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Urban–Rural and Racial Disparities in Paediatric Congenital Heart Disease Mortality in the United States, 1999–2020 : A National Surveillance Study

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Abstract

Background: Pediatric congenital heart disease (CHD) remains a major contributor to mortality in the United States. National trends by geography, sex, and race/ethnicity are not well characterized. This study aimed to identify temporal patterns in CHD-related mortality from 1999–2020 and to quantify disparities across urban–rural residence, sex, and race/ethnicity.

Methods: We analyzed mortality data from the CDC WONDER database to calculate age-adjusted mortality rates (AAMRs), and annual percent changes (APCs) were estimated using Joinpoint regression.

Results: Across the study period, 58,616 CHD-related deaths were recorded. Urban areas showed higher mortality rates than rural areas. Sex-stratified trends demonstrated sharper early declines among urban females (APC −2.51%) and a short-accelerated decline among urban males (APC −5.60%). Rural males and females showed similar long-term declines. Racial patterns revealed sustained reductions across all groups; however, rural White children showed a temporary increase (APC +4.11%), and Black children in both urban and rural areas consistently experienced the highest mortality and slowest improvement.

Conclusions: Pediatric CHD mortality declined nationally from 1999–2020, but improvements were uneven. These findings highlight the need for targeted policy efforts to expand access to specialized cardiac care, optimize referral networks, and strengthen health infrastructure in underserved regions.

Clinical trial number: not applicable.

INTRODUCTION

Congenital heart disease (CHD) represents one of modern medicine's most significant success stories. Once a condition with high early lethality, CHD has seen a dramatic reduction in mortality over the last three decades, driven by advances in prenatal diagnosis, critical care, and surgical interventions.[1,2] In the United States, survival to adulthood is now the expectation rather than the exception, even for complex lesions.[3] However, this aggregate success masks a growing structural divergence. As the management of complex CHD has become increasingly sophisticated, it has also become increasingly centralized.[4] The regionalization of pediatric cardiac surgery to high-volume centers, while necessary for lowering operative mortality, has inadvertently tethered survival outcomes to geography.[4,5] Distance from specialized care has emerged as a potent social determinant of health.[6] Rural populations face documented barriers to access, including delayed prenatal detection of critical defects,[7,8] workforce shortages in pediatric cardiology,[9] and longer transport times for emergency neonatal interventions.[10] Concurrently, racial and ethnic disparities in CHD outcomes remain entrenched. Black and Hispanic children consistently experience higher postoperative mortality and lower long-term survival rates than their White peers, driven by a complex interplay of socioeconomic factors and systemic bias.[2,11] Despite the recognition that both "place" and "race" determine outcomes, few studies have examined their

intersectionality over the long term. Prior analyses have largely assessed rurality or race in isolation, or have relied on short-term snapshots that obscure shifting temporal trends.[12,13] Specifically, it remains unknown whether the rising tide of universal pulse-oximetry screening and standardized surgical protocols has lifted rural and minority children at the same pace as their urban counterparts. We leveraged 22 years of national mortality data from the Centers for Disease Control and Prevention (CDC) to perform a granular intersectional analysis. Unlike previous aggregate studies, we stratified mortality trends by urban–rural residence across race and sex. We aimed to identify specific inflection points that aggregate data might obscure. By defining the specific blind spots in the national decline of CHD mortality, we provide the epidemiological foundation necessary to target future policy interventions.

METHODS

Study Data and Population

We queried the Centers for Disease Control and Prevention Wide-Ranging Online Data for Epidemiologic Research (CDC WONDER) Multiple Cause of Death database to identify CHD-related mortality. The study period spanned from 1999 to 2020. We identified all decedents aged 0 to 14 years where the underlying cause of death was listed as a congenital malformation of the circulatory system, defined by the International Classification of Diseases, 10th Revision (ICD-10) codes Q20 to Q28. These codes represent the standard surveillance definition for congenital heart defects in national mortality analyses. As this study utilized de-identified, publicly available aggregate data, the Institutional Review Board deemed it exempt from review.

Variables and Geographic Classification

The primary exposure of interest was residence at the time of death. We utilized the 2013 National Center for Health Statistics (NCHS) Urban–Rural Classification Scheme, aggregating county-level data into a binary classification: "Urban" (Large Central Metro, Large Fringe Metro, Medium Metro, and Small Metro) and "Rural" (Micropolitan and Non-Core). We stratified mortality trends by age group (< 1 year, 1–4 years, and 5–14 years), sex, and race/ethnicity within these urban and rural categories. Racial categories included Non-Hispanic White, Non-Hispanic Black, Hispanic/Latino, and Asian/Pacific Islander. American Indian/Alaska Native populations were excluded from trend analyses due to unreliable rate estimates.

Statistical Analysis

We calculated age-adjusted mortality rates (AAMRs) per 100,000 population, standardized to the 2000 U.S. Standard Population. To characterize temporal trends, we employed the Joinpoint Regression Program Version 5.4.0 (National Cancer Institute). This methodology fits a log-linear model to the data, using Monte Carlo permutation tests to identify the minimum number of inflection points (joinpoints)

required to describe significant changes in the trend slope. We report trends as the Annual Percent Change (APC) and 95% confidence intervals (CIs) for each segment. Statistical significance was defined as a two-sided p-value < 0.05.

RESULTS

Overall and Geographic Trends

Across the 22-year study period, we identified 58,616 pediatric deaths attributed to congenital heart disease. The overall AAMR demonstrated a significant national decline, dropping from 5.4 per 100,000 (95% CI: 5.2–5.6) in 1999 to 3.3 per 100,000 (95% CI: 3.2–3.5) in 2020. While urban counties accounted for the majority of absolute deaths (84.2%, n = 49,338), rural counties consistently exhibited higher mortality burdens throughout the entire study period. In 1999, the rural AAMR was 6.2 per 100,000 (95% CI: 5.6–6.7) compared to 5.4 in urban areas; by 2020, these rates had fallen to 4.1 (95% CI: 3.7–4.6) and 3.4, respectively, indicating a persistent survival disadvantage for rural children. **(**Fig. 1**)**

Joinpoint analysis revealed distinct temporal patterns by residence. Urban mortality declined in three phases: a moderate reduction from 1999 to 2007 (APC − 1.91%), a precipitous drop between 2007 and 2010 (APC − 4.87%), and a steady but slower decline from 2010 to 2020 (APC − 1.00%). In contrast, rural mortality followed a linear trajectory, declining at a constant annual rate of − 1.58% without significant inflection points.

Sex-Stratified Mortality

Male children experienced higher aggregate mortality than females in both geographic settings. In urban areas, the overall AAMR for males was 4.4 (95% CI: 4.4–4.5) compared to 4.1 (95% CI: 4.0–4.1) for females. A similar disparity was observed in rural areas, where the male AAMR was 5.2 (95% CI: 5.0–5.3) compared to 4.6 (95% CI: 4.5–4.8) for females. When stratified by time, urban males experienced a volatile trajectory characterized by a distinct period of accelerated improvement between 2007 and 2010, where mortality plummeted by 5.60% annually. Following this sharp reduction, the decline in urban male mortality plateaued to − 1.09% per year. **(**Fig. 2**)** Conversely, rural trends showed no such variability; rural males and females experienced nearly identical, linear rates of decline over the two decades (APC − 1.61% and − 1.57%, respectively).

Racial and Ethnic Disparities

Racial disparities remained entrenched across all geographic classifications. In urban settings, Non-Hispanic Black children exhibited the highest aggregate mortality (AAMR 5.9), followed by Hispanic (4.2), White (3.8), and Asian/Pacific Islander children (3.3). Although White children accounted for the largest proportion of urban deaths (46.3%), followed by Hispanic (25.8%) and Black (22.2%) children, the latter group experienced the highest risk per capita. Urban trend analysis showed that Black and Hispanic populations experienced steady linear declines (APC − 1.99% and − 1.96%, respectively),

whereas Urban White children followed a biphasic pattern, with a rapid decline until 2013 (APC − 2.84%) that significantly slowed thereafter (APC − 1.18%).

Rural populations displayed a unique and concerning anomaly among White children. While rural Black and Hispanic children saw consistent linear improvements (APC − 2.23% and − 2.18%, respectively), rural White children experienced a statistically significant reversal in progress. After an initial decline from 1999 to 2008 (APC − 3.47%), mortality among rural White children significantly increased by 4.11% annually between 2008 and 2011, before resuming a decline of − 2.13% through 2020. This transient spike was exclusive to the rural White population, which comprised 69.7% of total rural deaths (compared to 12.3% for Black and 11.9% for Hispanic children). **(**Fig. 3**)**

Age Distribution

Mortality was overwhelmingly concentrated in the first year of life. Infants (< 1 year) accounted for 83.3% of urban deaths and 83.4% of rural deaths. The crude mortality rate for rural infants was 64.0 per 100,000 (95% CI: 62.6–65.4), markedly higher than the urban infant rate of 54.9 (95% CI: 54.4–54.5). Survival improved drastically after infancy, with mortality rates dropping by an order of magnitude in the 1–4 year age group (Urban: 1.6; Rural: 1.9) and further in the 5–14 year age group (Urban: 0.4; Rural: 0.5).

DISCUSSION

Our analysis of 22 years of U.S. mortality data confirms a persistent rural penalty in pediatric congenital heart disease. While national mortality rates have significantly declined, the benefits of modern cardiac care have not accrued equally. Urban children experienced rapid, stepwise improvements, characterized by a precipitous 5.6% annual decline in males between 2007 and 2010, whereas rural children experienced a slower, linear decline that left them with a persistent survival disadvantage. Most concerningly, we identified a statistically significant reversal in progress among rural White children during the years surrounding the Great Recession (2008–2011), a finding that highlights the fragility of health outcomes in the face of economic instability.

The persistent disparity between urban and rural mortality (AAMR 3.4 vs. 4.1 in 2020) likely reflects structural barriers to specialized care. The difference in Joinpoint trends suggests that urban centers benefit rapidly from the adoption of new technologies and protocols, while these advancements trickle down to rural areas with significant latency.[10]10 For instance, the detection of critical CHD (CCHD) relies heavily on prenatal ultrasound and postnatal pulse-oximetry screening.[14,15] Research indicates that rural populations have lower rates of prenatal detection,[7] often due to a lack of local expertise or access to fetal echocardiography.[8] Consequently, rural infants with ductal-dependent lesions may present in extremis or die before transport to a surgical center.[6] Furthermore, the shortage of pediatric cardiologists in rural counties,[9] combined with the closure of rural labor and delivery units, exacerbates these delays.[16]

A unique finding of this study was the transient but significant increase in mortality (APC + 4.11%) among rural White children from 2008 to 2011. This period coincides exactly with the Great Recession and its immediate aftermath. While economic downturns typically lower aggregate adult mortality (due to reduced industrial accidents and pollution),[17] their impact on pediatric health is deleterious. Finch et al. demonstrated that recession-related stressors are linked to adverse birth outcomes.[18] We hypothesize that the rural White population, which may have relied on employer-sponsored insurance that evaporated during the recession, faced acute disruptions in access to care.[19] In contrast, rural Black and Hispanic populations, who historically have higher baseline reliance on safety-net programs like Medicaid/CHIP,[19,20] may have been partially insulated from this specific insurance shock, maintaining their (albeit higher) baseline mortality trajectory. This anomaly highlights that economic shocks can temporarily reverse medical progress, particularly in communities with fragile economic resilience.

The starkest improvement in the study occurred among urban males, who saw mortality plummet by 5.60% annually from 2007 to 2010. This timeline aligns with two major clinical shifts: the dissemination of the single ventricle reconstruction (SVR) trial protocols[21,22] and the widespread piloting of CCHD pulse-oximetry screening.[14,23] Male infants have a known higher prevalence of left-sided obstructive lesions (e.g., hypoplastic left heart syndrome, coarctation of the aorta).[24,25] These are precisely the lesions most likely to be detected by pulse-oximetry and most impacted by the surgical refinements of the SVR era (e.g., the Norwood procedure).[26] The specific acceleration of urban male survival suggests that high-volume urban centers adopted these lesion-specific improvements rapidly, disproportionately benefiting the male infants who carry the highest burden of these defects.

While White children accounted for the majority of deaths, Non-Hispanic Black children bore the highest risk per capita in every geographic stratum. Rural Black children face a double burden of systemic racism and geographic isolation, resulting in the highest sustained mortality rates (AAMR 5.8) of any group. This aligns with findings by Lopez et al.2 and reflects disparities that begin in utero, ranging from maternal environmental exposures[27] to lower rates of prenatal diagnosis and surgical referral.[11,28] The linear, unvarying decline in this group suggests that while they are benefiting from general improvements in medicine, they are not yet the beneficiaries of targeted equity interventions.

Limitations

This study has limitations inherent to death certificate data. First, we relied on ICD-10 codes, which may contain misclassification errors, though Q20–Q28 codes are the surveillance standard.[1,29] Second, CDC WONDER records residence at the time of death, not birth. This creates a potential migration bias: if families of children with severe CHD relocate to urban centers for care, urban mortality might be artificially inflated while rural mortality is underestimated.[30] However, the fact that rural mortality remained higher despite this potential migration suggests the true rural penalty may be even more severe than our data indicate. Finally, we lacked granular clinical data on specific defect types or surgical complexity.

CONCLUSION

Geography remains a decisive factor in the survival of children with congenital heart disease. While the last two decades have seen national improvements, the benefits have been unevenly distributed. The stepwise improvements in urban centers highlight the efficacy of modern cardiac systems, while the slow, linear declines in rural areas expose a failure of delivery. Furthermore, the transient mortality spike among rural White children during the Great Recession serves as a warning that economic instability can rapidly erode public health gains. Closing these gaps does not strictly require new surgical breakthroughs, but rather logistical ones: the expansion of telemedicine, the incentivization of rural cardiac networks, and economic safeguards for vulnerable families.[31]

Abbreviations

- **AAMR:** Age-Adjusted Mortality Rate
- **APC:** Annual Percent Change
- **CDC:** Centers for Disease Control and Prevention
- **CCHD:** Critical Congenital Heart Disease
- **CHD:** Congenital Heart Disease
- **CI:** Confidence Interval
- **ICD-10:** International Classification of Diseases, 10th Revision
- **NCHS:** National Center for Health Statistics
- **SVR:** Single Ventricle Reconstruction
- **WONDER:** Wide-Ranging Online Data for Epidemiologic Research

Declarations

Ethics approval and consent to participate As this study utilized de-identified, publicly available aggregate data from the CDC WONDER database, the Institutional Review Board deemed it exempt from review.

Consent for publication

Not applicable.

Availability of data and materials The mortality data supporting the findings of this study are available through the Centers for Disease Control and Prevention Wide-Ranging Online Data for Epidemiologic Research (CDC WONDER) Multiple Cause of Death database.

Competing interests The authors declare that they have no conflicts of interest.

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Authors' contributions MS, CCE, ASD, PKS, and AKB contributed to the study conception and design. All authors read and approved the final manuscript. All authors contributed to the interpretation of the data and critical revision of the manuscript.

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Authors' information (optional)

Not applicable.

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Figures

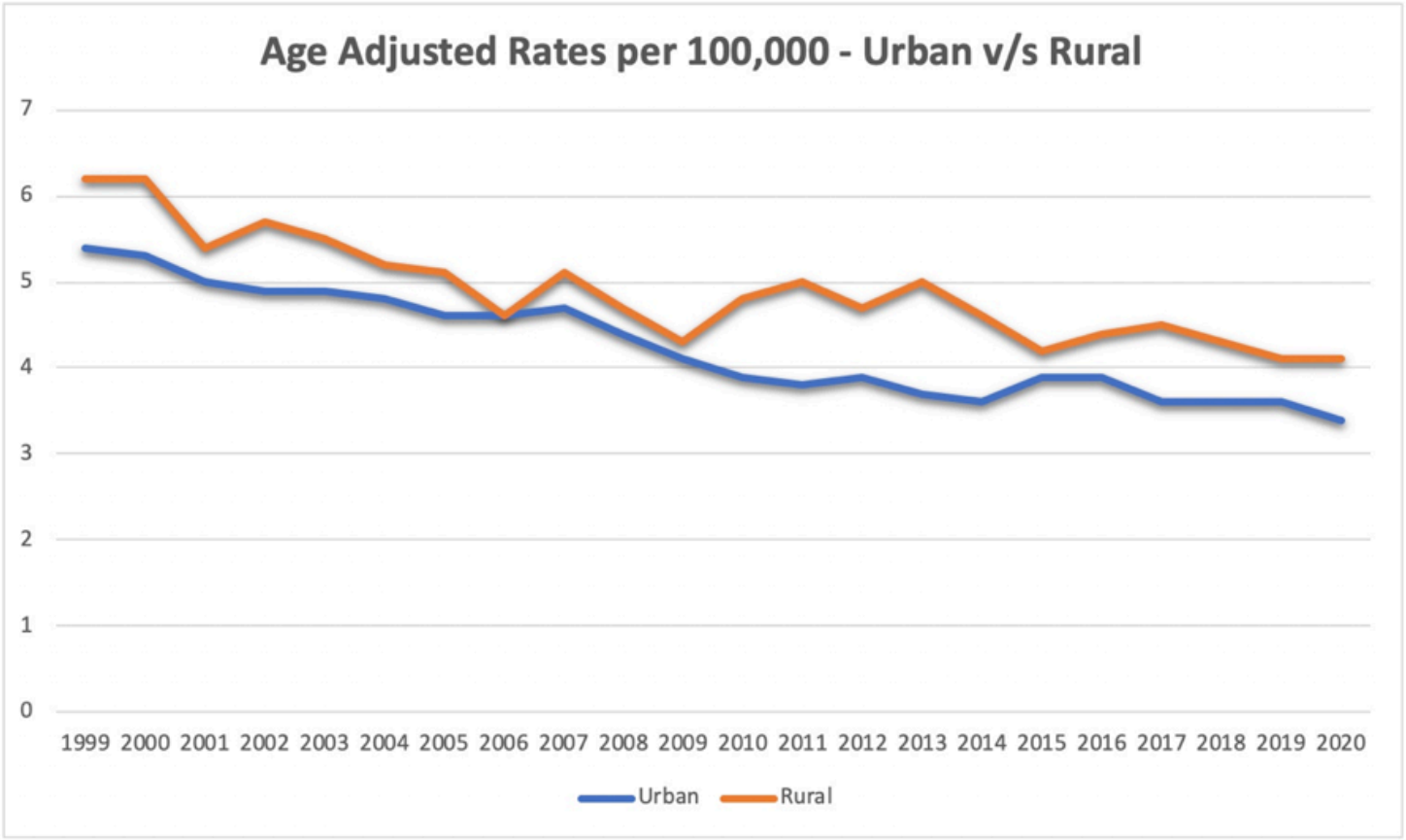


Figure 1

Age-adjusted mortality rates among children with congenital heart disease by geographic residence (urban vs rural), United States, 1999-2020.

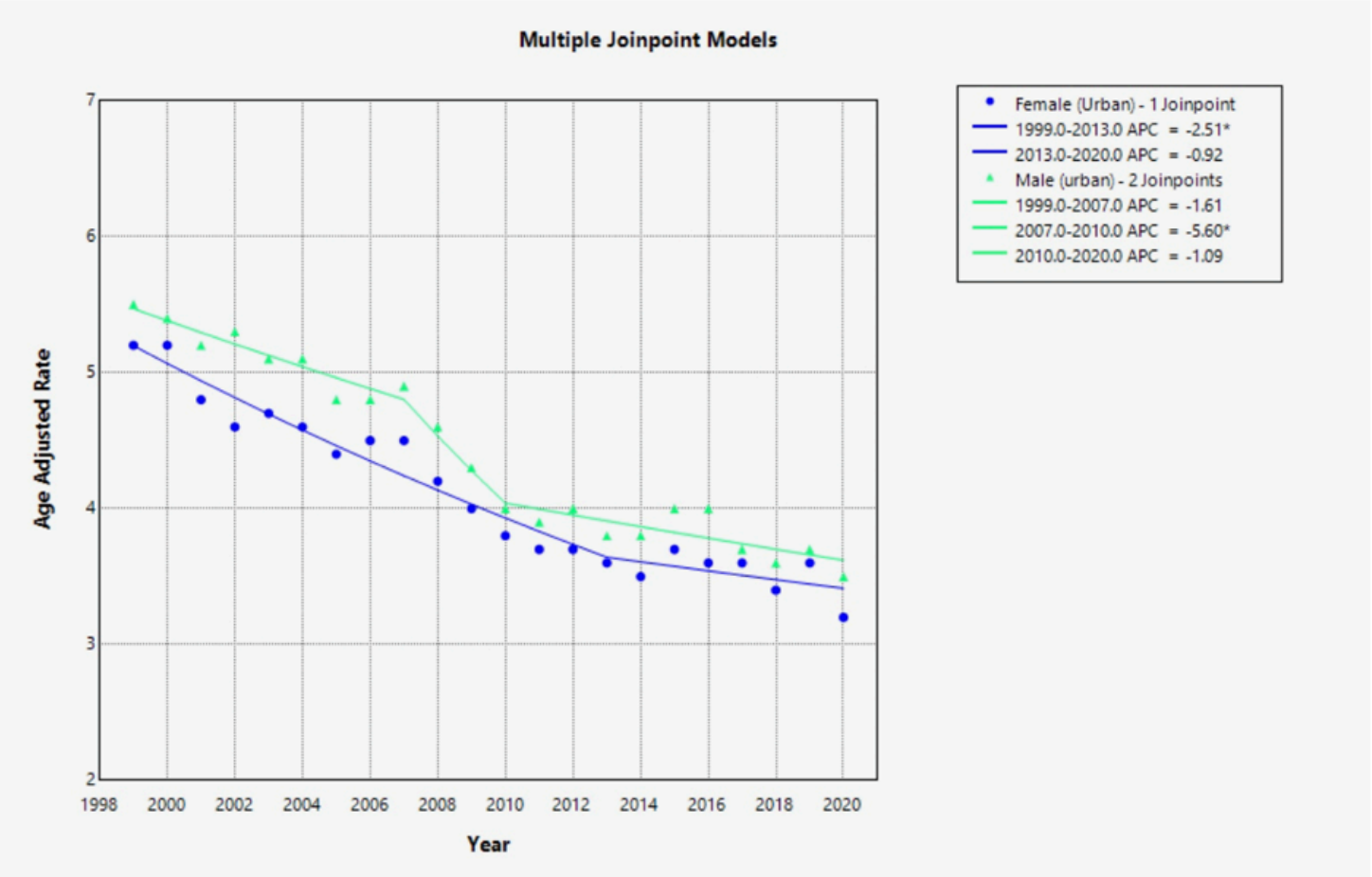


Figure 2

Joinpoint analysis of age adjusted mortality rates among urban children with congenital heart disease, stratified by sex, United States, 1999-2020

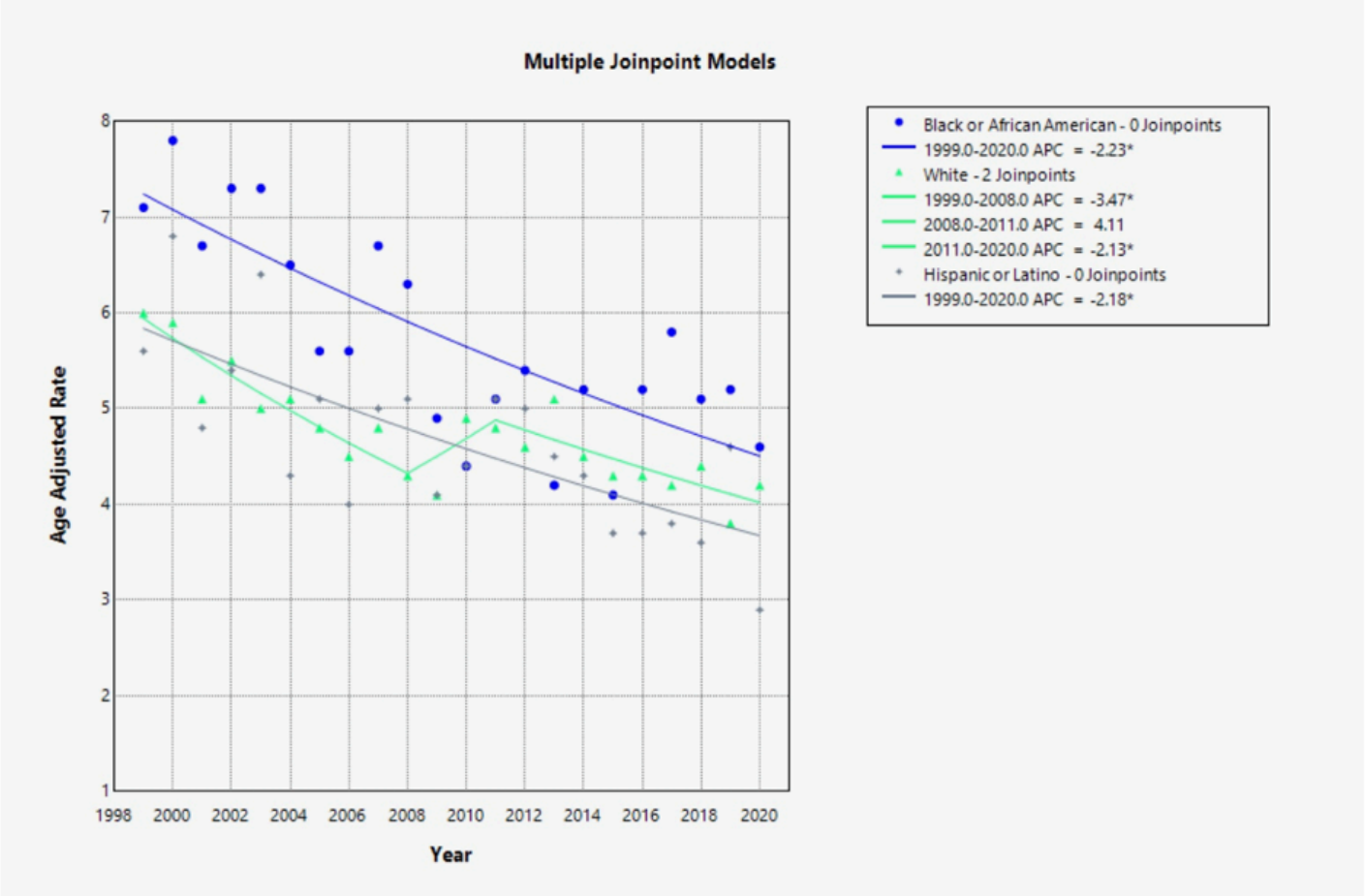


Figure 3

Joinpoint analysis of age adjusted mortality rates among rural children with congenital heart disease, stratified by race/ethnicity, United States, 1999-2020

Supplementary Files

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