Effect of Acculturation and Distance From Cardiac Center on Congenital Heart Disease Mortality

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WHAT’S KNOWN ON THIS SUBJECT: Disparities in outcomes of ethnic minority children have been reported, and have been ascribed to having barriers to access to health care. Minority parents have indicated that difficulties in access are because of problems with transportation and being non-English speaking.

WHAT THIS STUDY ADDS: This population-based study of Texas infants with severe congenital heart disease reports that neither home distance from a cardiac center nor Hispanic children having a Latin American–born parent were risk factors for first-year mortality.

abstract

BACKGROUND AND OBJECTIVE: Despite improvements in congenital heart disease (CHD) survival over the past 4 decades, ethnic disparities persist. Several studies have shown higher postoperative CHD adjusted mortality in black and Hispanic children. Others noted that non–English-speaking language at home was associated with appointment noncompliance, which the parents attributed to misunderstanding and living too far from a health center. The purpose of this study was to determine the effect of home distance to a cardiac center, or having a Latin American–born parent, on first-year mortality in infants with severe CHD.

METHODS: Infants with severe CHD, having an estimated first-year mortality >25%, born 1996–2003, were identified from the Texas Birth Defects Registry and linked to state and national vital records. We examined the effects of defect type; birth weight; gestational age; extracardiac anomalies; infant gender; maternal race/ethnicity, marital status, and education; residence in a Texas county bordering Mexico; home distance to cardiac center; and parental birth country on first-year survival.

RESULTS: Overall first-year survival was 59.9%, and no race/ethnic differences were noted; however, survival was significantly (P < .05) lower for Hispanic infants with hypoplastic left heart syndrome. Neither home distance to a cardiac center nor parental birth country was related to first-year survival; however, survival was noted to be lower in Texas counties bordering Mexico, counties that have high rates of poverty.

CONCLUSIONS: Further studies are needed to determine if these disparities in survival of infants with severe CHD are attributable to delays in referral to a cardiac center. Pediatrics 2012;129:1–7
Congenital heart disease (CHD) is a leading cause of mortality in childhood. Despite improvement in CHD survival over the past 4 decades, ethnic disparities in outcome continue. In 2001, Boneva et al reported mortality from CHD declined by 39% between 1979 and 1997 in the United States, but they noted mortality among black patients was 19% higher than among white patients. Gilboa and coworkers reported CHD mortality between 1989 and 2006 declined further by 24%. Overall first-year CHD mortality rates for non-Hispanic black (NH-black) infants were 40% higher and for Hispanic infants 4% higher than non-Hispanic white (NH-white) infants. Oster et al reported that in-hospital CHD post-operative mortality in 41 children’s hospitals was 27% higher for NH-black and 22% higher for Hispanic infants compared with NH-white infants, after adjusting for surgical complexity and insurance type. Other investigators have also shown ethnic disparities in mortality after CHD surgery after adjusting for surgical complexity and have proposed that unequal access to cardiac specialty care plays an important role in these differences. None of the post-surgical studies was population based, however, and hence could not account for mortality before referral or for patients not having had surgery. Nembhard and coworkers reported in their population-based study of Texas CHD births, that Hispanic children with pulmonary valve atresia and intact ventricular septum (PA-IVS) had a 76% higher mortality risk and those with hypoplastic left heart syndrome (HLHS) a 51% higher risk than NH-white children over the first 5 years of life. A similar study of Texas patients with functional single ventricle (SV) found a higher mortality in Hispanic children and in patients who resided in counties bordering Mexico, areas where cardiac surgical centers are relatively distant and where more than 60% speak Spanish at home. Flores et al in their study of disparities in children’s health care, noted that a non-English primary language at home was associated with the parents not bringing the child in for care, which the parents reported was because of the medical staff not understanding the family’s culture and because the health facility was too far away. Yu et al suggested that using birth country of parents may reflect barriers to health care access, which incorporates language as well as other cultural aspects.

To our knowledge, no previous report has studied parental acculturation and home proximity to a cardiac specialty center as risk factors for mortality in infants with CHD. Because Texas has a large Hispanic population dispersed throughout a large geographic area, it provides a basis to determine the extent these and other demographic factors affect survival in infants born with severe CHD. We selected cases from the Texas Birth Defects Registry having estimated first-year mortality >25% with the diagnoses of HLHS, SV, PA-IVS, pulmonary valve atresia with ventricular septal defect (PA and VSD), tricuspid atresia (TA), interrupted aortic arch (IAA), Ebstein’s malformation of the tricuspid valve, and truncus arteriosus. The primary purpose of this study was to determine the effect of parental birth country, a proxy measure of family acculturation, as well as residence distance to the cardiac center of care, on first-year survival in these high-risk infants.

**METHODS**

Data on infants came from the Texas Birth Defects Registry maintained by the Birth Defects Epidemiology and Surveillance Branch of the Texas Department of State Health Services. This population-based active registry collects information on major birth malformations in offspring of Texas resident mothers. During this study period, the registry covered 35% of Texas resident live births in 1996, 56% in 1997, 85% in 1998, and 100% in 1999–2003. The staff of this active surveillance system visited delivery units, pediatric hospitals, birthing centers, and midwife personnel in the state to identify cases among all types of pregnancy outcomes and abstract case information from the medical records. Registry infants were linked to their birth and death certificates, as described by Forrester and Canfield. Information on selected sociodemographic factors from vital records (birth and death certificates) was combined with registry medical records. Residence was assigned based on the mother’s reported address at the time of delivery, as determined from vital records or, if absent, from medical records. We chose to study infants with estimated first-year mortality >25%, having the diagnoses of HLHS, SV, PA-IVS, pulmonary valve atresia with ventricular septal defect, tricuspid atresia, interrupted aortic arch, Ebstein’s malformation of the tricuspid valve, and truncus arteriosus, born in Texas between January 1, 1996, and December 31, 2003. Infants with trisomy 13 and 18 were excluded; however, infants with trisomy 21 were not excluded in the analysis. In cases where the records had discrepant diagnoses, priority for reliability was as follows: noncardiologist note<cardiologist note<echocardiographic report<surgery/autopsy report. In 95% of the cases, diagnoses were ascertained from echocardiographic, operative, or autopsy reports. Registry information was reviewed by an experienced pediatric cardiologist (D.E.F.), who verified the diagnoses. Clinical data were not consistently available regarding the timing or type of surgical procedures performed. We ascertained the date of death from the registry records and the Texas death-to-birth-certificate matching performed by the Vital Statistics Unit of the Texas Department of State Health Services. In addition, information on patients not identified as deceased from
Texas vital records was sent to the National Death Index at the National Center for Health Statistics to identify Texas patients who died out of state (17 patients). For any infant not considered deceased, survival time was defined as the time from date of birth to time of censor or the end of the study death surveillance period (December 31, 2005). We examined the effect of demographic variables on survival including maternal race/ethnicity (NH-white, NH-black, and Hispanic), education, and marital status; residence in a Texas-Mexico border county; parental birth country (United States or Latin America [Mexico/ Central America/South America/Cuba/ Puerto Rico]); and distance from residence to the cardiac specialty center where the infant received the most care. Distances were estimated by the Geographic Information System section at the Texas Department of State Health Services by using Centrus Desktop Group 1 Software, version 5.0.0.00M, Centrus Tele Atlas data (build date 9/15/2010; Pitney Bowes Software, Inc, Troy, NY), ArcGIS 9.3, and Esri ArcMap(Esri, Inc, Redlands, CA). The primary cardiac center was identified in 90.2% of cases, and where the center was not identified, the closest cardiac center was selected. We stratified by distance categories based on usual means of transport, namely, land (<50 miles), land/helicopter (50–100 miles), and fixed wing (>100 miles). In 91% of the cases, the straight line distance from maternal residence to the cardiac center could be determined. Birth country for each parent could be determined from birth certificate data in 83.3% of Hispanic, 75.9% of NH-white, and 49.6% of NH-black patients. Infant variables included heart defect diagnosis, gender, birth weight, estimated gestational age, and presence of major extracardiac abnormalities. We calculated descriptive statistics for the main study variables and used the Kaplan-Meier method to determine the pattern of survival within the first year of life. Cox proportional hazards regression (PHREG procedure in SAS 9.2 [SAS Institute, Inc, Cary, NC]) was used to calculate unadjusted and adjusted hazard ratios and 95% confidence intervals. A hazard ratio was considered statistically significant if its 95% confidence interval excluded 1. Multivariable modeling was used to assess the adjusted effect of each factor on survival. Only variables with statistically significant findings ($P < .05$) in the unadjusted analyses were included in the multivariable analyses. The study was approved by the institutional review boards at the University of South Florida, University of Texas Southwestern Medical Center, the National Death Index, and the Texas Department of State Health Services.

**RESULTS**

As shown in Table 1, the total number of selected cases was 1213, with maternal race/ethnic distribution of 38.3% NH-white, 9.5% NH-black, and 52.3% Hispanic. The relatively low frequency of infants born to NH-black mothers was similar to their frequency of 9.6% among 50,268 infants in the Texas Birth Defects Registry born during the same period. Overall first-year survival for all cases was 59.9% and no significant race/ethnic differences were noted (Fig 1); however, for the highest-risk lesions, survival was significantly lower ($P < .05$) for Hispanic infants having HLHS ($P < .05$ and tended to be lower ($P = .10$) for infants having PA-IVS compared with NH-white infants (Table 1). No significant differences in survival were noted between NH-black and NH-white infants for any of the specific diagnoses, but the number of NH-black infants for each diagnosis was small. To validate our mortality statistics for HLHS, we compared our results with that of other population-based studies from a similar time period. The median age of death, 10 days, for HLHS in our study was similar to that reported in Gordon et al’s study,12 12 days (California infants 1995–2004), and in Gilboa et al’s study,2 14 days (US nationwide 1996–2006).

The results of the univariate and multivariate analyses of potential factors associated with first-year mortality are summarized in Table 2. To determine whether the smaller sampling of Texas live births in 1996 (35%) and 1997 (56%) affected the results, we reran the analysis excluding these years and found the findings did not change. After adjusting for defect type, we found infant birth weight, gestational age, and presence of extracardiac birth defects were the major risk factors for early mortality. The only other significant demographic

<table>
<thead>
<tr>
<th>Defect Type</th>
<th>NH-White</th>
<th>NH-Black</th>
<th>Hispanic</th>
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<tbody>
<tr>
<td>n</td>
<td>% Survival (95% CI)</td>
<td>n</td>
<td>% Survival (95% CI)</td>
</tr>
<tr>
<td>HLHS</td>
<td>148</td>
<td>46.6 (38.5–54.8)</td>
<td>29</td>
</tr>
<tr>
<td>IA</td>
<td>27</td>
<td>55.6 (35.5–75.6)</td>
<td>10</td>
</tr>
<tr>
<td>Truncus</td>
<td>51</td>
<td>62.7 (49.0–76.5)</td>
<td>10</td>
</tr>
<tr>
<td>PA-IVS</td>
<td>45</td>
<td>71.1 (57.3–84.9)</td>
<td>13</td>
</tr>
<tr>
<td>PA+VSD</td>
<td>36</td>
<td>75.0 (60.1–89.9)</td>
<td>3</td>
</tr>
<tr>
<td>SV</td>
<td>99</td>
<td>67.7 (58.3–77.1)</td>
<td>29</td>
</tr>
<tr>
<td>Ebstein’s</td>
<td>41</td>
<td>85.4 (74.1–96.7)</td>
<td>10</td>
</tr>
<tr>
<td>TA</td>
<td>17</td>
<td>64.7 (38.4–90.0)</td>
<td>11</td>
</tr>
<tr>
<td>Overall</td>
<td>464</td>
<td>62.1 (57.6–68.5)</td>
<td>115</td>
</tr>
</tbody>
</table>

CI: confidence interval; HLHS, hypoplastic left heart syndrome; Ebstein’s, Ebstein’s malformation of the tricuspid valve; IA, interrupted aortic arch; Truncus, truncus arteriosus; PA-IVS, pulmonary atresia and intact ventricular septum; PA+VSD, pulmonary valve atresia with ventricular septal defect; TA, tricuspid atresia; NA, not applicable; SV, single ventricle.

* P < .01, Hispanic versus NH-white.

* P < .05, Hispanic versus NH-white.

* P < .05, Hispanic versus NH-white.
The factor remaining was having the home located in a county bordering Mexico, all other factors having been taken into account. Because 9.8% of the cases did not have an identifiable cardiac center, we compared these cases with those having a documented cardiac center and found cases without an identified center had a higher mortality, 56.4% compared with 43.7% ($P < .01$) and died earlier; the age at death was 55.4 days compared with 128.7 days ($P < .001$). A higher proportion of cases with residence in a county bordering Mexico had no center identified compared with those in a nonborder county: 23.5% compared with 8.4% ($P < .001$).

We examined whether living a greater distance from the cardiac center was associated with increased risk of death and found overall first-year mortality was not related to the distance to the cardiac center. Looking at specific race/ethnic categories, we found that patients whose residence was 50 to 100 miles, or $>100$ miles from the center did not have a significantly higher risk than those who lived closer (Table 3). We also did not find higher risk for Hispanic patients with HLHS or PA-IVS who lived farther from their cardiac center.

As expected, the frequency of having parents born in Latin America was highest for Hispanic patients, of whom 28.8% had 1 parent and 31.1% had both parents born in Latin America, whereas for NH patients, only 2.9% had 1 or both parents born in Latin America. Analysis of the association between parental birth country and first-year mortality did not reveal a significant increase in risk for Hispanic patients with 1 parent or both parents born in Latin America compared with those with both parents born in the United States (Table 4).

**DISCUSSION**

This population-based study found that overall first-year survival was similar for NH-white, NH-black, and Hispanic...
infants born with severe CHD (Fig 1), in contrast to the reported ethnic disparities in outcomes of adults with coronary disease and in children with chronic disease. The finding of no overall race/ethnic differences in our study may be attributable to the study population being restricted to the first year of life and an expanded group of high-risk lesions, and not being able to take into account several other demographic variables. Several studies have shown that racial/ethnic differences in survival vary by specific diagnoses, regions, family income, and insurance type.2-5 Gonzalez et al4 reported interstate ethnic differences of in-hospital mortality after CHD surgery; for example, compared with NH-white, Hispanic patients had higher mortality risk in New York, but not California. Other studies5,5 using national databases reported higher mortality risks for black and Hispanic children after CHD surgery after adjusting for income, insurance type, and surgical-risk category. These authors speculated that unequal access to specialty care contributed to the disparities in outcome. Yu et al13 showed much of the disparity between Hispanic and NH access to care was attributable to language and not ethnicity. They further proposed that language was a proxy for immigrant status, both of which reflect social, cultural, and economic factors influencing access to care. Data from the Third NHANES showed that 53.8% of first-generation Mexican American children spoke Spanish as their primary language.14 In addition, 30% of parents with poor English proficiency had resided in the United States for more than 10 years, indicating many of these immigrant parents continue to use Spanish in the household. In the greater Boston area study,8 infants of parents who did not speak English well or not at all were at higher risk for adverse health outcomes. In the current study, we were unable to demonstrate an effect of Hispanic parental birth country on overall survival, or in survival of patients with HLHS or PA-IVS. Flores and Tomany-Korman,15 in their analysis of the National Survey of Children’s Health, found that Hispanic parents reported having a problem getting specialty care 60% more frequently than white parents. Data from the 2001 National Survey of Children with Special Health Care Needs showed that non–English-speaking parents were 90% more likely to have an unmet need for family support services, and 60% more likely to have a problem with specialty referrals.15 Previous population-based studies of CHD have reported no ethnic differences in the age at referral or in the age at operation, both of which can be proxy measures for access to pediatric cardiac specialty care. A population-based study of children with CHD born from 1974 to 1984 in Dallas County, Texas, reported the timing of referral for pediatric cardiac care was not related to ethnicity, median family income, or household education.16 Chang and coworkers,17 by using data from California hospital discharges for 1995–1996, found no ethnic differences in age at operation for CHD. In the current study, we documented that 90.2% were seen in cardiac specialty centers, and found no race/ethnic differences in the other 9.8%. Neither did we find any significant race/ethnic differences in the timing of the first postnatal echo-cardiogram, suggesting the ages at diagnoses were similar.

In the greater Boston area study,9 parents who spoke English not very well or not at all reported the health care facility was too far away 4 times more frequently and reported having transportation difficulties 2 to 3 times more frequently than parents who spoke English well. Chang et al17 found no relationship between home distance to the cardiac surgical center and age at operation for CHD. On the other hand, a study of referrals to Tucson cardiac specialists reported nonurban cases were referred at a later age than urban.18 In the current study, we were unable to show a correlation between distance to the cardiac center and first-year overall survival, or for any specific CHD diagnosis.

The strengths of this study are its population-based cohort design, the sizeable proportion of Hispanic patients, and the large number of patients with severe CHD, 1213, ascertained by an active surveillance system, with diagnoses verified by an experienced pediatric cardiologist. It included deaths that occurred before referral to a cardiac center, and those after discharge from the cardiac center. Several limitations of this study should be considered, however. The race/ethnic distribution of this study population differs from that of

<table>
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<tr>
<th>TABLE 3</th>
<th>Effect of Distance to a Cardiac Center on First-Year Mortality by Racial/Ethnic Group, Texas, Infants with Severe CHD 1996–2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distance Type</td>
<td>NH-White (n = 317)</td>
</tr>
<tr>
<td>50–100 miles</td>
<td>11.6 (0.89–3.91)</td>
</tr>
<tr>
<td>&gt;100 miles</td>
<td>1.20 (0.80–1.80)</td>
</tr>
</tbody>
</table>

CI, confidence interval; HR, hazard ratio.

<table>
<thead>
<tr>
<th>TABLE 4</th>
<th>Effect of Parental Birth Country on First-Year Survival in Hispanic Infants With Severe CHD, Texas, 1996–2003</th>
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</thead>
<tbody>
<tr>
<td>Parental Birth Country</td>
<td>NH-White</td>
</tr>
<tr>
<td>Both United States</td>
<td>212</td>
</tr>
</tbody>
</table>

CI, confidence interval.
other regions and the United States in general. The relatively small number of NH-black cases limits the statistical power to show significant differences in outcome in this subgroup. Another limitation is that information on family income and insurance type was not recorded in the registry. A major limitation of this study was that no clinical data were available for review other than that recorded by registry abstractors; hence, information regarding the timing and type of surgery for patients could not be determined, nor could we identify with certainty the patients who were not referred to a cardiac center. In 9.8% of the patients, a cardiac center was not noted in the abstracted records, and although one should not assume they were not referred, these infants had significantly higher mortality and died at an earlier age than those definitely seen at a cardiac center. Another limitation of the study was that in the cases without an identified center, we assigned the closest center for the analyses relating distance to the center and survival. To determine whether these cases modified our findings, we repeated the analyses excluding them, and no significant differences in the results were found.

An interesting finding in this study was the lower first-year survival in patients residing in Texas counties bordering Mexico at birth, even after adjusting for CHD defect type, extracardiac defects, birth weight, and gestational age. Of note, this area had a poverty rate of 27.6%, compared with a statewide rate of 17.1%, and a US rate of 11.9%. In addition, patients from the border counties more frequently had no identifiable referral center, 23.5%, compared with those from nonborder counties, 8.4%, suggesting they may have had a lower rate of referral. Also important, patients without an identified cardiac center had a mortality 30% higher than those with a documented center. Hence, the higher CHD mortality seen in patients from the Texas border counties may reflect their living in poverty and their limited access to specialty care, indicating a need for enhancement of health care delivery in such areas.

CONCLUSIONS

Our study shows that overall first-year mortality was similar for NH-white, NH-black, and Hispanic infants with severe CHD; however, regional differences in CHD mortality were found even after taking into account maternal race/ethnicity, infant risk factors, measures of acculturation, and home distance from a cardiac center. We conjecture that the higher CHD mortality seen in counties bordering Mexico may be attributable to the high rate of poverty in the region and the fear of illegal immigrants to apply for federal assistance, which may have delayed referral to a cardiac center. Further studies of regional differences in CHD mortality is warranted, as the causes of poorer local outcomes could possibly be corrected through improvement in parental health education and enhancement of family support services.

ACKNOWLEDGMENTS

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