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# Disparities in Insurance Coverage Among Hospitalized Adult Congenital Heart Disease Patients Before and After the Affordable Care Act

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**ABSTRACT**

**Background:** Data are lacking regarding the insurance status of adults with congenital heart disease (ACHD). We investigated whether the Affordable Care Act (ACA) impacted insurance status among hospitalized ACHD, identified associated sociodemographic factors, and compared coverage to other adults with other chronic childhood conditions.

**Methods:** Serial cross-sectional analysis of National Inpatient Sample hospitalizations from 2007-2016 was performed for patients 18-64 years old. ACHD were identified using ICD-9/10-CM codes and compared to patients with sickle cell disease (SCD), cystic fibrosis (CF), and the general population. Age was dichotomized as 18-25 years (transition aged) or 26-64 years. Groups were compared by era (pre-ACA [1/2007-6/2010]; early-ACA [7/2010-12/2013], which eliminated pre-existing condition exclusions; and full-ACA [1/2014-12/2016]) using interrupted time series and multivariable Poisson regression analyses.

**Results:** Overall, uninsured hospitalizations decreased from pre-ACA (12.0%) to full-ACA (8.5%). After full ACA implementation, ACHD had lower uninsured rates than the general hospitalized population (6.0% vs 8.6%, $p<0.01$), but higher rates than those with other chronic childhood diseases (SCD [4.5%]; CF [1.6%]). Across ACA eras, transition aged ACHD had higher uninsured rates than older patients (8.9% vs 7.6%, $p<0.01$), and Hispanic patients remained less insured than other groups.

**Conclusions:** Hospitalized ACHD were better insured than the general population but less insured than those with SCD or CF. Full ACA implementation was associated with improved insurance coverage for all groups, but disparities persisted for transition aged and Hispanic adults. Ongoing evaluation of the effects of insurance and health policy on ACHD remains critical to diminish health disparities.

**Keywords:** adult congenital heart disease, access to care, health disparities, health policy

## INTRODUCTION

Lapses in congenital heart disease (CHD) care are often a result of inadequate insurance coverage and lead to increased emergency healthcare utilization and poorer outcomes.[1, 2] Prior to 2010, preexisting condition exclusions and total lifetime dollar benefit caps were barriers to health insurance access for adults with CHD (ACHD) in the US.[3-8] The transition-age period (18-25 years), when CHD patients typically transfer from pediatric to adult care, has the highest rate of gaps in care.[1, 9] Given the US ACHD population growth of more than 50% from 2000 to 2010, these access to care issues and resulting sequelae hold increasingly significant clinical and financial implications for the healthcare system as a whole.[10]

The Affordable Care Act (ACA), a major overhaul of the US healthcare system, was signed into law in 2010. Key tenants of the ACA were to: 1) expand insurance coverage and affordability for individuals with chronic diseases, 2) eliminate prohibitive insurance limits for all patients, and 3) overhaul medical care delivery to lower overall insurance costs.[11] The first round of implementation in July 2010 included the expansion of dependent coverage to age 26, the elimination of preexisting condition exclusions and lifetime coverage caps, and the creation of multi-state insurance exchanges. Full implementation was achieved in January 2014 with additional changes including the expansion of state-based Medicaid, the enforcement of the individual mandate to have medical insurance, and a limitation of insurance coverage waiting periods to 90 days.[12]

The effects of the ACA on ACHD insurance status have been investigated in one single large tertiary care center outpatient setting, demonstrating very low (<3%) uninsured rates among CHD patients when compared to adults with acquired heart disease.[13] When only evaluating routine outpatient care, however, lack of insurance may be underestimated because uninsured patients may be less likely to seek routine outpatient care due to high out-of-pocket costs, especially if they are feeling well.

The objectives of this study were to investigate national insurance coverage among hospitalized US ACHD across three time periods corresponding to ACA implementation (pre, early, and full) and to compare insurance coverage to other adults with chronic childhood conditions as well as the general hospitalized adult population.

## PATIENTS AND METHODS

### Data source

Inpatient hospitalization data were queried from the National Inpatient Sample (NIS). The NIS, compiled by the Agency for Healthcare Research and Quality, constitutes the largest publicly available all-payer inpatient database in the US. Participating states (40 in 2007, increased to 47 in 2016) submit hospitalization-level data from all non-federal, short-term general, and specialty hospitals.[14] Each year, a systematic sampling design is implemented to ensure that hospitalizations selected for inclusion in the NIS are representative of the available hospitalizations based on key characteristics such as timing of admission, primary reason for hospitalization, and various hospital characteristics.[15, 16] In 2016, the NIS contained data on over seven million hospitalizations with weighted representation of more than 35 million hospitalizations – 97% of all hospitalizations in the US.[14] The NIS does not contain personal identifiers, precluding the ability to link multiple hospitalizations for the same person. As such, the unit of analysis for all studies using the NIS is the individual hospitalization.

As our study utilized publicly available, de-identified hospital discharge data within the NIS database, it was deemed exempt by the Baylor College of Medicine Institutional Review Board.

### Study sample

The study sample consisted of all hospitalizations among patients aged 18 to 64 years occurring between January 1, 2007 and December 31, 2016. Pregnancy-related hospitalizations and adults 65 years and older were excluded due to automatic Medicaid and Medicare eligibility, respectively. The primary exposure was timing of the hospitalization relative to implementation of the ACA. Three time periods were created: (1) *pre-ACA* from January 1, 2007 to June 30, 2010; (2) *early-ACA* from July 1, 2010 to December 31, 2013; and (3) *full-ACA* from January 1, 2014 to December 31, 2016. The primary study

outcome was the type of insurance coverage at the time of the hospitalization as reflected by the primary payer documented in the discharge record. Additionally, specific payer subgroups – (1) government (Medicare, Medicaid), (2) private, (3) self-pay, underinsured, and no charge (hereafter collectively referred to as 'uninsured'), and (4) other (e.g., military, disability, worker's compensation, Indian Health Service) were determined. Hospitalizations with insufficient information regarding primary payer (0.28%) were excluded from all analyses.

**Diagnostic subgroup and key covariates**

ACHD hospitalizations were identified in the NIS based on the presence of any of the following International Classification of Diseases (ICD) CHD codes documented at discharge: ICD-9-CM, 745.0-747.49; ICD-10-CM, Q20.0-Q26.9. To avoid overrepresentation of simple and potentially less clinically significant CHD[17], subanalysis of moderate/complex CHD[18] was performed using the subset of ICD-9/10 codes listed in **Table A1.** To compare the extent to which the association between ACA implementation and insurance coverage differed for patients with CHD and those with other conditions, three additional diagnostic subgroups were included in analysis. These groups included sickle cell disease (SCD: ICD-9-CM, 282.60-282.69; ICD-10-CM, D57.00-D57.819) and cystic fibrosis (CF: ICD-9-CM, 277.00-277.09; ICD-10-CM, E84.0-E84.9) – adults with other chronic childhood conditions – as well as all remaining hospitalizations, classified as 'other'. Adults with SCD and CF are relevant comparison groups for adults with CHD because the majority bear a heavy burden of disease in childhood with continued care needs and potential life-shortening complications in adulthood.

Patient age at the time of admission was dichotomized as 18-25 or 26-64 years given the ACA provision for expanding dependent coverage up to age 26. Race/ethnicity was classified as non-Hispanic white (NHW), non-Hispanic black (NHB), Hispanic, other, or missing/unknown. Although no individual-level employment or household income data are available in the NIS, zip-code level estimates of median household income were grouped into quartiles as a proxy for community-level socioeconomic status.[19]

**Statistical analyses**

Descriptive statistics including weighted frequencies and percentages were used to describe the study sample: subgroups were compared based on insurance type as well as the proportion of insured vs. uninsured hospitalizations with regard to age, race/ethnicity, disease type including CHD disease complexity, and time period strata. Rao-Scott modified chi-square tests were used to assess the statistical significance of differences in insurance coverage across time periods.

Two analytic approaches were used to investigate the impact of ACA implementation on rates of insurance coverage at the time of hospitalization: (1) an interrupted time series (ITS) framework and corresponding segmented analysis often used to evaluate the impact of events that take place at clearly-defined points in time, such as interventions[20] and policies,[21] and (2) a Poisson regression method with robust error variance estimation. These analytic approaches allowed estimation of the impact of ACA implementation on the immediate change in the average proportion of hospitalizations with insurance coverage and the extent to which ACA implementation changed temporal trends in insurance coverage.[22] Among CHD-related hospitalizations, the segmented regression model used to fit monthly hospital rates of having insurance was as follows:

$$Rate_t = \beta_0 + \beta_1 * time_t + \beta_2 * early\ ACA\ implementation_t + \beta_3 * time\ after\ early\ ACA\ implementation_t + \beta_4 * full\ ACA\ implementation_t + \beta_5 * time\ after\ full\ ACA\ implementation_t + e_t$$

In each model, $Rate_t$ is the proportion of hospitalizations that are insured in month *t*; *time* is a continuous variable documenting the month of analysis from 1 (January 2007) to 120 (December 2016); *early ACA implementation* and *full ACA implementation* are dichotomous indicators of which time period was in effect; *time after implementation* variables reflect the number of months after the transition to that time period (0 for all months during which the time period was not in effect); and $e_t$ estimates the random error for each month. $\beta_2$ and $\beta_4$ provide estimates the immediate absolute change in insurance coverage rates following early ACA implementation and full ACA implementation, respectively, compared to the pre-ACA period. Similarly, $\beta_3$ and $\beta_5$ estimate the change in the trend (i.e., slope) insurance rates

following these two implementation periods. We used the Durbin-Watson statistic and test to examine autocorrelation and the Dickey-Fuller unit root test to appraise seasonal fluctuations (stationarity) in the data. For comparison, these models were repeated for non-CHD hospitalizations.

Poisson regression was used to estimate prevalence ratios and corresponding 95% confidence intervals (CI) representing the association between time period and insurance status, accounting for the various phases of the ACA rollout and limitations of the NIS database regarding state-level analysis. As opposed to analyzing monthly aggregated data as in the ITS approach, this hospitalization-level analysis sets the three-level ACA-relevant time period as the main independent variable with the outcome of being uninsured at the time of hospitalization. The models were adjusted for zip code-level household income, hospital region, and hospital type. To assess differences in the impact of ACA implementation, a separate model was run for each age, racial/ethnic, and diagnostic subgroup. To evaluate the possible impact of overrepresentation of simple and clinically less relevant CHD, a sensitivity analysis was performed by re-running all analyses using only moderate or complex CHD in place of all CHD.

All statistical tests were performed with SAS version 9.4 (Cary, NC) using two-sided statistical tests and a 5% type I error rate.

**RESULTS**

Overall, a total of 138,583,079 hospitalizations were included for analysis. ACHD accounted for 1 in 210 hospitalizations (0.48%; n=659,281) compared to 1 in 161 for adult patients with SCD (0.62%; n=860,533) and 1 in 714 for adult patients with CF (0.14%; n=190,079). Of all ACHD hospitalizations, 18.7% (n=123,586) occurred in patients with moderate or complex CHD overall, with patients with moderate or complex disease accounting for 33.3% (n=19,698) of CHD hospitalizations in the transition aged group. The remaining 98.8% (n=136,873,186) of the population were hospitalized for other diagnoses. Of all hospitalizations, 7.3% (n=10,154,583) occurred in transition aged patients. With regard to time period, 36.0% (n=49,872,522) of hospitalizations occurred during the pre-ACA era, 35.1% (n=48,678,093) occurred during the early-ACA era, and 28.9% (n=40,032,463) occurred in the full-ACA

era. Patient characteristics and details of hospitalizations are further described in **Table 1** with additional stratification of the ACHD group in **Table A2**.



**ACA era effect on CHD insurance status**

ACHD patients were less likely to be uninsured in the full-ACA era compared to the pre-ACA era (6.0%, 95% CI: 5.7, 6.3 vs. 7.7%, 95% CI: 7.0, 8.5; p<0.01). As shown in **Figure 1** and **Figure A1**, uninsured rates were higher for transition aged patients compared to older adults across all ACA eras for the CHD group as a whole (8.9%, 95% CI: 8.2, 9.6 vs. 7.6%, 95% CI: 7.2, 7.9; p<0.01), but among patients with moderate or complex CHD, transition aged patients were better insured than older patients after implementation of the ACA (p<0.01). Increases in private insurance were the main drivers of overall increased insurance coverage for all ages (**Figure 1**), with stable public insurance coverage throughout.

All CHD subgroups regardless of age and/or race/ethnicity were significantly more likely to be insured in the full-ACA era compared to pre-ACA and early-ACA eras (p<0.01 for transition aged NHW and older adults of all races/ethnicities, p=0.01 for transition aged Hispanics, and p=0.03 for transition aged NHB; **Figure 2**).

**Comparison of CHD insurance status to other conditions across ACA eras**

ACHD had higher insured rates than the general hospitalized population across all eras and age groups (**Figure 3**). However, CHD insurance rates, including those for patients with moderate or complex CHD, were lower than those for other adults with chronic childhood diseases (SCD or CF). Subanalysis of moderate or complex CHD showed similar lower insurance rates compared to those with SCD or CF (**Figure A2).**

All subgroups by diagnostic group and age were more likely to be insured when comparing pre-ACA and early-ACA eras with the full-ACA era (p<0.01) with the exception of transition aged CF patients whose improved full-ACA coverage did not meet statistical significance in the setting of

excellent coverage in all eras. While the full-ACA era was associated with an increased proportion on government insurance for all chronic childhood disease subgroups, adult patients with either SCD or CF were more likely to have public insurance than those with CHD across all eras (**Figure 3**; **Table A3**).

**Multivariable modeling and interrupted time series analyses**

Prevalence ratios from Poisson regression revealed that CHD patients were between 14% and 46% less likely to be uninsured during the full-ACA time period compared to the pre-ACA era, depending on the age and race/ethnic subgroup assessed. Differences in race/ethnic and age distributions are seen in **Figure 4** and detailed in **Table A4**. Hispanic patients had the most pronounced decrease in the proportion of uninsured hospitalizations in the full-ACA era compared to the pre-ACA era but remained more likely than other race/ethnic groups to be uninsured across all eras (**Table A5**). None of these results changed meaningfully with sensitivity analysis when the CHD group was restricted to moderate or complex CHD.

**DISCUSSION**

While previous work has looked at uninsured rates for patients with CHD in outpatient clinics[13] and in individual centers and states[23], this study adds to this body of literature by assessing a national sample of hospitalized CHD patients over time. To the authors' knowledge, this is the first study to describe the insurance status of hospitalized ACHD in the US before and after implementation of the ACA, which sought to reducing patient morbidity and mortality by impacting multiple measures of health including obtaining insurance, accessing services and medications, and accessing behavioral health.[12] Overall, all diagnoses and age groups had lower uninsured rates following full-ACA implementation; this improvement may have been due to any combination of ACA features, including elimination of preexisting condition exclusions, expansion of family insurance coverage through age 26, the reduction of insurance coverage waiting periods to 90 days, and expansion of Medicaid coverage. For patients with CHD, the majority of improved insurance coverage for adults of all ages was due to gains in private

insurance coverage, suggesting that Medicaid expansion may have been less important for this population than other tenets of the ACA.

Patients with moderate or complex CHD are estimated to comprise approximately 10% of all ACHD[10]but accounted for 18.7% of all ACHD hospitalization and 33.7% of transition aged hospitalizations. While patients with moderate or complex CHD group were better insured than those with less complex CHD – particularly in transition aged patients – the differences in insurance status were small.

Another key question brought up by this study centers around the differences in insurance status and type of insurance for CHD patients compared to those with SCD and CF. Further work is needed to look at advocacy, social work, and other efforts that have been successful in the SCD and CF communities to identify ways in which CHD insurance coverage can continue to be improved, specifically regarding qualification for and access to public insurance options. Studies of transition aged patients with CF and childhood cancers have shown disparities in which sociodemographic groups saw improved insurance coverage following ACA implementation, highlighting the importance of outreach efforts to connect all patients, especially those who struggle with health literacy, with available resources.[24, 25]

Transition aged and Hispanic ACHD of all ages were more uninsured than the rest of the ACHD population in all time periods. For transition aged patients, this may be due to feeling well, not understanding the need for ongoing follow-up, low healthy literacy, changing from a pediatric to an adult care system, and/or the logistical challenges of being personally responsible for obtaining health insurance for the first time.[1, 26-31] For Hispanic patients, lack of access to appropriate ACHD care, immigration status, language barriers, and/or cultural differences may present additional challenges. Preparation for the transition and transfer process for transition aged patients during pediatric care as well as outreach and planning for higher risk Hispanic communities will be critical in improving these disparities for CHD patients in the future, ideally focusing on the importance of maintaining insurance as well as options for obtaining coverage.

A key tenet of the ACA was that improved insurance coverage would lead to proactive healthcare utilization and improved outcomes, but the effects of insurance coverage and type of insurance on healthcare utilization and outcomes for all US CHD patients remain unknown. Data demonstrate that self-reported health, access to care, utilization of services, and the affordability of care have improved nationally for all patients since ACA implementation, particularly in states which accepted the Medicaid expansion.[12] Certainly, part of the goal of the ACA implementation was to improve preventative care to reduce gaps in care, hospitalizations and mortality rates for individuals with chronic diseases. Given what is known about the association between lapses in care due to insurance issues and poorer outcomes in CHD[1, 2] as well as documented evidence of ongoing disparities in mortality for patients with CHD[32], we are hopeful that the demonstrated improvements in clinical outcomes following the ACA in the general population[33-36] have a similar effect in this high-risk patient group.

While this study adds to our understanding of insurance coverage for hospitalized ACHD, we ultimately would like to describe the coverage of all ACHD regardless of whether they require admission to a hospital in a given year. A national registry of CHD patients would be the best way to be inclusive of the entire population and allow for better correlation of insurance type, status, and outcomes, but unfortunately no such database exists. Track-and-trace studies based on pediatric CHD care could more accurately estimate the ACHD population, but these studies are time-intensive and costly, especially on a national scale. Thankfully, there are ongoing efforts to create a nationwide patient registry as well as create mobile technologies to improve patient care.[37]

Additionally, there is a desperate need for more ACHD specialists to care for this ever-growing population.[12, 38] Developing policies and practices that increase this workforce is particularly critical as the ACHD population becomes increasingly insured. Both insurance coverage and access to quality medical expertise are critical components in achieving better outcomes for this high-risk population.

Finally, ongoing work is needed to examine the effects of possible future changes in the US healthcare and insurance system if facets of the ACA are eliminated, such as repeal of the individual mandate, increases in predatory insurances, or allowance for temporary insurances which allow for preexisting condition exclusions and limited terms of coverage.

**Limitations**

Our understanding of the insurance status of the CHD population as a whole remains incomplete. Specifically, ACHD who are not receiving care of any kind, either in clinic or in a hospital setting, have not been included in any population-based studies. One key limitation of this study is the inclusion of only hospitalized patients, as the majority of adults with CHD are not hospitalized in a given year. Given what we know about increased emergency department utilization and need for emergent procedures in patients who have gaps in care and the association between being uninsured and gaps in care,[2] it is possible that our sample overestimates the number of uninsured patients as they may be more likely to require hospitalization and urgent or emergent care. Additionally, the NIS does not allow for state-level analysis so we were not able to evaluate for differences between states which did or did not expand Medicaid as a result of the ACA.

We were limited by the accuracy of diagnosis coding during hospitalizations in identifying CHD patients as with any study based on hospital discharge data, although analyzing the subset of patients with moderate or complex CHD was performed to help minimize inaccuracies in coding simple disease. Finally, despite incorporating a comparative interrupted time series framework into our analyses, we were unable to comprehensively evaluate other factors that may have impacted insurance coverage: the study period covered significant events related to healthcare changes in the US based on the implementation of the ACA. Some important societal factors which may have differentially influenced the rates of insurance of the studied age, race/ethnic, and diagnostic groups but were not accounted for in this study include but are not limited to: changes in standard of care for CHD, changes in unemployment rates, economic fluctuations in local and national terms, immigration/emigration/migration patterns, and trends in socio-politico-economic movements.

**CONCLUSION**

Hospitalized ACHD, including the subset of patients with moderate or complex CHD, were better insured than the general hospitalized adult population but less insured than adults with SCD or CF during

all ACA eras. These data raise interesting questions about socioeconomic differences between the disease groups as well as about potential social work and advocacy interventions which may be effectively assisting SCD and CF patients in obtaining public insurance. Additionally, transition aged and Hispanic ACHD of all ages had higher uninsurance rates than the rest of the ACHD population in all time periods. Having a timely transition and transfer process for transition aged patients during pediatric care as well as outreach and planning for higher risk Hispanic communities will be critical in improving these disparities for CHD patients in the future. Ongoing advocacy to protect preexisting condition exclusions is of utmost importance in protecting access-to-care for CHD patients as well as other survivors of chronic childhood illnesses.

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None

**DISCLOSURES**

None

**DATA AVAILABILITY STATEMENT**

Data from the National Inpatient Sample can be purchased from the Agency for Healthcare Research and Quality at https://www.hcup-us.ahrq.gov/tech_assist/centdist.jsp.

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**Table 1.** Distribution of patient and hospital characteristics of inpatient hospitalizations for patients aged 18 to 64 years stratified by diagnostic subgroup, National Inpatient Sample, 2007–2016

| | Diagnostic group | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Congenital heart disease | | Sickle cell disease | | Cystic fibrosis | | Other conditions | |
| | N* | %* | N* | %* | N* | %* | N* | %* |
| **All hospitalizations** | 659,281 | 100.0 | 860,533 | 100.0 | 190,079 | 100.0 | 136,873,186 | 100.0 |
| **ACA era** | | | | | | | | |
| Pre ACA | 210,040 | 31.9 | 276,697 | 32.2 | 61,872 | 32.6 | 49,323,913 | 36.0 |
| Early ACA | 234,390 | 35.6 | 303,996 | 35.3 | 69,682 | 36.7 | 48,070,025 | 35.1 |
| Full ACA | 214,850 | 32.6 | 279,840 | 32.5 | 58,525 | 30.8 | 39,479,248 | 28.8 |
| **Age, in years** | | | | | | | | |
| 18-25 | 59,081 | 9.0 | 269,429 | 31.3 | 87,186 | 45.9 | 9,738,887 | 7.1 |
| 26-64 | 600,200 | 91.0 | 591,103 | 68.7 | 102,893 | 54.1 | 127,134,299 | 92.9 |
| **Gender** | | | | | | | | |
| Male | 364,467 | 55.3 | 392,868 | 45.7 | 88,243 | 46.4 | 67,823,103 | 49.6 |
| Female | 294,586 | 44.7 | 467,162 | 54.3 | 101,730 | 53.5 | 68,887,298 | 50.3 |
| **Race/ethnicity** | | | | | | | | |
| NH-White | 412,557 | 62.6 | 11,470 | 1.3 | 148,778 | 78.3 | 78,609,978 | 57.4 |
| NH-Black | 75,439 | 11.4 | 738,759 | 85.8 | 6,545 | 3.4 | 22,425,926 | 16.4 |
| Hispanic | 55,846 | 8.5 | 25,506 | 3.0 | 8,528 | 4.5 | 13,519,123 | 9.9 |
| NH-Other | 36,383 | 5.5 | 17,233 | 2.0 | 3,641 | 1.9 | 7,121,651 | 5.2 |
| Unknown | 79,055 | 12.0 | 67,565 | 7.9 | 22,588 | 11.9 | 15,196,509 | 11.1 |
| **Primary payer** | | | | | | | | |
| Government | 233,303 | 35.4 | 647,702 | 75.3 | 96,258 | 50.6 | 55,221,594 | 40.3 |
| Private | 348,118 | 52.8 | 145,544 | 16.9 | 80,572 | 42.4 | 59,451,331 | 43.4 |
| Uninsured † | 50,586 | 7.7 | 46,170 | 5.4 | 4,022 | 2.1 | 14,846,952 | 10.8 |
| Other ‡ | 27,273 | 4.1 | 21,117 | 2.5 | 9,227 | 4.9 | 7,353,309 | 5.4 |
| **Community-level median household income** | | | | | | | | |
| Lowest | 166,074 | 25.2 | 419,437 | 48.7 | 44,135 | 23.2 | 42,735,582 | 31.2 |
| 2nd | 161,083 | 24.4 | 191,807 | 22.3 | 48,084 | 25.3 | 34,375,755 | 25.1 |
| 3rd | 163,446 | 24.8 | 141,676 | 16.5 | 49,905 | 26.3 | 30,722,696 | 22.4 |
| Highest | 153,536 | 23.3 | 85,916 | 10.0 | 44,767 | 23.6 | 25,352,934 | 18.5 |
| **Hospital census region** | | | | | | | | |
| Northeast | 135,211 | 20.5 | 173,151 | 20.1 | 35,542 | 18.7 | 26,744,635 | 19.5 |
| Midwest | 171,470 | 26.0 | 163,307 | 19.0 | 46,897 | 24.7 | 30,999,239 | 22.6 |
| South | 220,668 | 33.5 | 448,443 | 52.1 | 69,320 | 36.5 | 53,571,687 | 39.1 |
| West | 131,932 | 20.0 | 75,632 | 8.8 | 38,321 | 20.2 | 25,557,624 | 18.7 |
| **Hospital type** | | | | | | | | |
| Rural | 35,922 | 5.4 | 43,534 | 5.1 | 7,071 | 3.7 | 13,588,843 | 9.9 |
| Urban, non-teaching | 167,189 | 25.4 | 222,661 | 25.9 | 17,499 | 9.2 | 48,001,830 | 35.1 |
| Urban, teaching | 453,452 | 68.8 | 589,622 | 68.5 | 163,605 | 86.1 | 74,578,127 | 54.5 |

ACA, Affordable Care Act; NH, non-Hispanic

* Weighted to estimate national frequencies and percentages; sum of all groups may not add up to the total and percentages may not add to 100% due to missing data.

† Uninsured includes self-pay, underinsured, and charity.

‡ Other payer type includes include worker's compensation, Indian Health Service, CHAMPUS/VA.

**FIGURE LEGENDS**

**Figure 1.** Impact of Affordable Care Act implementation on insurance coverage of hospitalized patients with congenital heart disease

**Legend:** Insurance coverage of hospitalizations for adults with congenital heart disease stratified by age, time periods relevant to the Affordable Care Act implementation, and insurance type, 2007-2016, National Inpatient Sample.

Footnote: Uninsured includes self-pay and no charge. Other includes payer types not included in the specified groups; examples include worker's compensation, Indian Health Service, CHAMPUS/VA. Era of the Affordable Care Act was assigned based on each hospitalizations discharge date: Pre-ACA, 01/01/2007 – 6/30/2010; Early ACA, 07/01/2010 – 12/31/2013; Full ACA, 01/01/2014 – 12/31/2016.

**Figure 2.** Impact of Affordable Care Act implementation on proportion of insured hospitalizations for patients with congenital heart disease by age and race/ethnicity.

**Legend:** Differences in the proportion of hospitalizations among adults with congenital heart disease that were insured across time periods relevant to the Affordable Care Act implementation by age and race/ethnicity, 2007-2016, National Inpatient Sample.

Footnote: An insured hospitalization includes all payer types except self-pay and no charge. Era of the Affordable Care Act was assigned based on each hospitalizations discharge date: Pre-ACA, 01/01/2007 – 6/30/2010; Early ACA, 07/01/2010 – 12/31/2013; Full ACA, 01/01/2014 – 12/31/2016.

**Figure 3.** Insurance coverage before and after implementation of the Affordable Care Act by diagnostic subgroup.

**Legend:** Insurance coverage of hospitalized adults by diagnostic subgroup and time periods relevant to the Affordable Care Act implementation, 2007-2016, National Inpatient Sample.

Footnote: Uninsured includes self-pay and no charge. Other includes payer types not included in the specified groups; examples include worker's compensation, Indian Health Service, CHAMPUS/VA. Era of the Affordable Care Act was assigned based on each hospitalizations discharge date: Pre-ACA, 01/01/2007 – 6/30/2010; Early ACA, 07/01/2010 – 12/31/2013; Full ACA, 01/01/2014 – 12/31/2016.

**Figure 4.** Likelihood of being uninsured by age and race/ethnicity for hospitalized adults with and without CHD before and after implementation of the Affordable Care Act.

**Legend:** Prevalence ratios describing the likelihood of being uninsured by age and race/ethnicity, for CHD-related and other hospitalizations.

Footnote: Uninsured includes self-pay and no charge. Prevalence ratios less than 1 represent a decreased likelihood of being uninsured (increased likelihood of being insured). A separate model was run for each diagnostic (CHD versus other), age, and race/ethnic subgroup. Each model was adjusted for zip-code level household income level, hospital region, and hospital type (urban teaching, urban nonteaching, or rural). 'Other hospitalizations' includes patients hospitalized without a diagnosis of congenital heart disease, cystic fibrosis, or sickle cell disease.

## APPENDICES

**Table A1.** Diagnosis codes used to identify moderate or complex congenital heart disease

| Condition | ICD-9-CM codes | ICD-10-CM codes |
|---|---|---|
| Common truncus | 745.0 | Q20.0 |
| Transposition of the great vessels | 745.10, 745.19 | Q20.3 |
| Double outlet right ventricle | 745.11 | Q20.1 |
| Double outlet left ventricle | n/a | Q20.2 |
| Corrected transposition of great vessels | 745.12 | Q20.5 |
| Tetralogy of Fallot | 745.2 | Q21.3 |
| Common ventricle | 745.3 | Q20.4 |
| Cor biloculare | 745.7 | Q22.6 |
| Endocardial cushion defect | 745.6 | Q21.2 |
| Atresia of pulmonary valve, congenital | 746.01 | Q22.0, Q25.5 |
| Stenosis of pulmonary valve, congenital | 746.02 | Q22.1 |
| Other congenital pulmonary valve anomaly | 745.00, 746.09 | Q22.2, Q22.3 |
| Tricuspid atresia and stenosis, congenital | 746.1 | Q22.4 |
| Ebstein's anomaly | 746.2 | Q22.5 |
| Hypoplastic left heart syndrome | 746.7 | Q23.4 |
| Subaortic stenosis | 746.81 | Q24.4 |
| Cor triatriatum | 746.82 | Q24.2 |
| Infundibular pulmonic stenosis | 746.83 | Q24.3 |
| Coronary artery anomaly | 746.85 | Q24.5 |
| Patent ductus arteriosus | 747.0 | Q25.0 |
| Coarctation of aorta | 747.10 | Q25.1 |
| Interruption of aortic arch | 747.11 | Q25.21, Q25.41 |
| Atresia and stenosis of aorta | 747.22 | Q25.3 |
| Congenital anomalies of pulmonary artery | 747.3 | Q25.71, Q25.79 |
| Total anomalous pulmonary venous connection | 747.41 | Q26.2 |
| Partial anomalous pulmonary venous connection | 747.42 | Q26.3 |

**Table A2.** Distribution of patient and hospital characteristics among inpatient hospitalizations to persons aged 18 to 64 years, stratified by complex versus other congenital heart disease, National Inpatient Sample, 2007–2016

| | Moderate or complex congenital heart disease | | Other congenital heart disease | |
|---|---|---|---|---|
| | N[a] | %[a] | N[a] | %[a] |
| **All hospitalizations** | 123,586 | 100.0 | 535,695 | 100.0 |
| **ACA era** | | | | |
| Pre ACA | 40,331 | 32.6 | 169,709 | 31.7 |
| Early ACA | 43,675 | 35.3 | 190,715 | 35.6 |
| Full ACA | 39,580 | 32.0 | 175,270 | 32.7 |
| **Age** | | | | |
| 18-25 y | 19,698 | 15.9 | 39,383 | 7.3 |
| 26-64 y | 103,888 | 84.1 | 496,312 | 92.7 |
| **Gender** | | | | |
| Male | 66,523 | 53.8 | 297,944 | 55.6 |
| Female | 57,009 | 46.1 | 237,577 | 44.3 |
| **Race/ethnicity** | | | | |
| NH-White | 72,604 | 58.7 | 339,953 | 63.5 |
| NH-Black | 15,754 | 12.7 | 59,685 | 11.1 |
| Hispanic | 13,352 | 10.8 | 42,494 | 7.9 |
| NH-Other | 8,029 | 6.5 | 28,354 | 5.3 |
| Unknown | 13,847 | 11.2 | 65,208 | 12.2 |
| **Primary payer** | | | | |
| Government | 48,538 | 39.3 | 184,765 | 34.5 |
| Private | 60,301 | 48.8 | 287,817 | 53.7 |
| Underinsured | 9,539 | 7.7 | 41,047 | 7.7 |
| Other | 5,207 | 4.2 | 22,066 | 4.1 |
| **Community-level median household income** | | | | |
| Lowest | 32,821 | 26.6 | 133,253 | 24.9 |
| 2nd | 30,664 | 24.8 | 130,419 | 24.3 |
| 3rd | 30,240 | 24.5 | 133,206 | 24.9 |
| Highest | 26,453 | 21.4 | 127,083 | 23.7 |
| **Hospital census region** | | | | |
| Northeast | 23,882 | 19.3 | 111,329 | 20.8 |
| Midwest | 28,450 | 23.0 | 143,020 | 26.7 |
| South | 44,286 | 35.8 | 176,382 | 32.9 |
| West | 26,967 | 21.8 | 104,965 | 19.6 |
| **Hospital type** | | | | |
| Rural | 6,638 | 5.4 | 29,284 | 5.5 |
| Urban, non-teaching | 27,647 | 22.4 | 139,542 | 26.1 |
| Urban, teaching | 88,739 | 71.8 | 364,713 | 68.1 |

ACA, Affordable Care Act; NH, non-Hispanic

[a] Weighted to estimate national frequencies and percentages; sum of all groups may not add up to the total and percentages may not add to 100% due to missing data.

**SUPPLEMENTAL FIGURE LEGENDS**

**Figure A1.** Insurance coverage of hospitalized patients with congenital heart disease (CHD), by age and time periods relevant to the Affordable Care Act implementation, stratified by overall versus moderate/complex CHD, 2007-2016, National Inpatient Sample

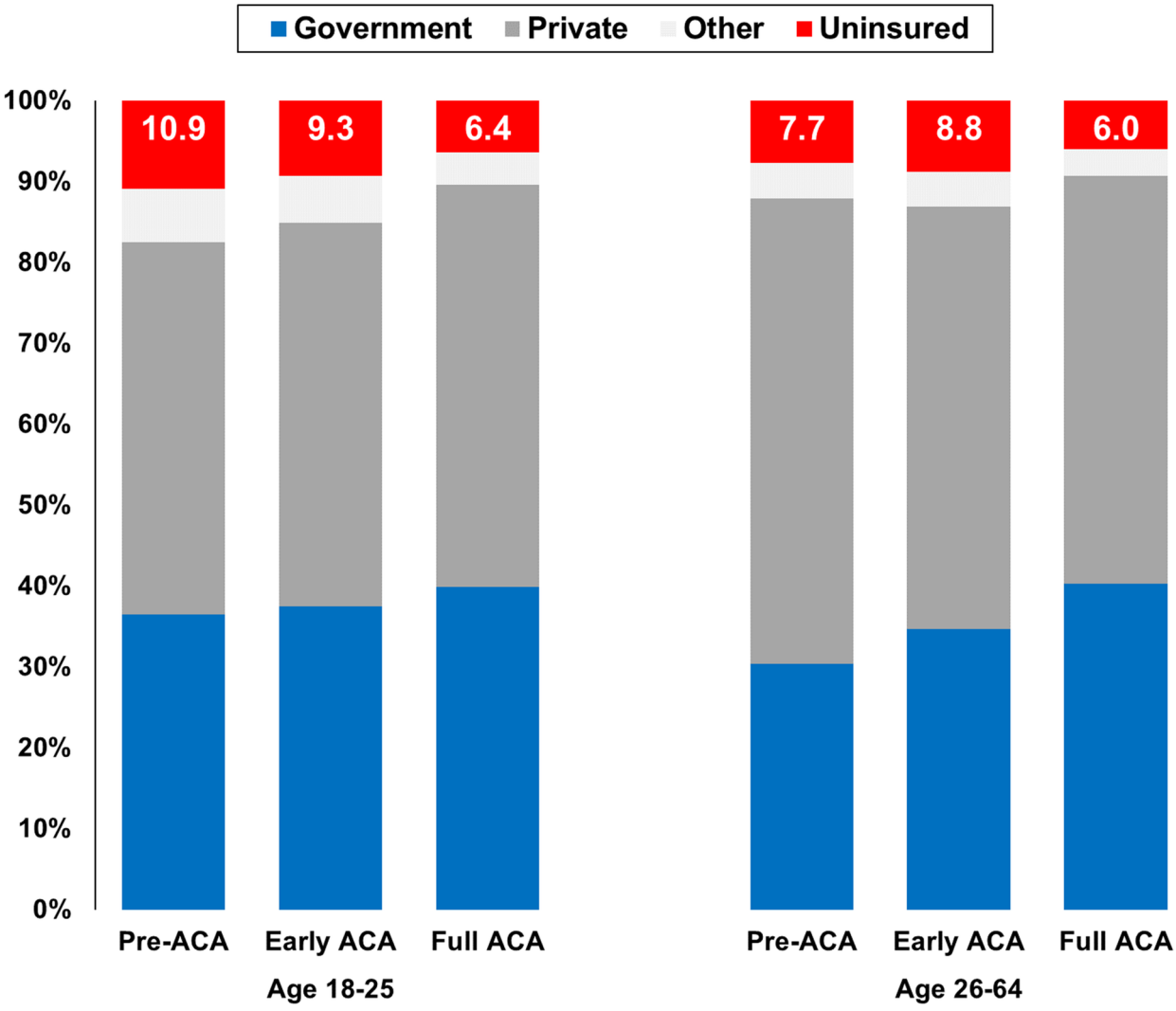
**Legend:** Insurance coverage of hospitalizations for adults with congenital heart disease stratified by age, time periods relevant to the Affordable Care Act implementation, insurance type, and disease complexity, 2007-2016, National Inpatient Sample.

Footnote: Uninsured includes self-pay and no charge. Other includes payer types not included in the specified groups; examples include worker's compensation, Indian Health Service, CHAMPUS/VA. Era of the Affordable Care Act was assigned based on each hospitalizations discharge date: Pre-ACA, 01/01/2007 – 6/30/2010; Early ACA, 07/01/2010 – 12/31/2013; Full ACA, 01/01/2014 – 12/31/2016.

**Figure A2.** Insurance coverage before and after implementation of the Affordable Care Act by diagnostic subgroup.

**Legend:** Insurance coverage of hospitalized adults by diagnostic subgroup and time periods relevant to the Affordable Care Act implementation, 2007-2016, National Inpatient Sample.

Footnote: Uninsured includes self-pay and no charge. Other includes payer types not included in the specified groups; examples include worker's compensation, Indian Health Service, CHAMPUS/VA. Era of the Affordable Care Act was assigned based on each hospitalizations discharge date: Pre-ACA, 01/01/2007 – 6/30/2010; Early ACA, 07/01/2010 – 12/31/2013; Full ACA, 01/01/2014 – 12/31/2016.

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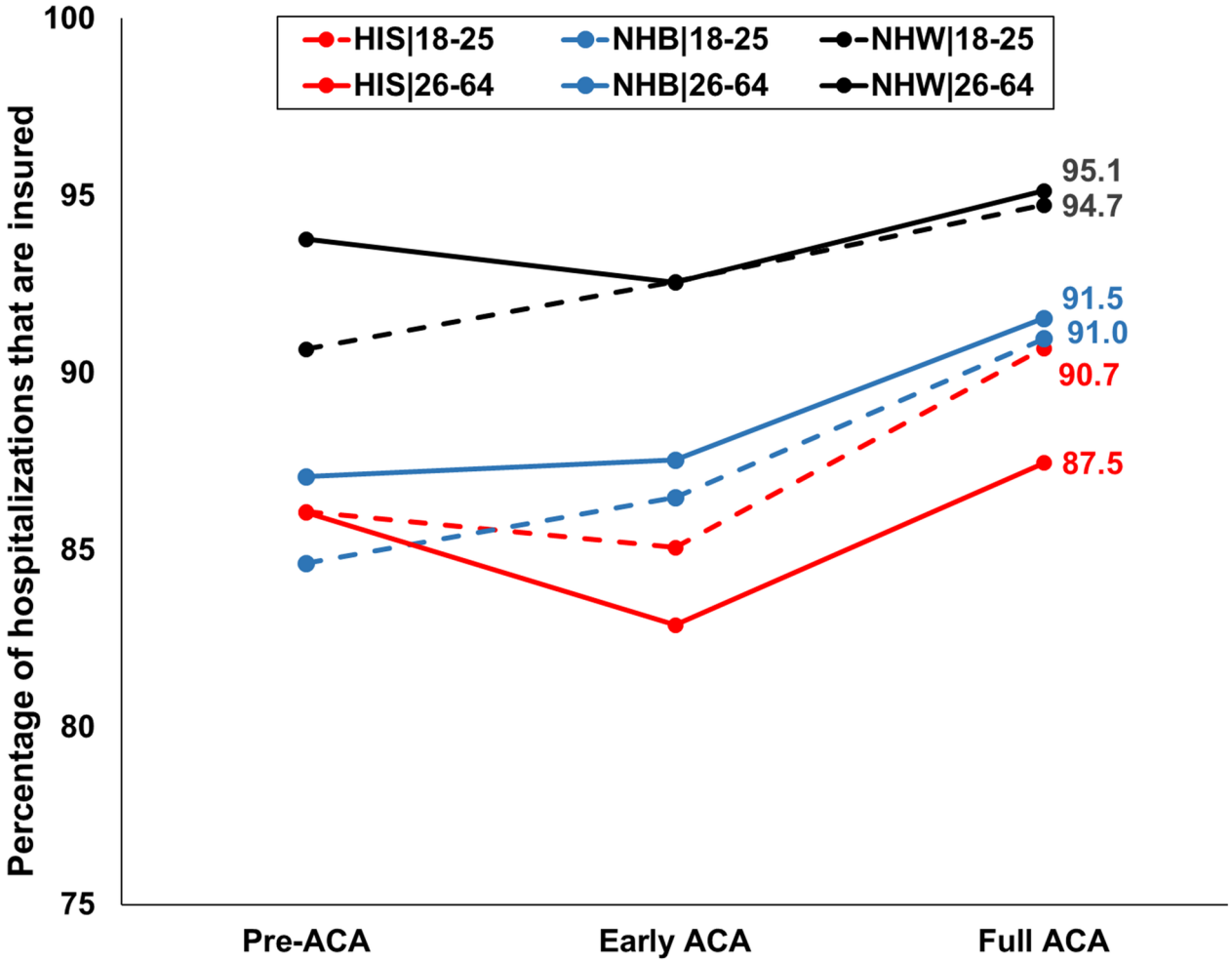


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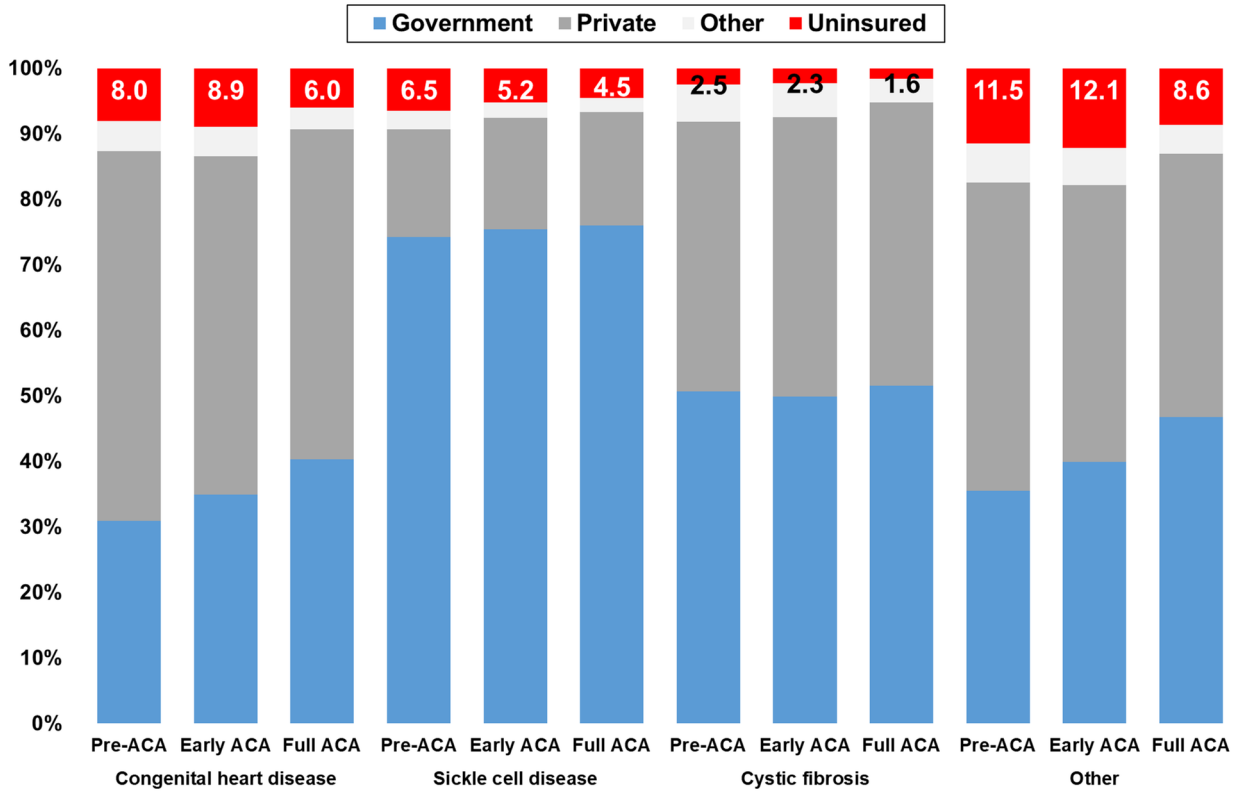


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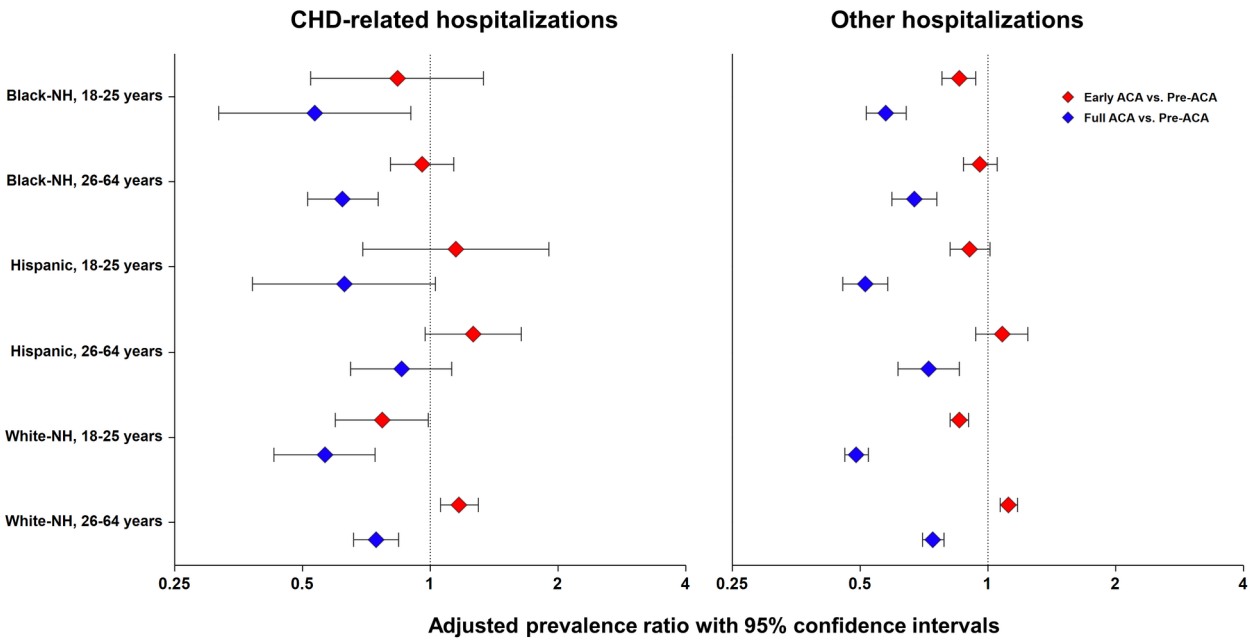


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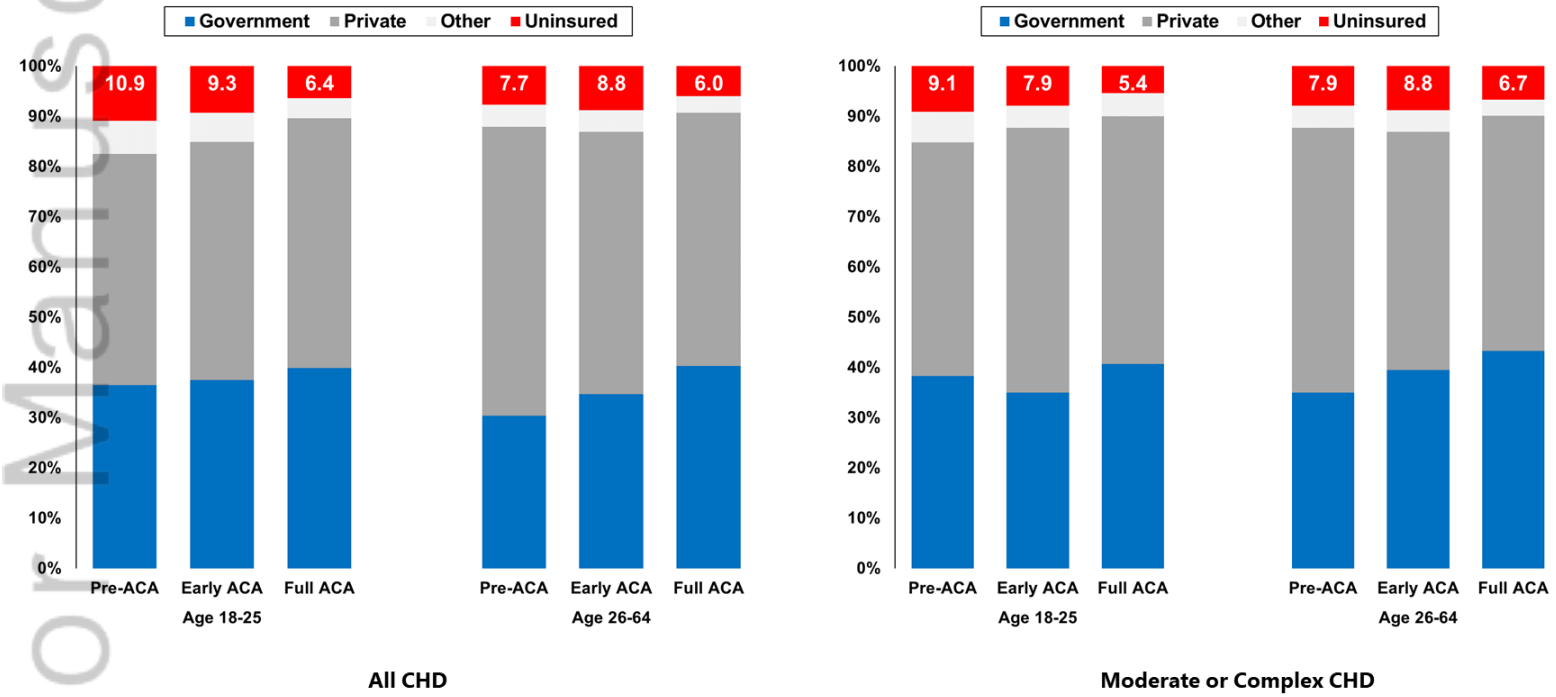


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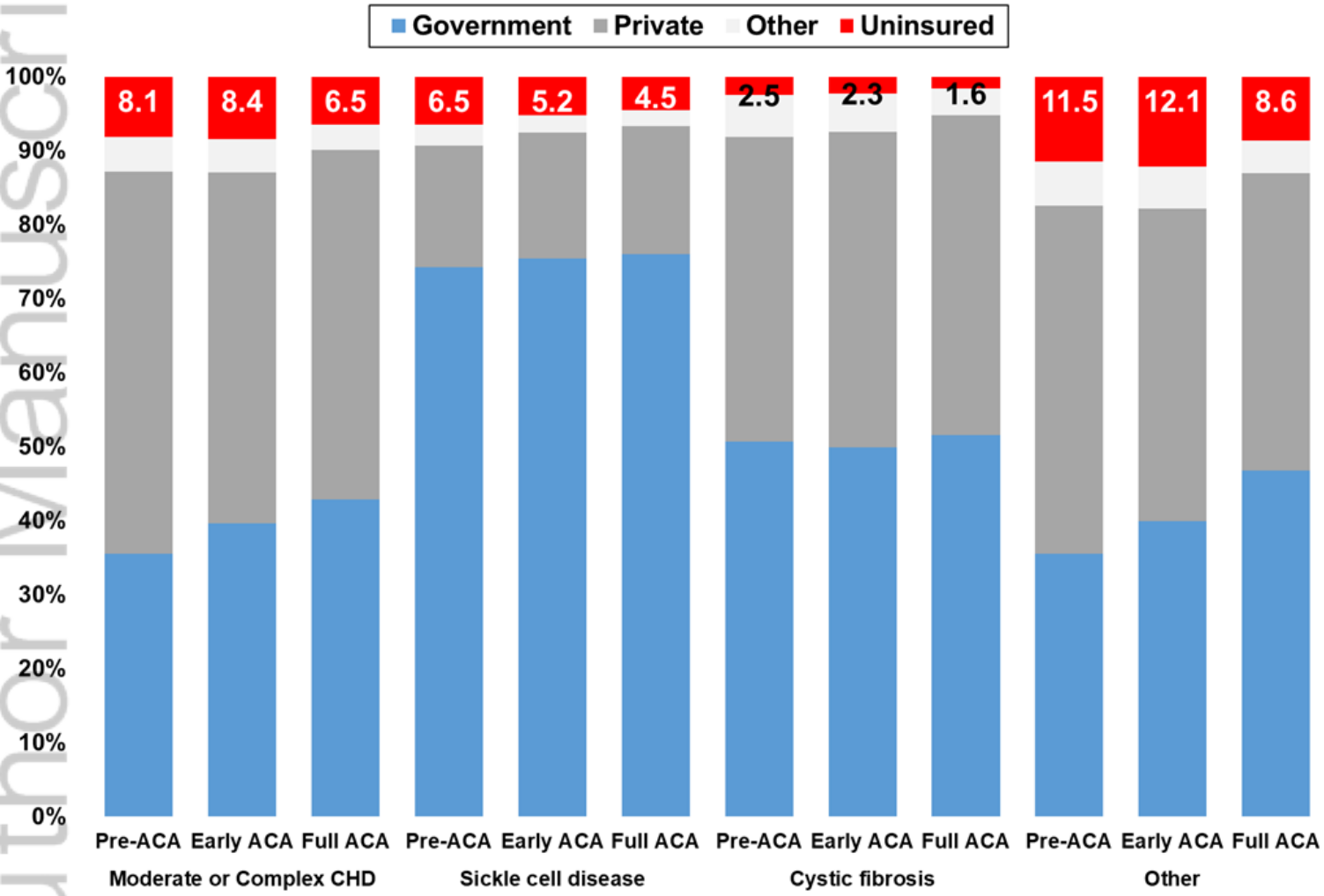


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