 1989–1999	$N = 25,402$	Adjusted for 1 covariate—"risk adjustment"	[91, 92]—Chang
Poverty/parental educational attainment/transportation barriers —Low SES associated with mental outcomes —SES, maternal educational attainment, and "location of family home" not associated with growth and health outcomes	Interprovincial inception cohort study in Western Canada from 1996 through 2004	$N = 41$	No covariates. Descriptive analysis—chi-square and Fisher's exact test performed only	[43]—Alton

Table 2. continued

Social determinant(s) of health (SDH)	Study design	Sample size	Notes	Reference number—first author
Low income —After adjustment for time since Fontan procedure, multivariate linear regression demonstrated that lower annual family income associated with lower functional score, indicating worse functional state	Pediatric Heart Network Fontan Cross-Sectional Study completed in 2004 by 7 Network centers	$N = 476$	Adjusted for 1 covariate (time since the Fontan procedure)	[93]—Williams
Poverty —After adjusting for age/weight, infants with HLHS in high-poverty areas 1.8 times (95% CI: 1.1–2.8; $P = 0.015$) more likely to die than those in high-poverty areas	Michigan Birth Defect Registry from 1992 to 2005	Control $N = 4060$; case N = 406	Adjusted for 2 covariates	[33]—Hirsch
Low income —Medicaid coverage associated with mortality, non-elective admission for congenital heart surgery, and referral to high-mortality hospitals	Kids' Inpatient Database from 1997 to 2006	$N = 44{,}910$	Adjusted for 5 covariates	[94]—Chan
Parental educational attainment —Lower maternal educational attainment associated with lower Mental Developmental Index score ($P = 0.04$)	SVR trial—15 centers in North America between May 2005 and July 2008	$N = 373$	Adjusted for 5 covariates	[42]—Newburger
Low income —Lower SES associated with intermediate-term mortality	SVR trial between May 2005 and July 2008 at 15 centers in US and Canada	$N = 549$	Adjusted for 7 covariates	[95]—Tweddell
Poverty —Census-block poverty associated with inter-stage mortality ($P = 0.003$) —But subjects in communities with 5.4–13% poverty had greater risk of inter-stage mortality vs. subjects in poorest communities (OR, 2.5)	Single Ventricle Reconstruction trial	$N = 426$	Adjusted for 4 covariates	[35]—Ghanayem
Low income —Low SES associated with lower physical summary scores and school functioning scores and decreased quality of life	Prospective cohort study at Stollery Children's hospital from July 2000 to June 2005	$N = 242$	Adjusted for 8 covariates Family SES determined by Blishen Index	[41]—Garcia Guerra
Low income —Lower income quartiles associated with surgical ligation —Payer status and income quartile not associated with survival	Kids' Inpatient Data from the 1997, 2000, 2003, 2006, and 2009 releases	$N = 63{,}208$	Adjusted for covariates; regression adjusted for comorbid risk factors using Elixhauser method, which has been validated in multiple previous studies	[37]—Tashiro
Low income —Public insurance associated with longer length of stay and increased in-hospital neonatal mortality	2012 Healthcare Cost and Utilization Project Kids Inpatient Database	$N = 13{,}130$	Multivariable logistic regression with sample weights, stratification, and clustering	[40]—Peterson
Low income/educational attainment —After adjustment for patient demographics, birth characteristics, and anatomy, patients in lowest SES tertile had significantly higher risk of death or transplant than patients in highest SES tertile	Pediatric Heart Network Single Ventricle Reconstruction (SVR) Trial Public Use dataset between May 2005 and July 2008 at 15 centers in US and Canada	$N = 525$	Adjusted for 6 covariates	[96]—Bucholz

Table 2. continued

Social determinant(s) of health (SDH)	Study design	Sample size	Notes	Reference number—first author
—Low neighborhood SES associated with worse 1-year transplant-free survival after Norwood procedure				
Poverty —income not significantly associated with risk for readmission in adjusted analysis	State Inpatient Databases for Washington, New York, Florida, and California	$N = 8585$	Adjusted for 7 covariates	[97]—Benavidez
Low income —Lower median household income associated with increased resource utilization and lower in-hospital mortality in single-ventricle CHD patients who undergo OHT	PHIS database between January 2004 and September 2015	$N = 1599$	Adjusted for 12 covariates	[34]—Bradford
Low income —Low income associated with difficulties in adaptive behavior, behavioral symptoms, QOL, and functional status in children with hypoplastic left heart syndrome at 6 years old	Single Ventricle Reconstruction Trial from 2005 to 2008	$N = 250$	Adjusted for 7 covariates	[98]—Goldberg
Low income/transportation barrier —Lower SES risk factor for unplanned readmissions in first 90 days after surgery —Distance to hospital inversely associated with readmissions ($P < 0.01$), with odds of patient getting readmitted decreasing by 33% for each 100 miles of distance lived farther from the hospital	Retrospective review of patients at University of Wisconsin School of Medicine and Public Health, August 2011–June 2015	$N = 265$	No covariates. Bivariable logistic regression, general linear model	[38]—Lushaj
Access to care, loss to follow-up, and hospital readmissions—10				
Low income —Medicaid coverage associated with high resource utilization	Review of hospital discharge data from Healthcare Cost and Utilization Project (HCUP) Kids' Inpatient Database (KID) year 2000 (data from 27 states) for patients <18 years old who had congenital heart surgery	$N = 10,569$	Adjusted for 30 covariates	[39]—Connor
Low income —Lower median family income associated with increased risk of loss to follow-up (adjusted odds of 1.2 per $10,000 decrement in income)	Matched case-control design to examine risk factors for loss to cardiology follow-up among children and young adults with CHD using Western Canadian Children's Heart Network database	$N = 296$	Adjusted for 12 covariates	[47]—Mackie
Low SES (public insurance) —Significant trend over time in proportion of publicly insured admissions (42–61%; $P < 0.0001$) to and bed days in pediatric cardiology specialty-care centers from 1983 to 2011	Retrospective analysis of pediatric CHD patients seen at pediatric cardiology specialty-care centers from 1983 to 2011, using California Office of Statewide Health Planning and Development unmasked database	$N = 164,310$	Adjusted for 6 covariates	[99]—Chamberlain
Low income —Public insurance and lower household income (<$52,950) associated with/missed appointments in bivariate analysis	Single-center retrospective study of patients with outpatient congenital or pediatric cardiac MR appointments from January 1, 2014, through December 31, 2015	$N = 795$	No multivariable adjustment for covariates	[46]—Lu

Table 2. continued

Social determinant(s) of health (SDH)	Study design	Sample size	Notes	Reference number—first author
Poverty/transportation barriers —Significant interaction between region rurality and census-tract poverty in multivariate analysis of one-way drive-time predictors	Population-based, 11-county surveillance system of CHDs in New York, to characterize proximity to nearest pediatric cardiac surgical care center among adolescents 11–19 years old with CHDs	$N = 2522$	Adjusted for 9 covariates	[49]—Sommerhalter
Poverty/educational attainment/transportation barriers —Median income below 25th percentile ($P = 0.03$) and less than college education ($P = 0.03$) associated with non-attendance at neurodevelopmental follow-up clinic —Residing ≥200 miles from surgical center show non-significant trend for non-attendance in multivariate analysis (adjusted OR, 2.86; $P = 0.054$) —Public insurance associated with non-attendance ($P = 0.01$)	Single center retrospective review of survivors of infant (<1 year old) cardiac surgery (4/2011–3/2014) to examine prevalence of neurodevelopmental evaluation	$N = 552$	Adjusted for 20 covariates	[48]—Loccoh
Low income (public insurance) —Medicaid coverage associated with 1.2 adjusted odds of lapsing in (missing) yearly cardiology follow-ups	Single center retrospective review of CHD patients with moderate to severe complexity in large, urban pediatric hospital in Midwest between 2007 and 2011	$N = 1034$	Adjusted for 6 covariates	[45]—Jackson
Low income —Cumulative social risk associated with readmission days for CHD patients with low risk of morbidity by procedure	Single center retrospective review of patients who underwent infant cardiac surgery with CPB	$N = 219$	Adjusted for 6 covariates	[100]—Demianczyk
Low income/transportation barriers —Among publicly insured infants with CHD who require early surgery, many live far away from surgical centers that can provide definitive care, with some demographic and geographic groups at a particular disadvantage	2012 Medicaid Analytic eXtract data from 40 states reviewed for infants with CHD requiring surgery in first year of life	$N = 4598$	Adjusted for 13 covariates	[101]—Woo
Immigration status —Higher appointment no-show rate (16–20%) in cardiology outreach clinic targeting immigrant and resettled refugee community, compared with national benchmark of <10%	Data obtained between 2014 and 2017 from a monthly pediatric cardiology clinic at a Federally Qualified Health Center	$N = 366$	Observational study No statistical analysis	[50]—Agrawal
Neurodevelopmental outcomes and QOL—8				
Poverty —Family's SES not associated with parental stress	Abidin's Parenting Stress Index administered to parents of children 2–12 years old with CHD	$N = 80$	Adjusted for 7 covariates	[55]—Uzark
Parental educational attainment —Lower maternal educational attainment associated with worse outcomes for performance IQ, socialization, adaptive	Prospective study of infants with CHDs who underwent surgical repair in infancy	$N = 94$	Adjusted for 8 covariates	[52]—Majnemer

Table 2. continued

Social determinant(s) of health (SDH)	Study design	Sample size	Notes	Reference number—first author
behavior, and cognition at 5 years old after CHD surgery in infancy				
Poverty —Lower SES significantly associated with more perceived cognitive problems in parent proxy-report model	CHD patients (8–18 years old) and their caregivers at Cincinnati Children's Hospital Medical Center completed QoL assessment	$N = 246$	Adjusted for 9 covariates	[102]—Limbers
Low income/parental educational attainment —Lower parental educational attainment and household income associated with less genetic knowledge in parents of children with CHD	Survey of parents between 2005 and 2010 of children (0–20 years old) in the LVOT genetics study at Nationwide Children's Hospital	$N = 287$	Adjusted for 12 covariates	[103]—Fitzgerald-Butt
Poverty/educational attainment/transportation —Lower maternal educational attainment and lower SES (free lunch at school) associated with higher odds of not achieving grade-level proficiency in literacy and math; distance to hospital associated with higher odds (1.8) of not achieving grade-level proficiency in literacy but not math	Data from Arkansas-born children who had CHD surgery at Arkansas Children's Hospital at <1 year old from 1996–2004	$N = 458$	Adjusted for 16 covariates	[51]—Mulkey
Poverty —In multivariate models, lower SES associated with memory and learning impairments	Data were combined from two single-center studies of neurodevelopmental outcomes in critical CHD	$N = 268$	Adjusted for 9 covariates	[104]—Cassidy
Poverty/parental educational attainment —SES and maternal educational attainment not associated with risk of screening positive for autism spectrum disorder in multivariable analyses	Longitudinal study of children with CHD at CHOP who underwent surgical repair between 1998 and 2003	$N = 195$	Adjusted for 11 covariates	[53]—Bean Jaworski
Poverty —Lower family income associated with lower family quality of life	Cross-sectional design study of children (1–3 years old) with CHD or innocent heart murmur at Children's Hospital of Eastern Ontario (CHEO) and McMaster Children's Hospital	$N = 154$	Adjusted for 12 covariates	[54]—Lee
Adult congenital heart disease—19				
Low income/uninsured —Uninsurance and public insurance associated with higher risk of hospital admission via the ED	Patients 12–44 years old with CHD selected from 2000 to 2003 via California Office State Health Planning and Development hospital discharge database	$N = 9017$	Adjusted for 19 covariates	[56]—Gurvitz
Parental educational attainment —Low parental educational attainment associated with significantly lower mean scores for purpose of life	Survey (sociodemographic and psychological well-being) of 380 patients from Adult Congenital Heart Clinic in Calgary, Alberta, Canada	$N = 380$	Adjusted for 12 covariates	[68]—Balon
Low income —Public insurance associated with death after ACHD surgery in bivariate analysis	Analysis of Pediatric Health Information System (PHIS) from 2000 to 2008 to identify adult congenital heart surgery admissions	$N = 97,563$	Adjusted for 31 covariates	[58]—Kim

Table 2. continued

Social determinant(s) of health (SDH)	Study design	Sample size	Notes	Reference number—first author
Low income —Public insurance associated with high inpatient resource utilization, which was associated with higher death rates	Analysis of PHIS from 2000–2008 to identify adult congenital heart surgery admissions	$N = 97,563$	Adjusted for 9 covariates	[59]—Kim
Low income/uninsured —Higher proportions of uninsured and publicly insured admitted to hospital from ED vs. those with private insurance —Publicly insured costs significantly lower than privately insured	California State Inpatient Databases 2005–2009 used to conduct retrospective study on inpatient admissions of CHD patients 10–29 years old and all patients of same age	$N = 1,202,652$	No multivariable analysis of ED admissions Cost analysis: adjusted for 7 covariates	[65]—Lu
Poverty/low income —Low family income and public insurance associated with high inpatient resource use	Population-based retrospective study via Nationwide Inpatient Sample 2005–2009 examining ACHD surgical admissions in 3120 hospitals for patients 18–49 years old	$N = 16,231$	Adjusted for 18 covariates	[64]—Bhatt
Transportation barrier —Increased distance of patient's home to specialty center associated with performing ACHD surgery (for those with moderate or complex CHD) outside an ACHD specialty center (with 88% having very low surgical volume)	Retrospective population analysis used California's Office of Statewide Health Planning and Development's discharge database to analyze ACHD cardiac surgery outcomes (in patients 21–65 years old) in California from 2000 to 2011	$N = 4611$	Adjusted for 8 covariates	[71]—Fernandes
Uninsured —Uninsured ACHD patients had increased rates of loss to follow-up and decreased successful transfer of care from pediatric to adult congenital cardiology	Single-institution review of patients >18 years old with CHD seen by pediatric cardiology from 2002 to 2007 and their follow-up visits from 2008 to 2011	$N = 916$	Adjusted for 8 covariates	[66]—Bohun
Uninsured —Uninsurance associated with significantly higher likelihood of being lost to follow-up	Single-center, cross-sectional study of patients with CHD who had outpatient visits with pediatric cardiology before 18 years old	$N = 306$	Adjusted for 9 covariates	[67]—Goossens
Poverty —Income ≤$30,000 associated with poorer physical quality of life	Cross-sectional study of young adult survivors of CHD—survey of patients from May 2012 to December 2013 to examine quality of life	$N = 218$	Adjusted for 23 covariates	[60]—Jackson
Uninsured —Uninsured patients had lower rates of hospital admission from ED, vs. insured	NEDS (nationwide emergency department sample) database (includes 30 states) review to evaluate trend in ED visits among patients with ACHD from 2006 to 2012	$N = 72,090$	Adjusted for 15 covariates	[105]—Agarwal
Low income —Median annual income <$40,000 and public insurance associated with increased odds of readmission after adult congenital heart surgery	Retrospective cohort study using State Inpatient Databases for Washington, New York, Florida, and California from 2009 to 2011	$N = 9863$	Adjusted for 11 covariates	[57]—Kim
Poverty —Lower parental SES associated with poorer performance on neurocognitive tests	Assessment of neurocognitive function in patients ≥18 years old born with dTGA between 1984 and 1995 ($n = 67$) and matched control group of healthy individuals ($n = 43$)	$N = 110$	Adjusted for 22 covariates	[61]——Kasmi

Table 2. continued

Social determinant(s) of health (SDH)	Study design	Sample size	Notes	Reference number—first author
Low income —Non-significant trend toward public insurance associated with less successful transfer from pediatric to adult care for patients with CHD	Single-center retrospective analysis of patients seen in a dedicated young adult CHD transition clinic from January 2012 to December 2015	$N = 73$	Adjusted for 7 covariates	[106]—Vaikunth
Low income/uninsured —Low SES and being uninsured associated with increased odds of endocarditis-related admissions	Review of National Inpatient Sample (NIS) admission in TOF patients (>18 years old), 2000–2014, examining factors associated with endocarditis admissions	$N = 18,353$	Adjusted for 26 covariates	[62]—Egbe
Low income —Median income ≤$50,000 and public insurance significantly associated with higher rate of post-surgical complications vs. private insurance	ACHD surgery admissions for 18–49 year-olds from the 2005–2009 Nationwide Inpatient Sample database	$N = 16,841$	Adjusted for 27 covariates	[63]—Setton
Poverty/low income/transportation barriers —Lower median household income, public insurance, having PCP, being Philadelphia resident, history of no-show visits, and shorter driving distance significantly associated with clinic non-attendance in bivariable, but not multivariable, analysis	Analysis of patients (≥18 years old) scheduled for ACHD outpatient clinic appointment in Philadelphia and relationship to adverse events over a 3.5-year period	$N = 527$	Appears to have adjusted for 16 covariates but does not state which ones were included in multivariable analysis	[72]—Awh
Educational attainment —Lower educational attainment associated with decreased exercise frequency	Single-center, cross-sectional study of adults ≥18 years old with CHD in the Washington Adult Congenital Heart Program at Children's National Health System seen during September 2015–December 2016 to evaluate factors associated with exercise frequency	$N = 446$	Adjusted for 10 covariates	[69]—Connor
Poverty/uninsured/transportation barriers —ACHD patients with uninsurance, poverty, and lower educational attainment significantly more likely to reside farther away from ACHD center	Geographic information system used to compare sociodemographic characteristics of US residents based on their drive times to an ACHD center	$N = 56$	Adjusted for 5 covariates	[70]—Salciccioli

NEDS nationwide emergency department sample.

stay and higher resource utilization in patients who underwent congenital heart surgery,[39,40] and lower school functioning and QOL.[41]

One study found that lower maternal educational attainment was associated with a lower Mental Developmental Index score in children who underwent the Norwood procedure,[42] but another study found that maternal educational attainment was not associated with neurodevelopmental outcomes in multivariable analyses.[43] Two studies found that distance to the hospital was actually associated with a lower risk of readmission post-operatively.[38,44] One study also found no association of uninsurance with post-surgical outcomes.[44]

Access to care, loss to follow-up, and hospital readmissions

Nine articles examined the association of SDH with access to care, loss to follow-up, and hospital admissions (Table 2). Poverty/low SES, transportation barriers, parental educational attainment, and immigrant status were significantly associated with these outcomes. Eight studies documented significant associations of poverty/low SES with these outcomes, including increased risk of missed appointments, loss to follow-up, and hospital readmissions, as well as increases over time of the proportion of admissions to and bed days in pediatric cardiology specialty-care centers. For example, a study of 1034 patients in a large urban pediatric hospital in the Midwest revealed that Medicaid coverage was associated with a significant higher adjusted odds of missing at least one scheduled annual cardiology clinic follow-up visit.[45] A study of nearly 800 patients showed that Medicaid coverage and lower median household income were associated with double the unadjusted odds of missed appointments for cardiac magnetic resonance imaging.[46] A matched case–control study on risk factors for loss to cardiology clinic follow-up among children and young adults with CHD documented a 1.2 times greater odds of loss to follow-up for every $10,000 reduction in family income.[47]

Two studies examined transportation barriers and found having to travel ≥200 miles was associated with missed appointments (significantly in bivariate analysis, but with a non-significant trend in multivariable analysis),[48] and residence in rural poor communities was associated with the longest mean drive time (69 min) to cardiology clinics.[49] One study of a pediatric cardiology outreach clinic for immigrant and refugees found a no-show rate that was higher than the national benchmark.[50]

Neurodevelopmental outcomes and QOL

Eight articles examined the association of SDH with neurodevelopmental outcomes and QOL in children with CHD and their parents (Table 2). Poverty, parental educational attainment, and transportation barriers were significantly associated with worse neurodevelopmental outcomes and QOL in most studies. Five articles found that poverty/low income was significantly associated with adverse neurodevelopmental or QOL outcomes, including decreased intelligence quotient (IQ), socialization, adaptive behavior, cognition, parental perceived cognitive problems, genetic knowledge, grade-level literacy and math proficiency, memory, and family QOL. For example, an analysis of Arkansas data on children who had CHD surgery at <1 year old found that poverty was associated with double the adjusted odds of not achieving grade-level proficiency in literacy and triple the adjusted odds of not achieving grade-level proficiency in math.[51]

Lower maternal educational attainment was significantly associated with lower child performance IQ, socialization, adaptive behavior, and cognition in one study[52] and with lower grade-level proficiency in literacy in another study.[51] Two studies, however, found no association of maternal educational attainment with grade-level proficiency in math or with screening positive on a measure of autism spectrum disorder.[51,53]

A recent study of 140 parents of young children found that, even when accounting for the severity of the child's CHD defect (ranging from an innocent murmur to CHD treatment necessitating cardiopulmonary bypass), low income was associated with a significantly lower family QOL.[54] Another study found that SES was not associated with parental stress.[55]

One study showed that a greater travel distance to the hospital was associated with double the adjusted odds of not achieving grade-level proficiency in literacy, but no such association was found for math proficiency.[51]

Adult congenital heart disease (ACHD)

Nineteen articles examined associations of SDH with ACHD outcomes. Poverty/low income (13 studies), uninsurance (5 studies), educational attainment (3 studies), and transportation barriers (3 studies) were significantly associated with adverse ACHD outcomes (Table 2). Poverty/low income was significantly associated with a variety of adverse ACHD outcomes, including hospital admissions,[56] hospital readmission[57] and death after ACHD surgery,[58] higher inpatient resource utilization,[59] physical QOL,[60] worse neurocognitive test performance,[61] endocarditis-related hospitalizations,[62] surgical complications,[63] and missed clinic appointments.[64] For example, analyses of national databases documented double the odds of inpatient death for low-income (Medicaid) patients after ACHD surgery[58] and that patients in the lowest income quartile had significantly higher adjusted odds of hospitalization for infective endocarditis vs. the next income quartile.[62]

All five studies on uninsurance found significant associations with adverse ACHD outcomes, including significantly greater odds of hospitalization,[56,65] outpatient loss to follow-up,[66,67] unsuccessful transfer of care from pediatric to adult congenital cardiology care,[66] and hospitalization for infective endocarditis.[62] For example, one study found that uninsured ACHD patients were significantly less likely to have their pediatric care transferred to ACHD cardiologists, at only 8%, and most likely to have no follow-up, at 74%.[66]

Three studies found that ACHD patient educational attainment was significantly associated with adverse ACHD outcomes, including lower purpose-of-life scores,[68] decreased exercise frequency,[69] and residing farther from an ACHD center.[70] Three studies also examined the association of transportation barriers with adverse ACHD outcomes. One found that transportation barriers were significantly associated with performance of ACHD surgery outside of an ACHD specialty center.[71] Another study revealed that uninsurance, poverty, and lower educational attainment were significantly associated with ACHD patients with >6-h drive to the nearest ACHD center.[70] The third study, however, found no association of driving distance with attendance at ACHD outpatient clinic appointments.[72]

DISCUSSION

This systematic review documented that a wide variety of SDH are significantly associated with adverse outcomes across the lifespan of CHD patients, from prenatal diagnosis to ACHD. Indeed, the study findings dramatically underscore that SDH are significantly associated with many of the most important and serious CHD outcomes, including a lower likelihood of prenatal diagnosis, increased CHD incidence, higher infant mortality, worse post-surgical outcomes, greater inpatient resource utilization, more missed clinic appointments, increased loss to follow-up, lower performance IQ, worse cognition, decreased grade-level proficiency in literacy and math, reduced family QOL, a higher risk for ACHD endocarditis, more ACHD hospitalizations and hospital readmissions, unsuccessful transfer of care from pediatric to adult congenital cardiology care, and increased odds of complications and death after ACHD surgery.

These study findings indicate that an urgent priority and one of the most important interventions for CHD patients would be routinely screening for SDH, with referrals to appropriate services for those who screen positive. The study results suggest that this SDH screening and referral should occur in all CHD care settings, including prenatal visits, neonatal intensive care units and pediatric intensive care units, primary-care and specialty practices, and ACHD clinics. Major national organizations, including the American Academy of Pediatrics, American College of Cardiology, American Academy of Family Physicians, and National Academy of Sciences, Engineering, and Medicine, have all endorsed SDH screening and referral to appropriate services.[6,73–76] Research shows that patients and caregivers are comfortable with SDH screening.[73,77–80] A recent study showed that SDH screening and referral can reduce the number of SDH and improve child health.[7]

Parent mentors are an evidence-based intervention that has the potential to prove effective in both reducing SDH and improving outcomes for children with CHD and their families. Parent mentors are a special category of community health workers who already have a child with a particular condition (such as CHD) who then receive training to help other parents with children with that condition, including obtaining appropriate healthcare and addressing SDH. A randomized, controlled trial (RCT) of the effects of parent mentors on children with asthma and their families revealed that parent mentors were associated with significant reductions in wheezing, asthma exacerbations, emergency-department visits, and missed parental work days, while improving parental self-efficacy, and saving money.[81] Another RCT of a parent-mentor intervention to enroll uninsured children documented that parent mentors are significantly more effective than traditional Medicaid/CHIP outreach and enrollment methods in insuring uninsured minority children; obtaining insurance faster; renewing coverage; improving access to primary, dental, and specialty care; reducing unmet needs and out-of-pocket costs; achieving parental satisfaction and care quality; and sustaining long-term coverage; they also saved $6045 per insured child per year, an 850% return on investment.[82] This RCT resulted in federal legislation in the 2018 CHIP Reauthorization bill[83] and $120 million in Centers for Medicare and Medicaid Services funding for parent mentors.[84–86] Thus, parent mentors could analogously prove to be highly effective in addressing SDH in children with CHD and their families.

Study findings on the associations of SDH with ACHD have important implications for practice, research, and policy. CHD has morphed from a critical disease among children to a chronic condition in which the number of ACHD patients (~1.3 million) now exceeds the number children with CHD.[9,58,66] Given that at least 85% of children with CHD survive to adulthood, there is an urgent need to provide high-quality specialty care to the growing ACHD population.[68] Over time, the number of ACHD hospitalizations has doubled, from ~36,000 in 1998 to >72,000 in 2005.[58] Furthermore, the increasing complexity of ACHD has warranted creation of an ACHD subspecialty for centers treating ACHD. SDH screening and appropriate referral to services is thus increasingly critical for ACHD patients. The study results also underscore the importance of consistently considering SES as well as SDH in general when examining health and healthcare outcomes for fetuses, children, and adults with CHD. Furthermore, the study findings suggest that additional research is warranted on the association between SDH and CHD in other developed countries and in developing nations, as well as country comparative studies, particularly regarding the impact of variations in welfare state configurations. Until such research is conducted, caution should be exercised regarding generalizing our study results beyond populations in the US and Canada.

This systematic review revealed several unanswered questions. No published studies were identified on the association of housing instability with CHD outcomes, and a paucity of research was noted on several SDH, including food insecurity, transportation barriers, and lack of health insurance, so more research is need on these topics. The fewest number of studies was noted for fetal diagnosis of CHD, so more investigations are needed of which specific SDH are associated with CHD fetal diagnosis and that provide a deeper exploration for the reasons behind these associations. Although several studies found associations of low maternal educational attainment with infant mortality and other CHD outcomes, only a single study examined paternal educational attainment, so an ongoing unanswered question is whether and how low paternal educational attainment is associated with CHD outcomes.

Based on the findings of this systematic review, a research agenda is proposed. More studies are needed on the unanswered questions noted above. Research is needed on whether multiple SDH are associated with even worse CHD outcomes and how the various SDH might interact. For example, would an uninsured child with household poverty, food insufficiency, and low parental educational attainment be at especially high risk for adverse CHD outcomes? Studies are needed on whether SDH screening and referral to appropriate services results in reduction of SDH and improved outcomes. RCTs are urgently needed of innovative interventions, such as parent mentors, that might eliminate SDH and achieve better outcomes for children and adults with CHDs and their families. More research also is warranted on interventions tailored to reducing SDH for ACHD patients.

CONCLUSION

SDH are significantly associated with adverse outcomes across the lifespan of CHD patients, from prenatal diagnosis to ACHD. The study findings dramatically underscore that SDH are significantly associated with many of the most important and serious CHD outcomes, including a lower likelihood of prenatal diagnosis, increased CHD incidence, higher infant mortality, worse post-surgical outcomes, greater inpatient resource utilization, more missed clinic appointments, increased loss to follow-up, lower performance IQ, worse cognition, decreased grade-level proficiency in literacy and math, reduced family QOL, a higher risk for ACHD endocarditis, more ACHD hospitalizations and hospital readmissions, unsuccessful transfer of care from pediatric to adult congenital cardiology care, and increased odds of complications and death after ACHD surgery. SDH screening and referral to appropriate services has the potential to improve outcomes for CHD patients across the lifespan. RCTs are urgently needed of innovative interventions, such as parent mentors, that might eliminate SDH and achieve better outcomes for children and adults with CHDs and their families.

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AUTHOR CONTRIBUTIONS

All authors made substantial contributions to the study conception and design, acquisition of data, analysis, interpretation of data, drafting the article, and revising the article critically for important intellectual content. Conceptualization: B.D. and G.F.; methodology: B.D., M.G., and G.F.; data curation: B.D., J.H.L., and M.G.; writing: all authors.

ADDITIONAL INFORMATION

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