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## Neighborhood social deprivation and healthcare utilization, disability, and comorbidities among young adults with congenital heart defects: Congenital heart survey to recognize outcomes, needs, and well-being 2016–2019

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### Abstract

**Background:** Research on the association between neighborhood social deprivation and health among adults with congenital heart defects (CHD) is sparse.

**Methods:** We evaluated the associations between neighborhood social deprivation and health care utilization, disability, and comorbidities using the population-based 2016–2019 Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG (CH STRONG) of young adults. Participants were identified from active birth defect surveillance systems in three U.S. sites and born with CHD between 1980 and 1997. We linked census tract-level 2017 American Community Survey information on median household income, percent of 25-year-old with greater than a high school degree, percent of 16-year-olds who are unemployed, and percent of families with children <18 years old living in poverty to survey data and used these variables to calculate a summary neighborhood social deprivation z-score, divided into tertiles. Adjusted prevalence ratios (aPR) and 95% confidence intervals (CI) derived from a log-linear regression model with a Poisson distribution estimated the association between tertile of neighborhood social deprivation

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#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

#### CONFLICT OF INTEREST STATEMENT

None.

and healthcare utilization in previous year (no encounters, 1 and 2 emergency room [ER] visits, and hospital admission), 1 disability, and 1 comorbidities. We accounted for age, place of birth, sex at birth, presence of chromosomal anomalies, and CHD severity in all models, and, additionally educational attainment and work status in all models except disability.

**Results:** Of the 1435 adults with CHD, 43.8% were 19–24 years old, 54.4% were female, 69.8% were non-Hispanic White, and 33.7% had a severe CHD. Compared to the least deprived tertile, respondents in the most deprived tertile were more likely to have no healthcare visit (aPR: 1.5 [95% CI: 1.1, 2.1]), 2 ER visits (1.6 [1.1, 2.3]), or hospitalization (1.6 [1.1, 2.3]) in the previous 12 months, a disability (1.2 [1.0, 1.5]), and 1 cardiac comorbidities (1.8 [1.2, 2.7]).

**Conclusions:** Neighborhood social deprivation may be a useful metric to identify patients needing additional resources and referrals.

### Keywords

comorbidities; congenital heart defect; disability; healthcare utilization; neighborhood deprivation

## 1 | BACKGROUND

Congenital heart defects (CHD) are the most common birth defect, with an estimated prevalence of 1 in 110 live births (Reller et al., 2008). Due to improvements in medical care over the past half century, declining mortality has resulted in an increased proportion of children with CHD surviving into adulthood. Researchers estimate there are 1.4 million adults living with CHD in the U.S. (Gilboa et al., 2016). However, health inequities remain, such as those in mortality by race/ethnicity (Lopez et al., 2020). As greater numbers of individuals with CHD survive into adulthood, identifying health inequities across the lifespan among this growing population may help eliminate differences in health status.

Prior research among individuals with CHD has identified individual-level disparities in health by socioeconomic status (Davey et al., 2021; Yu et al., 2014) and race/ethnicity (Jackson, Harrison, & Keim, 2019; Jackson, Morack, et al., 2019; Lopez et al., 2020). However, fewer studies have examined how the health of individuals with CHD is affected by their neighborhoods. Due to social and historical processes, residential segregation and inequities in resource distribution have differentially sorted individuals into neighborhoods by factors that include race/ethnicity and socioeconomic position (Diez Roux & Mair, 2010; Williams & Collins, 2001). Neighborhoods themselves, via social and physical properties such as the built environment, may influence health behaviors and stress to ultimately affect health outcomes, for example through psychosocial- or stress-related factors, one's ability to engage in protective health behaviors, and the type and quality of healthcare available (Diez Roux & Mair, 2010).

Among children with CHD, a growing body of literature has demonstrated associations between neighborhood social context and health outcomes, such as CHD prevalence (Deguen et al., 2016; Li et al., 2016; Peyvandi et al., 2020), healthcare utilization (Anderson et al., 2018; de Loizaga et al., 2022; Demianczyk et al., 2019), and mortality/survival (Best et al., 2019; Bucholz et al., 2020; de Loizaga et al., 2022; Kucik et al., 2014; Udine et

al., 2021). Research on associations between neighborhood social context and health among adults with CHD, who have greater healthcare needs and a higher prevalence of disability (Downing et al., 2021) and comorbidities (Gurvitz et al., 2020) than the general adult population, is scarce. One study, conducted in a single state, examined healthcare utilization, cardiac-related medical procedures, and adverse outcomes among adults with CHD but could not adjust for individual-level socioeconomic status (Tillman et al., 2021). Therefore, the objectives of this analysis are to examine (1) associations between neighborhood social deprivation and healthcare utilization, disability status, and cardiac and non-cardiac comorbidities among young adults with CHD and (2) whether these associations persist after accounting for individual-level educational attainment and employment status.

## 2 | METHODS

### 2.1 | Data source

We used data from the Congenital Heart Survey To Recognize Outcomes, Needs, and well-being (CH STRONG), a Centers for Disease Control and Prevention (CDC)-funded population based, cross-sectional survey on longer-term outcomes of adults with CHD born between 1980 and 1997 from three sites: Arkansas (AR), Arizona (AZ), and metropolitan Atlanta, Georgia (GA). Methods for sampling and design have been described elsewhere (Farr et al., 2020). Briefly, individuals with CDC-modified *International Classification of Diseases, Ninth Revision* (ICD-9) codes and the British Paediatric Association (BPA) Classification of Diseases diagnosis code extensions between 745.000 and 747.432, excluding minor or unconfirmed CHD codes, were identified in state birth defect surveillance registries. Eligible individuals were recruited from 2016 to 2019 using current contact information ascertained from tracing databases that used information from the birth defects surveillance system and vital records or through contact with an individual's mother. Surveys were mailed to individuals with current contact information ( $n = 6943$  of 9312 eligible individuals). Of those, 1656 returned surveys from 2016 to 2019, for an overall response rate of 17.8% and a survey response rate of 23.9%. Survey data were linked to birth defect surveillance registry information and U.S. census information from respondents' counties of birth and respondents' census-tracts of residence at time of survey. Each address was geocoded to the census tract level through two different services (e.g., Arizona used The Texas A&M geocoder and the Census geocoder). If there was a conflict in geocodes, a third source was used as a tiebreaker (e.g., for Arizona, the Federal Financial Institutions Examination Council (FFIEC) Geocoding/Mapping System). PO boxes and Indian reservation addresses were excluded. CH STRONG was approved by CDC and University of Arkansas for Medical Sciences' Institutional Review Boards. The University of Arizona deferred to the CDC institutional Review Board.

### 2.2 | Neighborhood deprivation

Our exposure of interest was neighborhood social deprivation based on census tract-level information from the 2017 American Community Survey (ACS) of the respondent's census tract at time of survey. We created a neighborhood deprivation index using available indicators available in the data that were relevant to the health of individuals with CHD based on prior literature. Sites extracted the following census-tract level ACS measures to

link to the survey data: median household income (e.g., “income”), percent of 25-year-olds with a high school degree or higher (e.g., “education”), percent of 16-year-olds who are unemployed (e.g., “unemployment”), and percent of families with children <18 years old living in poverty (e.g., “poverty”).

Census-tract level data for this project was collected by sites. Sites submitted data to CDC without census-tract geo-identifiers. Therefore, individuals with the same values for all census tract-level indicators were assumed to belong to the same census tract. As has been done previously (Diez Roux et al., 2001), for each indicator, we calculated the mean and standard deviation across all census tracts and a z-score for each respondent by subtracting the mean from each respondent’s value and dividing by the standard deviation. We multiplied z-scores for income and education by negative one to ensure all indicators had a positive association with increasing neighborhood deprivation. Then, we summed each respondent’s z-scores across indicators to produce the respondent’s neighborhood deprivation z-score. To create our exposure of interest, we categorized respondents into equal tertiles based on their neighborhood deprivation z-score, and assigned values of 1 (lives in the least deprived tertile) to 3 (lives in the most deprived tertile).

### 2.3 | Outcomes

Outcomes of this analysis were self-reported healthcare utilization, presence of a disability, and presence of cardiac and non-cardiac comorbidities at time of survey. For healthcare utilization, we examined the number of office visits with any health care provider in the previous 12 months (0, 1–3, 4; categorized based on the distribution of our sample), most recent cardiology visit (2 years, 3–5 years, or >5 years or none), number of emergency room (ER) visits in the previous 12 months (0, 1, 2), and number of hospital admissions in the previous 12 months (0 or 1).

For disability, CH STRONG respondents were asked a six-item set of Department of Health and Human Services Standard Disability Status Questions which identified individuals who have serious difficulties with hearing; vision even when wearing glasses; cognition (e.g., concentrating, remembering, or making decisions because of a physical, mental, or emotional condition); mobility (e.g., walking or climbing stairs); self-care (e.g., dressing or bathing); and living independently (e.g., doing errands alone because of a physical, mental, or emotional condition). Our outcome variable of disability was created based on the presence of one or more of the disabilities noted above versus none.

A respondent was classified as having one or more cardiac comorbidities if the respondent reported ever being diagnosed with any of the following conditions: congestive heart failure, hypertension, myocardial infarction, or stroke. Non-cardiac related comorbidities were coded similarly, but included one or more of the following conditions: self-reported asthma, cancer, mood disorder or depression, diabetes (type 1 or type 2, excluding gestational diabetes), rheumatologic disease (arthritis, gout, lupus, or fibromyalgia), a current body mass index  $\geq 25$  kg/m<sup>2</sup>, or depressive symptoms (assessed by the Patient Health Questionnaire-2).

## 2.4 | Covariates

Potential confounders included age (19–24, 25–29, and 30–38 years), place of birth (Arizona, Arkansas, or metro Atlanta), sex at birth (male, female), presence of chromosomal anomalies (yes/no), and CHD severity (severe/non-severe). Chromosomal anomalies were identified by BPA codes between 758.000 and 758.999 in birth defects registry data. CHD severity was determined based on CHD reported in the birth defect registry and by using a previously published algorithm (Glidewell 2018), in which severe CHDs are defined as those that typically require surgical intervention in the first year of life. We assessed individual-level socioeconomic status (SES) at survey completion using self-reported educational attainment (<high school education, high school degree or equivalent, >high school education) and employment status (any full-time work, part-time, or none). We assessed early-life SES using information on percent of families with children <18 years old living in poverty within the respondent's birth county, collected from the Decennial Census nearest the respondent's year of birth and categorized into quintiles of increasing deprivation. We assessed rurality of the individual's census tract at survey completion using information on percent of individuals that live in rural areas (>75% = rural, 25%–75% = mixed, or <25% = urban). We assessed health insurance type (none, any private, public only, unspecified), race/ethnicity (Hispanic, non-Hispanic White, non-Hispanic Black, non-Hispanic Other), and place of birth as potential effect modifiers.

## 2.5 | Statistical analysis

We excluded from the analytic sample individuals missing data on any variable of interest except for percent family poverty at birth; those included were compared to those excluded using chi-square tests. We also used chi-square tests to assess differences in covariates by tertile of deprivation. To assess trends in outcomes by increasing tertile of deprivation, we used type 3 analysis likelihood ratio tests. In multivariate analyses, we estimated adjusted prevalence ratios (aPR) and 95% confidence intervals (CI) for each outcome using log-linear regression with a Poisson distribution in the following three models after considering a theoretical directed acyclic graph (Figure S1). Model 1 was an unadjusted model. In model 2, we adjusted for age, sex at birth, place of birth, CHD severity, and presence of chromosomal anomalies. In our final model, model 3, we additionally adjusted for individual-level SES through educational attainment and employment status. When modeling the association between neighborhood deprivation and disability, we did not adjust for individual SES (model 3) due to the possibility of reverse causality. To examine effect modification, we stratified model 3 separately by health insurance type, race/ethnicity, and place of birth. For health insurance type and race/ethnicity, estimates were too imprecise to make meaningful comparisons and results are not shown. In supplemental analyses, we further adjusted model 3 for county-level percent family poverty at birth.

As a sensitivity analysis, to account for clustering by census tract, we also calculated models using generalized estimating equations (GEE) with an exchangeable correlation matrix and robust standard errors. We performed a second sensitivity analysis assessing whether results remained the same after excluding individuals whose surveys were completed by proxies (e.g., a parent or spouse). Finally, we estimated aPRs for associations between our

outcomes and tertiles for each indicator of neighborhood deprivation (i.e., poverty, income, unemployment, and education). All analyses were conducted using SAS 9.4.

### 3 | RESULTS

Of the 1656 individuals who completed a CH STRONG survey, one was missing information on census-tract level indicators of neighborhood deprivation, 176 (10.6%) were missing information on outcomes of interest, 20 (1.4%) were missing data on educational attainment and/or employment status, and 24 (1.6%) were missing data on covariates of interest except quintile of family poverty at birth. In total, we excluded 221 (12.9%) respondents with missing information on variables of interest.

The remaining 1435 respondents were divided into tertiles of deprivation based on the four neighborhood characteristics (Table S1). Of respondents in the analytic sample, 43.8% were less than 25 years old, 54.4% were female, 69.8% were of NH White race/ethnicity, 33.7% had a severe CHD, 10.2% had a chromosomal anomaly, and 55.7% had private insurance (Table S2). Tertile of deprivation was significantly associated with place of birth, race/ethnicity, CHD severity, educational attainment, employment status, and insurance type (Table 1). Respondents residing in census tracts with higher levels of deprivation (tertiles 2 and 3) at survey completion, compared to those living in tertile 1, the least deprived tertile, were born in Arkansas, were of Hispanic ethnicity or NH Black or NH Other race/ethnicity, had a non-severe CHD, had a high school education or less, were unemployed, and had public, unspecified, or no insurance ( $p < .01$  for all).

Increasing tertile of neighborhood deprivation was statistically associated with lack of an office visit in the previous year, 2 ER visits in the previous year, 1 hospital admissions in the previous year, 1 cardiac comorbidities, and 1 non-cardiac comorbidities ( $p < .01$  for all; Figure 1). Outcomes reported were 7.7–15.8 percentage points higher among individuals in tertile 3 compared to those in tertile 1.

Increasing tertile of deprivation was associated with increasing likelihood of having no office visit in the previous 12 months (unadjusted PRs [95% CIs] = 1.3 [0.9, 1.7] and 1.6 [1.2, 2.2], for tertiles 2 and 3 vs. tertile 1, respectively; Table 2). These associations remained after adjusting for age, sex, place of birth, CHD severity, and presence of chromosomal anomalies, but were slightly attenuated after further adjusting for educational attainment and employment status (1.2 [0.9, 1.7] and 1.5 [1.1, 2.1], for tertiles 2 and 3 vs. tertile 1, respectively). We found no statistically significant association between tertile of deprivation and having four or more office visits in the previous 12 months or timing of last cardiology visit.

Neighborhood deprivation was statistically significantly associated with number of ER visits and having one or more hospital admissions in the previous 12 months. In unadjusted models, compared to respondents in tertile 1, respondents in tertile 3, were more likely to have 1 (1.4 [1.0, 1.9]) and 2 or more (1.8 [1.3, 2.5]) ER visits. Associations slightly strengthened for 2 or more ER visits after adjusting for demographic and health characteristics (1.9 [1.4, 2.6]); however, associations slightly attenuated after additionally



adjusting for educational attainment and employment status (1.3 [0.9, 1.8] and 1.6 [1.1, 2.3], respectively). Compared to tertile 1, respondents in tertile 3, the most deprived tertile, were 1.8 [1.2, 2.5] times more likely to have a hospital admission, which was slightly attenuated after adjusting for educational attainment and employment status (1.6 [1.1, 2.3]). Neighborhood deprivation (tertile 3 compared to tertile 1) was also associated with disability (1.2 [1.0, 1.5]), although the lower confidence limit included 1.0.

Neighborhood deprivation was also associated with having cardiac and non-cardiac related comorbidities. Respondents in tertiles 2 and 3 were more likely to have a cardiac (unadjusted PRs 1.8 [1.2, 2.7] and 1.9 [1.3, 2.9]) and non-cardiac related comorbidity (both unadjusted PRs 1.3 [1.1, 1.5]). Associations remained after adjusting for demographic and health characteristics. Associations slightly attenuated after additionally adjusting for educational attainment and employment status (for tertile 2 and tertile 3 respectively, cardiac 1.7 [1.1, 2.5] and 1.8 [1.2, 2.7]; non-cardiac 1.2 [1.1, 1.5] and 1.2 [1.0, 1.4]). When stratifying by place of birth, results were modified for ER visits and hospitalizations only. Compared to individuals who lived in the least deprived areas, individuals in the most deprived areas were more likely to have one ER visit in the past 12 months if born in AZ [2.2 (1.3, 3.9)], but no more likely if born in AR [1.0 (0.6, 1.3)] and GA [1.0 (0.7, 1.5)]. Stratified by place of birth, compared to individuals who lived in the least deprived areas, individuals who lived in the most deprived areas were more likely to have had one or more hospital admission in the past 12 months if born in AZ [2.3 (1.2, 4.5)] and GA [1.8 (1.0, 3.3)], but not in AR [1.0 (0.5, 1.8)].

In a sensitivity analysis, we found point estimates from the GEE models to be almost identical and confidence intervals to be similar or tighter than the original model. Estimates did not differ substantially after adjusting for percent family poverty at birth (Table S3). After excluding individuals with a proxy report, the associations between neighborhood deprivation and having one or more hospital admissions and cardiac-related comorbidities strengthened, while the remaining outcomes did not change considerably (Table S4). Findings for the associations between outcomes and each separate component of neighborhood deprivation can be found in Tables S5–S8.

## 4 | DISCUSSION

This analysis found that young adults with CHD living in the most deprived neighborhoods reported poorer health outcomes compared to those living in the least deprived neighborhoods. Specifically, living in the most deprived neighborhood was associated with a 20%–80% relative increase in prevalence of having no office healthcare visits in the previous 12 months, use of emergency care in the previous 12 months, hospital admission in the previous 12 months, disability, and presence of cardiac and non-cardiac-related comorbidities, independent of individual educational attainment and employment status. These findings suggest that individuals living in the most deprived neighborhoods may not be receiving preventative outpatient care and, as a result, may utilize emergency care and hospitalizations more often. While these associations were typically strongest among individuals living in the most deprived neighborhoods, tertile 3, prevalence of cardiac and non-cardiac comorbidities was also elevated among individuals living in tertile 2.

Our results align with one other study among adults with CHD living in Colorado that also examined neighborhood deprivation and healthcare utilization and cardiac-related comorbidities. Similar to this study, the authors found that, compared to individuals living in the least deprived census tracts, individuals living in more deprived census tracts had increased odds of hospitalization, emergency department visit, cardiac events, and comorbidities, such as heart failure (Tillman et al., 2021). However, unlike the present study, the authors were unable to adjust for individual SES. Additionally, previous research among children with CHD has found associations between neighborhood deprivation and healthcare utilization. A study using data from the Pediatric Health Information System of 86,104 children with CHD undergoing cardiac surgery found patients from the lowest income neighborhoods had greater odds of mortality, longer hospital stays, and higher total inpatient hospital costs (Anderson et al., 2018). A single center study among 219 infants with CHD who underwent cardiac surgery found that infants with high cumulative social risk (defined as two or more of the following: non-White race/ethnicity, 40% or greater regional poverty level using patient zip code, Medicaid/CHIP health insurance, maternal age at time of birth less than 21 years of age, non-English primary parental language, and greater than 25 miles to cardiac outpatient clinic) had more readmission days than infants with low social risk (Demianczyk et al., 2019).

Prior research among children and adults with CHD has also found an association between neighborhood deprivation and distance to care, a barrier to healthcare access and utilization. A study using population-based data from 11 counties in New York among 2522 adolescents with CHD found participants living in rural, high poverty census tracts had the longest drive time to the nearest pediatric cardiac surgical care center (Sommerhalter et al., 2017). In this study, we found greater rurality in census tracts with higher neighborhood deprivation, with 28.7% and 21.8% of individuals in tertiles 2 and 3, respectively, living in rural census tracts, compared to 4.5% of participants in tertile 1, the least deprived tertile. However, our results did not change after adjusting for rurality. Future researchers may consider examining how living in a rural or urban area influences the association between neighborhood deprivation and outcomes among individuals with CHD.

In our study, greater percentages of Hispanic, non-Hispanic Black, and non-Hispanic Other individuals and greater percentages of individuals with public, unspecified, or no insurance lived in census tracts with more deprivation. We were unable to examine effect modification by these variables due to low sample size for some groups. Understanding whether insurance type and race/ethnicity modify the association between neighborhood deprivation and outcomes among individuals with CHD may provide insight into potentially modifiable social determinants of health, in the case of insurance type, and potentially unmeasured social determinants of health, in the case of race/ethnicity.

Documenting neighborhood deprivation within the electronic health record, alongside or in lieu of individual-level indicators of SES, may be useful to clinicians, healthcare systems, and public health practitioners in understanding the unique needs of their patient population and identifying patients at risk of adverse health outcomes and increased barriers to care (Johnson et al., 2021). Clinicians may find indicators of neighborhood deprivation useful for identifying patients with CHD who may need additional screening for unmet social



needs and referral to community services and social programs, or whether screening of all patients is warranted if most come from neighborhoods with higher deprivation. Further, these neighborhood deprivation indicators have the potential to be transformed into ICD-10 Z-codes and integrated into the medical record. However, to be useful, Z codes must be commonly (Truong et al., 2020) and accurately (Vest et al., 2021) documented. Further, considerations to ensure that this information does not promote stigma, stereotyping, or discrimination by clinicians may help prevent disparities in healthcare.

The strengths of this study are in our use of population-based data of over 1400 individuals identified through active ascertainment birth defects surveillance systems near the time of birth. This methodology enabled us to capture information from the entire CHD population, including individuals who were not receiving healthcare. The self-reported nature of this data allows us to understand perceived health and well-being and collect information rarely found in the medical record, such as educational attainment and work status. However, all outcomes were self-reported and not confirmed by medical records. We also did not have information on the reason for hospital admission or ER visit. Further, we do not have information on whether the reported disability was a short or long-term disability, nor whether these young adults' employment status was affected by their enrollment in higher education. We also did not have relational geographic information and were unable to account for the proximity of census tracts to one another, since census tracts closer to each other may be more similar than those farther away. Personally identifiable data, including current state of residence, was not shared between sites and CDC and place of birth was not equivalent to current residence. Therefore, interpretation of differences in associations by place of birth are limited. Finally, we identified common census tracts by assuming census tracts with the same values for all four continuous neighborhood deprivation indicators represented the same census tract.

In summary, this study found individuals with CHD living in census tracts of greater deprivation had fewer office healthcare visits in the previous 12 months, greater use of emergency care in the previous 12 months, more hospital admissions in the previous 12 months, disability, and greater presence of cardiac and non-cardiac related comorbidities, independent of individual educational attainment and employment status. Neighborhood deprivation may be a useful metric by which clinicians, healthcare systems, and public health practitioners can identify patients who may need additional resources and referrals.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## ACKNOWLEDGMENTS

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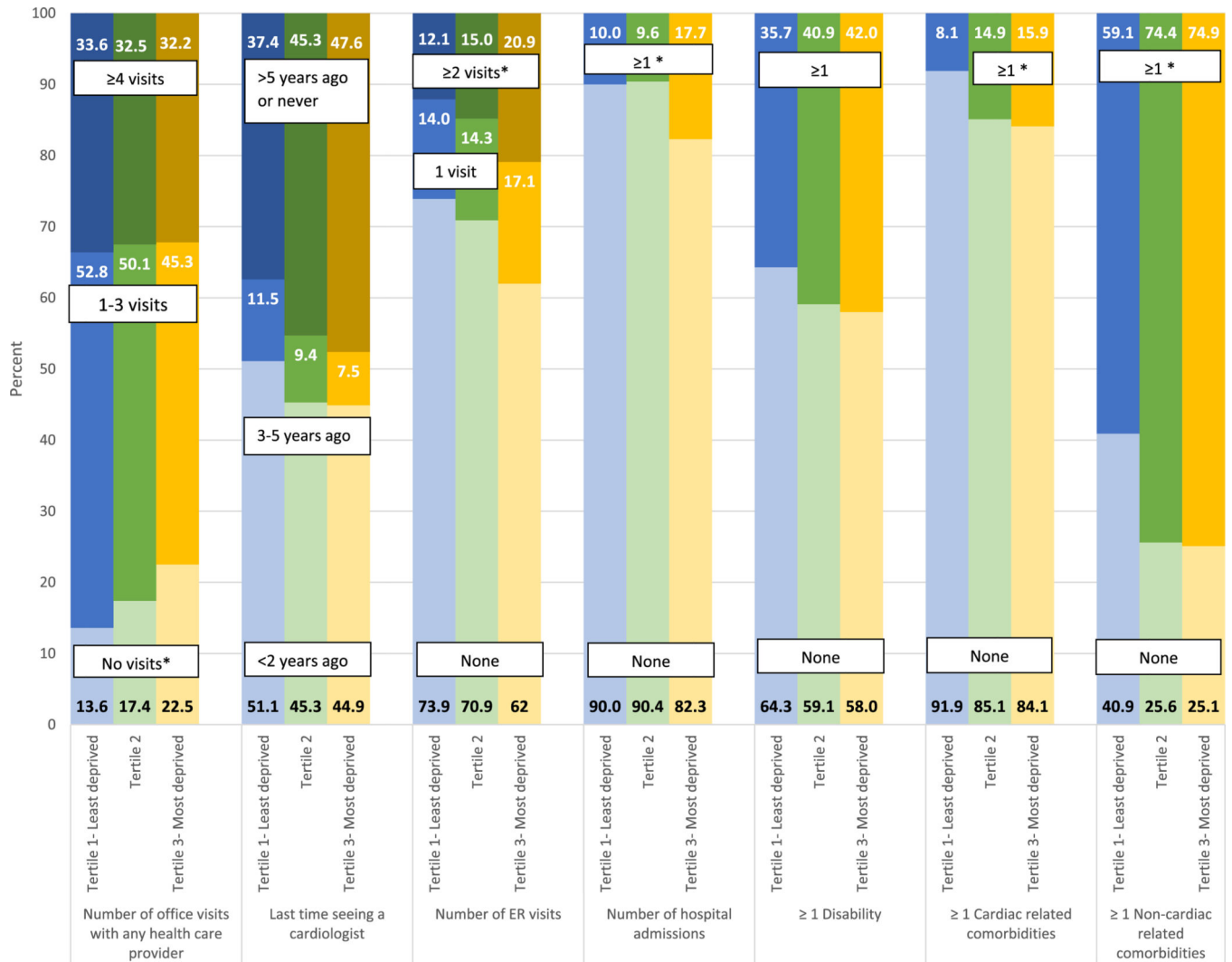
## DATA AVAILABILITY STATEMENT

Requests to access the data set from qualified researchers trained in human subject confidentiality protocols may be sent to the Centers for Disease Control and Prevention (CDC) at [chstrong@cdc.gov](mailto:chstrong@cdc.gov).

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**FIGURE 1.** Prevalence of healthcare utilization by tertile of neighborhood deprivation, CH STRONG 2016–2019. CH STRONG, Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG; ER, emergency room. \*Likelihood ratio *p*-value < 0.01.

Prevalence of demographic and health characteristics by tertile of neighborhood deprivation among young adults with congenital heart defects, CH STRONG, 2016–2019.

TABLE 1

Characteristic	Levels	Tertile 1-lowest deprivation		Tertile 2		Tertile 3-highest deprivation		p-value
		N	Percent	N	Percent	N	Percent	
Total		479	33.3	477	33.3	479	33.3	
Age at survey completion (years)	19–24	213	44.5	202	42.3	213	44.5	.83
	25–30	186	38.8	200	41.9	184	38.4	
	31–38	80	16.7	75	15.7	82	17.1	
Place of birth	Arizona	181	37.8	134	28.1	123	25.7	<.001
	Arkansas	105	21.9	221	46.3	224	46.8	
Sex at birth	Metropolitan Atlanta	193	40.3	122	25.6	132	27.6	
	Male	227	47.4	228	47.8	200	41.8	.11
Chromosomal anomalies	Female	252	52.6	249	52.2	279	58.2	
	No	428	89.4	427	89.5	434	90.6	.79
CHD severity	Yes	51	10.6	50	10.5	45	9.4	
	Severe	177	37.0	172	36.1	135	28.2	.007
Educational attainment	Non-severe	302	63.0	305	63.9	344	71.8	
	<HS	33	6.9	27	5.7	50	10.4	<.001
Employment history in the previous 12 months	HS or equivalent	101	21.1	145	30.4	163	34.0	
	>HS	345	72.0	305	63.9	266	55.5	
% of families living in poverty in county at birth	None	93	19.4	98	20.5	161	33.6	<.001
	Any full time	241	50.3	266	55.8	222	46.3	
Insurance type	Part time only	145	30.3	113	23.7	96	20.0	
	Quintile 1-least deprived	113	24.7	87	19.6	60	13.4	<.001
	Quintile 2	89	19.4	76	17.1	67	14.9	
	Quintile 3	124	27.1	116	26.1	82	18.3	
	Quintile 4	70	15.3	88	19.8	109	24.3	
Any private	Quintile 5-most deprived	62	13.5	77	17.3	131	29.2	
	None	23	4.8	48	10.1	59	12.3	<.001
		333	69.5	264	55.3	203	42.4	

Characteristic	Levels	Tertile 1-lowest deprivation			Tertile 2			Tertile 3-highest deprivation			p-value
		N	Percent	N	Percent	N	Percent	N	Percent		
Race/ethnicity	Public only	66	13.8	106	22.2	138	28.8				
	Unspecified	57	11.9	59	12.4	79	16.5				
	Hispanic	34	7.1	41	8.6	71	14.8				<.001
Survey completed by a proxy	Non-Hispanic White	398	83.1	357	74.8	246	51.4				
	Non-Hispanic Black	27	5.6	47	9.9	117	24.4				
	Non-Hispanic Other	20	4.2	32	6.7	45	9.4				
No	Yes	98	20.5	90	18.9	90	18.8				.76
	381	79.5	387	81.1	389	81.2					
	Rural	21	4.4	135	28.3	106	22.1				<.001
% of individuals that live in rural areas <sup>a</sup>	Mixed	61	12.7	58	12.2	52	10.9				
	Urban	397	82.9	284	59.5	321	67.0				

Abbreviations: CH STRONG, Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG; CHD, congenital heart defect; HS, high school.

<sup>a</sup>At the census tract-level at survey completion.



**TABLE 2**  
Crude and adjusted associations between tertile of neighborhood deprivation and healthcare utilization, disability, and comorbidities, CH STRONG 2016–2019.

Outcome	Levels	Tertile 2 (REF Tertile 1-least deprived)			Tertile 3-most deprived (REF Tertile 1-least deprived)		
		Model 1	Model 2 <sup>a</sup>	+Model 3 <sup>b</sup>	Model 1	Model 2 <sup>a</sup>	+Model 3 <sup>b</sup>
Number of office visits with a healthcare provider in previous 12 months	None	1.3 (0.9,1.7)	1.3 (0.9,1.8)	1.2 (0.9,1.7)	1.6 (1.2,2.2)	1.6 (1.2,2.3)	1.5 (1.1,2.1)
	1–3	-	-	-	-	-	-
	4	1.0 (0.8,1.3)	1.0 (0.8,1.3)	1.0 (0.8,1.3)	1.1 (0.9,1.3)	1.1 (0.8,1.3)	1.0 (0.8,1.3)
Last time seeing a cardiologist	2 years	-	-	-	-	-	-
	3–5 years	0.9 (0.6,1.4)	0.9 (0.6,1.3)	0.9 (0.6,1.3)	0.8 (0.5,1.2)	0.7 (0.4,1.1)	0.7 (0.5,1.1)
	>5 years or never	1.2 (1.0,1.4)	1.2 (0.9,1.4)	1.1 (0.9,1.4)	1.2 (1.0,1.5)	1.1 (0.9,1.4)	1.1 (0.9,1.4)
Number of ER visits in previous 12 months	None	-	-	-	-	-	-
	1	1.1 (0.8,1.5)	1.1 (0.8,1.5)	1.1 (0.8,1.5)	1.4 (1.0,1.9)	1.4 (1.0,1.9)	1.3 (0.9,1.8)
	2	1.2 (0.9,1.7)	1.3 (0.9,1.8)	1.2 (0.9,1.7)	1.8 (1.3,2.5)	1.9 (1.4,2.6)	1.6 (1.1,2.3)
Number of hospital admissions in previous 12 months	None	-	-	-	-	-	-
	1	1.0 (0.6,1.4)	1.0 (0.6,1.4)	0.9 (0.6,1.4)	1.8 (1.2,2.5)	1.8 (1.3,2.6)	1.6 (1.1,2.3)
	Disability <sup>c</sup>	-	-	-	-	-	-
Cardiac related comorbidities	1	1.1 (0.9,1.4)	1.2 (0.9,1.4)	-	1.2 (1.0,1.4)	1.2 (1.0,1.5)	-
	None	-	-	-	-	-	-
	1	1.8 (1.2,2.7)	1.8 (1.2,2.6)	1.7 (1.1,2.5)	1.9 (1.3,2.9)	2.0 (1.4,3.0)	1.8 (1.2,2.7)
Non-cardiac related comorbidities	None	-	-	-	-	-	-
	1	1.3 (1.1,1.5)	1.3 (1.1,1.5)	1.2 (1.1,1.5)	1.3 (1.1,1.5)	1.3 (1.1,1.5)	1.2 (1.0,1.4)

Abbreviations: CH STRONG, Congenital Heart Survey To Recognize Outcomes, Needs, and well-being; CI, confidence interval; ER, emergency room; PR, prevalence ratio; SES, socioeconomic status.

<sup>a</sup> Adjusted for age, sex, place of birth, presence of chromosomal anomalies, congenital heart defect severity.

<sup>b</sup> Additionally adjusted for educational attainment and employment history.

<sup>c</sup> We did not adjust for individual SES (model 3) due to the possibility of reverse causality.