Received: 28 September 2017 | Revised: 11 December 2017 | Accepted: 3 January 2018

DOI: 10.1111/chd.12582

ORIGINAL ARTICLE

WILEY Congenital Heart Disease

Insurance access in adults with congenital heart disease in the Affordable Care Act era

Chien-Jung Lin MD, PhD[1] | Eric Novak MS[1] | Michael W. Rich MD[1] | Joseph J. Billadello MD[1,2]

[1]Cardiovascular Division, Department of Internal Medicine, Washington University School of Medicine, St. Louis, Missouri, USA

[2]Center for Adults with Congenital Heart Disease, Department of Internal Medicine, Washington University School of Medicine, St. Louis, Missouri, USA

Correspondence
Chien-Jung Lin, Cardiovascular Division, Department of Internal Medicine, Washington University School of Medicine, 660 South Euclid Ave, Campus Box 8086, St. Louis, MO 63110.
Email: clin1@wustl.edu

Funding information
None

Abstract

Background: Adults with congenital heart disease (ACHD) have traditionally been viewed as an underinsured population. Whether this is true in the Affordable Care Act era is unknown. We determined insurance patterns in ACHD patients compared to the non-ACHD cardiology population in a contemporary cohort.

Methods: All cardiology outpatient visits between July 2016 and February 2017 to a large referral center in the United States were reviewed. The primary payer was categorized as health maintenance organization (HMO), preferred provider organization (PPO), Medicare, Medicaid, self-pay, or other. Diagnosis and lesion severity of ACHD were extracted from ICD-10 diagnostic codes and assigned according to the 2008 American College of Cardiology/American Heart Association ACHD guidelines. Age-matching was used to account for baseline age differences between ACHD and non-ACHD patients.

Results: E ACHD and 17 154 non-ACHD patients were identified. Without age-matching, ACHD patients were significantly younger than non-ACHD patients (mean age 38.5 vs 63.8 years). After age-matching (N = 805 in each group), mean age was 39.5 years in both groups. ACHD patients had less HMO (29.1% vs 34.7%, $P = .012$) and Medicaid (12.4% vs 17.3%, $P = .006$) coverage, but more PPO (34.4% vs 27.5%, $P = .003$) and Medicare (23.2% vs 18.1%, $P = .005$) coverage compared to non-ACHD patients. No differences were found in private insurance, public insurance, or self-pay. Lesion complexity had no effect on insurance in ACHD patients. Eligibility of parental plan coverage did not affect use of private insurance. ACHD patients in states with Medicaid expansion had higher rates of Medicaid (15.6% vs 10.6%, $P = .045$) but lower rates of HMO coverage (24.5% vs 31.7%, $P = .036$) and self-pay (0% vs 3.3%, $P < .001$). ACHD status, age, income, and residence in Medicaid expansion states were independent determinants of insurance types.

Conclusions: In the Affordable Care Act era, ACHD patients are a well-insured population. Governmental policy has substantial effects on individual-level choice and access to insurance.

KEYWORDS

adults with congenital heart disease, health maintenance organization, insurance, Medicare, Medicaid, Medicaid expansion, preferred provider organization

1 | INTRODUCTION

Congenital heart disease (CHD) is a spectrum of structural abnormalities resulting from abnormal embryonic development of the heart or great vessels. CHD is estimated to occur in 0.4%–1% of live births.[1] Advances in surgical and medical management have not only allowed survival for previously fatal lesions, but also significantly prolonged life expectancy in patients with CHD. As a result, adults with congenital heart disease (ACHD) comprise a rapidly growing population.[2] The prognosis of CHD depends on lesion severity. While some simple

lesions are associated with normal to near normal life expectancy, other more complex lesions may lead to intermediate, uncertain or poor outcomes.[3] As advances in ACHD care improve the prognosis of ACHD patients,[4] continued access to specialized care is critical in sustaining favorable outcomes,[5] and has been associated with improved survival.[6]

Evidence from the 1990s suggests ACHD patients, especially those with complex lesions, face higher insurance premiums, exclusion of benefit for their cardiac conditions, or no insurability at all.[7] The Affordable Care Act (ACA) of 2010 attempts to expand health insurance access in part by providing states with options to expand their Medicaid programs, requiring insurers to offer dependent coverage for children under 26 years of age, and preventing insurers from denying coverage to people with preexisting conditions, such as CHD.[8–10] With the advent of these policies, it is unclear whether ACHD patients remain an underinsured population.

Based on our anecdotal experience we hypothesize that ACHD patients have similar insurance coverage compared to non-ACHD patients in the ACA era. To address this question, we analyzed billing data at an academic referral center for ACHD to assess patterns of insurance in patients with ACHD compared to those of non-ACHD adult cardiology patients. We also analyzed insurance patterns among subgroups of ACHD patients.

2 | METHODS

2.1 | Study population

We performed a retrospective study of all patient visits to the Cardiovascular Division's outpatient clinics at Barnes-Jewish Hospital and Barnes-Jewish West County Hospital/Washington University in St. Louis. Billing data for all visits during an 8-month period from July 2016 through February 2017 were analyzed. Multiple visits by the same patient were compressed to a single record. ACHD patients were identified by a code specific to the ACHD clinic. All other visits were classified as non-ACHD related. The study was approved by the institutional review board at Washington University in St. Louis.

Information was collected on patients' demographic characteristics, diagnoses, and payment methods. From the billing data we identified the primary payer, which was categorized as health maintenance organization (HMO), preferred provider organization (PPO), Medicare, Medicaid, self-pay, or other. Diagnoses for individual patients were extracted from ICD-10 diagnostic codes supplemented by manual curation of individual patient records. The severity of ACHD was assigned according to the 2008 American College of Cardiology/American Heart Association ACHD guidelines.[5] Income was estimated using 2015 median household income according to ZIP code obtained from US Census Bureau 2011–2015 American Community Survey 5-Year Estimates (factfinder.census.gov). The Medicaid expansion status of individual states was obtained from the National Conference of State Legislatures website (www.ncsl.org) accessed on June 1, 2017.

2.2 | Statistical analysis

Because ACHD patients were younger than non-ACHD patients and preliminary analysis identified age as a major confounding factor with respect to insurance status, we matched ACHD and non-ACHD patients by age. For each ACHD patient, a non-ACHD patient with the same age was randomly selected to create a 1-to-1 age-matched sample. There were 17 patients in the matched cohort with more than 1 insurance type across multiple visits throughout the study period. In such cases each primary insurance type was included in the analysis. Paired *t* test, Wilcoxon matched-pairs signed-rank test, and McNemar's test were used to compare continuous, non-normally distributed, and dichotomous variables, respectively, between age-matched groups. Within the ACHD population, comparisons between two independent groups were conducted using Student's two-sample *t* test for continuous variables, Mann-Whitney *U* test for non-normally distributed variables, and Fisher's exact test for categorical variables. When comparing more than two groups, ANOVA, Kruskal-Wallis test, and Fisher's exact test were used, and, when overall significance was found, all pair-wise comparisons were adjusted using a Bonferroni correction to control the type I error rate. Multivariable logistic regression analysis was used to investigate the association between insurance type and ACHD/non-ACHD status adjusting for age, income, and Medicaid expansion state residence status in the age-matched cohorts. Generalized estimating equations were used to account for the age-matching. In all analyses, a P value $< .05$ was considered statistically significant.

Public insurance was defined as Medicare and Medicaid insurance. Private insurance was defined as commercial, HMO, PPO, and worker's compensation. Patients who did not have public or private insurance and who did not self-pay were classified as other, which includes insurance type labeled as "hospital special contracts" and "other" in the billing data. All analyses were conducted in SAS v9.4 (SAS Institute Inc., Cary, North Carolina).

3 | RESULTS

3.1 | The ACHD population and age-matched cohorts

We identified 18 024 unique patients during the study time span, of whom 871 (4.8%) were ACHD patients and 17 153 (95.2%) were non-ACHD patients. Compared to non-ACHD patients, those with ACHD were significantly younger (38.5 vs 63.8 years of age, $P < .001$ [Table 1]). There was no difference between groups in the median income based on residential ZIP codes (Table 1). We identified 805 age-matched patient pairs whose characteristics are shown in Table 2. No difference was found in the median income or residence in Medicaid expansion states between the matched groups.

3.2 | Insurance pattern in ACHD compared to non-ACHD patients

Overall, there were no differences in the proportion of ACHD patients with either public or private insurance relative to non-ACHD patients. Compared to the matched non-ACHD population, ACHD patients were less likely to have HMO (29.1% vs 34.7%, $P = .012$) and more likely to have PPO as their primary coverage (34.4% vs 27.5%, $P = .003$ [Figure 1

TABLE 1 Patient demographics before age-matching

Characteristic	Total (N = 18024)	Non-ACHD (N = 17153)	ACHD (N = 871)	*P* value
Age (yr, mean ± SD)	62.6 ± 16.3	63.8 ± 15.4	38.5 ± 14.2	< .001
Age ≥ 26, No. (%)	17470 (96.9%)	16778 (97.8%)	692 (79.4%)	< .001
ACHD complexity, no. (%)				
High	222 (25.5%)	n/a	222 (25.5%)	
Moderate	428 (49.1%)	n/a	428 (49.1%)	
Low	221 (25.4%)	n/a	221 (25.4%)	
Median income (min, max)	51 435 (12 917, 169 547)	51 435 (12 917, 169 547)	51 060 (13 283, 153 190)	.53

and Table 3]). ACHD patients were more likely to have Medicare (23.2% vs 18.1%, $P = .005$) and less likely to have Medicaid as primary coverage (12.4% vs 17.3%, $P = .006$). There was no difference in the proportion of patients who were self-pay.

3.3 | Insurance pattern in ACHD patients of different complexity

To understand whether lesion complexity is associated with different insurance patterns in ACHD patients, we investigated the composition of our ACHD population. We adopted the 2008 ACC/AHA ACHD guidelines[5] to determine lesion complexity. Approximately half (403, 50.1%) of the ACHD patients were of moderate complexity, while a quarter each were of high (195, 24.2%) and low (207, 25.7%) complexity (Table 2). The mean age of patients inversely correlated with lesion complexity, from 43.4 years in low complexity, to 39.9 years in moderate complexity, and 34.4 years in high complexity ($P < .001$ for ANOVA). There was no difference in median income by ZIP codes between patients with different levels of complexity. There were no significant differences in insurance coverage as a function of lesion complexity.

3.4 | Insurance pattern in ACHD patients eligible for parental coverage

To understand whether eligibility for parental coverage affects private insurance coverage in ACHD patients, we analyzed insurance patterns in ACHD patients below 26 years of age versus those ages 26 or above. There was no difference in the proportion of ACHD patients with private insurance, HMO or PPO coverage (Figure 2), suggesting parental plan eligibility does not play a major role in insurance patterns for ACHD patients. However, ACHD patients 26 years of age or above were more likely to be covered by Medicare (26.6% vs 8.1%, $P < .001$) and less likely to be covered by Medicaid (9.4% vs 25.7%, $P < .001$ [Figure 2]) than ACHD patients less than age 26, a finding consistent across all levels of lesion complexity.

3.5 | Insurance pattern in ACHD patients in states with or without medicaid expansion

Due to the geographical location of our center, approximately 65% of our ACHD population resided in states without Medicaid expansion, such as Missouri, whereas 35% lived in states with Medicaid expansion, such as Illinois (Figure 3). Compared to ACHD patients from non-Medicaid expansion states, a higher proportion of those from states with Medicaid expansion used Medicaid as primary coverage (15.6% vs 10.6%, $P = .045$) and a lower proportion used HMO as primary coverage (24.5% vs 31.7%, $P = .036$ [Figure 4]). None of the ACHD patients from Medicaid expansion states were self-pay (0% vs 3.3%, $P < .001$ [Figure 4]).

3.6 | Demographic and socioeconomic characteristics influence insurance

We next performed multivariable regression analysis in the age-matched cohorts to identify factors that influence insurance patterns. After adjusting for age, median income, and residence in Medicaid expansion states, ACHD status was independently associated with lower odds of having HMO and Medicaid, as well as increased odds of having PPO and Medicare (Table 4). These findings are concordant

TABLE 2 Patient characteristics among matched cohorts

Characteristic	Total (N = 1610)	Non-ACHD (N = 805)	ACHD (N = 805)	*P* value
Age (yr, mean ± SD)	39.5 ± 14.3	39.5 ± 14.3	39.5 ± 14.3	n/a
Age ≥ 26, No. (%)	1314 (81.6%)	657 (81.6%)	657 (81.6%)	n/a
ACHD complexity, no. (%)				
High	195 (24.2%)	n/a	195 (24.2%)	
Moderate	403 (50.1%)	n/a	403 (50.1%)	
Low	207 (25.7%)	n/a	207 (25.7%)	
Median income, (min, max)	50 588 (13 283, 153 190)	50 532 (13 283, 153 190)	51 080 (13 283, 153 190)	.19
Residence in Medicaid expansion states, No. (%)	562 (34.9%)	268 (33.3%)	294 (36.5%)	.18

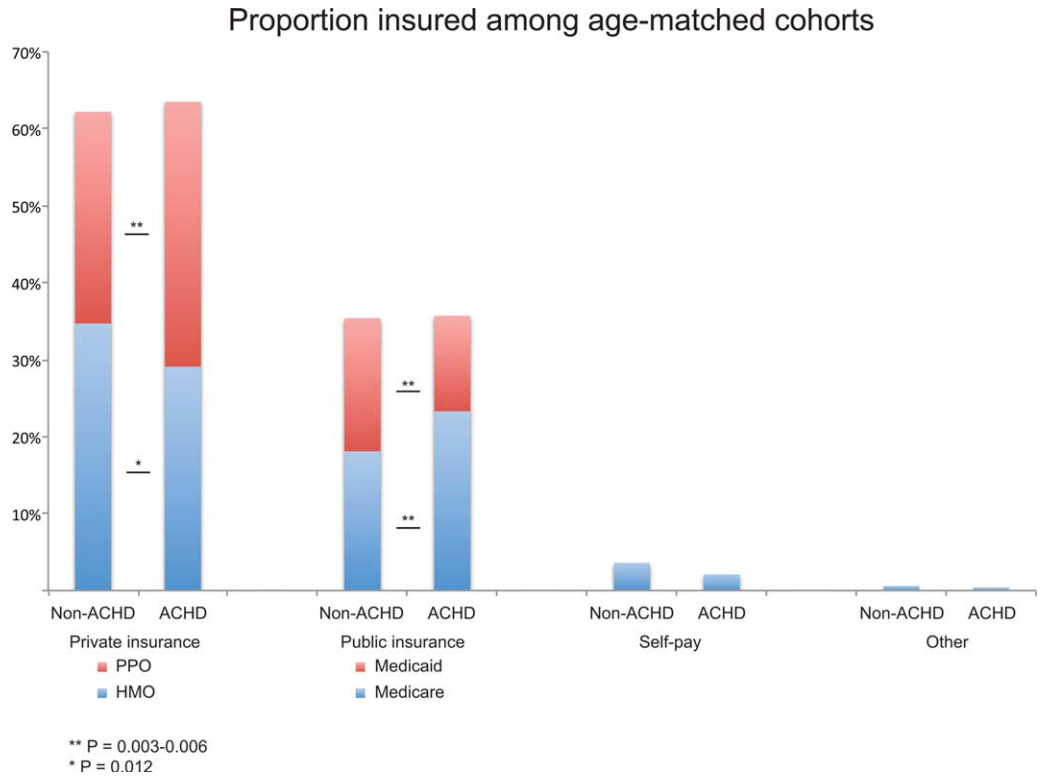

FIGURE 1 Proportion insured among age-matched cohorts. Bar graphs indicate percentages of patients with different types of primary insurance as indicated. $^{**}P = .003–.006$. $^{*}P = .012$. ACHD, adults with congenital heart disease. Abbreviations: HMO, health maintenance organization. PPO, preferred provider organization

with the unadjusted analyses presented above, indicating that ACHD status is an independent determinant of insurance type. Increasing age was independently associated with lower odds of having HMO, PPO and Medicaid, as well as increased odds of having Medicare. Increasing income was independently associated with increased odds of having HMO and PPO, as well as reduced odds of having Medicare, Medicaid, and self-pay. Residence in a Medicaid expansion state was independently associated with increased odds of having PPO, as well as lower odds of having HMO and self-pay (Table 4).

4 | DISCUSSION

We assessed patterns of insurance coverage in patients with ACHD. We found that almost all ACHD patients have insurance coverage and that very few self-pay. Compared to an age-matched non-ACHD cohort, ACHD patients have more PPO and Medicare coverage, as well as less HMO and Medicaid coverage. No difference was found in private insurance, public insurance, or self-pay. Lesion complexity was not found to affect access to insurance in ACHD patients. The private insurance coverage in ACHD patients cannot be explained by eligibility for coverage as dependents under their parental plans. Residence in states with Medicaid expansion affects insurance coverage in ACHD patients, such that no ACHD patients from Medicaid expansion states were self-pay. Multivariable regression analysis revealed ACHD status, age, income, and residence in states with Medicaid expansion were independent determinants of most insurance types.

To the best of our knowledge, this study is the first to systemically investigate insurance patterns in ACHD patients and directly compare

TABLE 3 Proportion insured among matched cohorts

Characteristic	Total (N = 1610)	Non-ACHD (N = 805)[a]	ACHD (N = 805)[a]	*P* value
HMO, No. (%)	513 (31.9%)	279 (34.7%)	234 (29.1%)	.012
PPO, No. (%)	498 (30.9%)	221 (27.5%)	277 (34.4%)	.003
Medicare, no. (%)	333 (20.7%)	146 (18.1%)	187 (23.2%)	.005
Medicaid, no. (%)	239 (14.8%)	139 (17.3%)	100 (12.4%)	.006
Self-pay, no. (%)	46 (2.9%)	29 (3.6%)	17 (2.1%)	.07
Other, no. (%)	8 (0.5%)	5 (0.6%)	3 (0.4%)	.48

[a]A small proportion of patients have more than 1 primary insurance type during multiple visits.

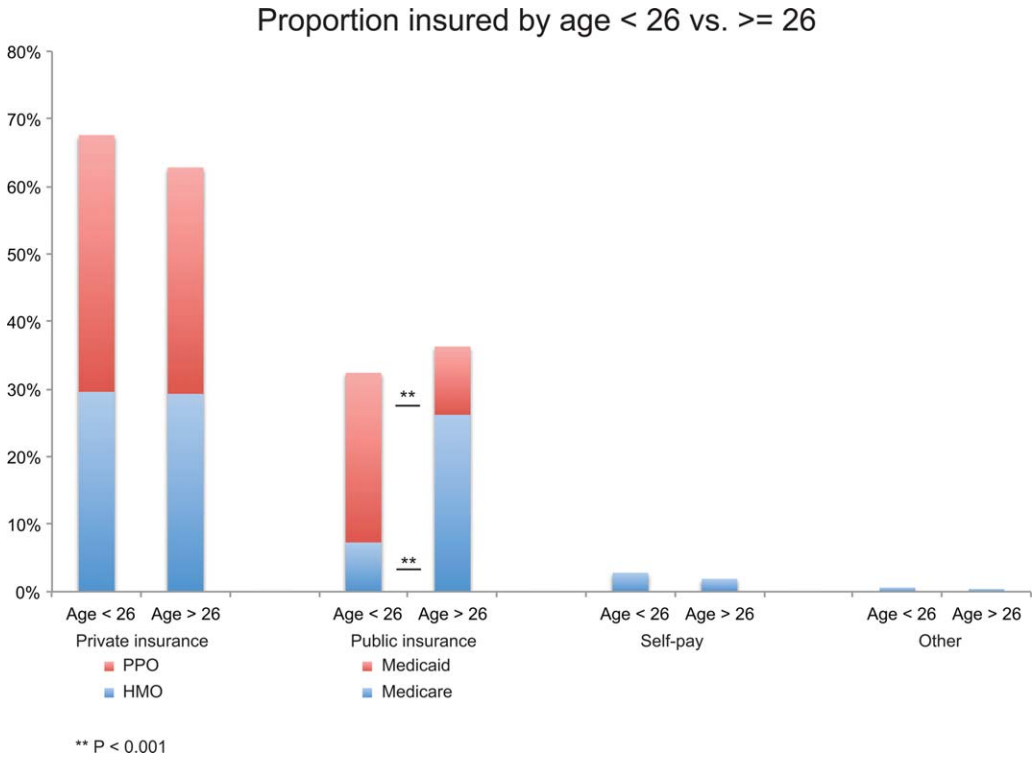

FIGURE 2 Proportion insured by age < 26 vs ≥ 26. Bar graphs indicate percentages of patients with different types of primary insurance among ACHD patients with age below 26 years versus those 26 years and above. $^{**}P < .001$. Abbreviations: HMO, health maintenance organization. PPO, preferred provider organization

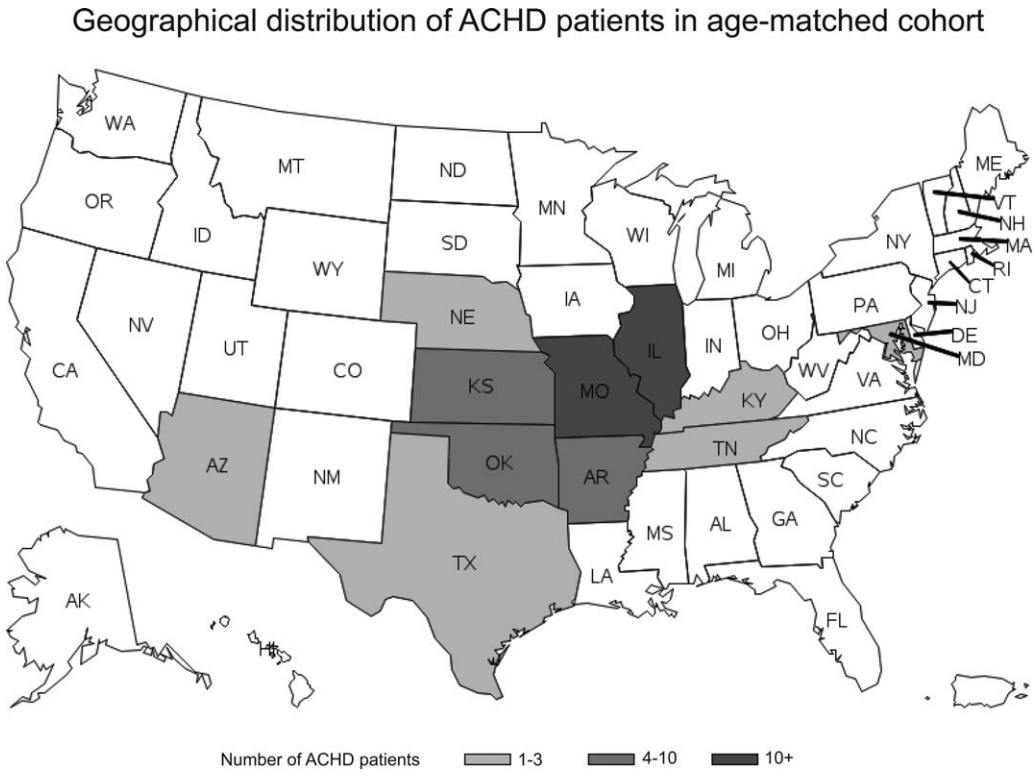

FIGURE 3 Geographical distribution of ACHD patients in age-matched cohort. A map of the United States showing state of residence of ACHD patients in the matched cohort. Abbreviations: ACHD, adults with congenital heart disease

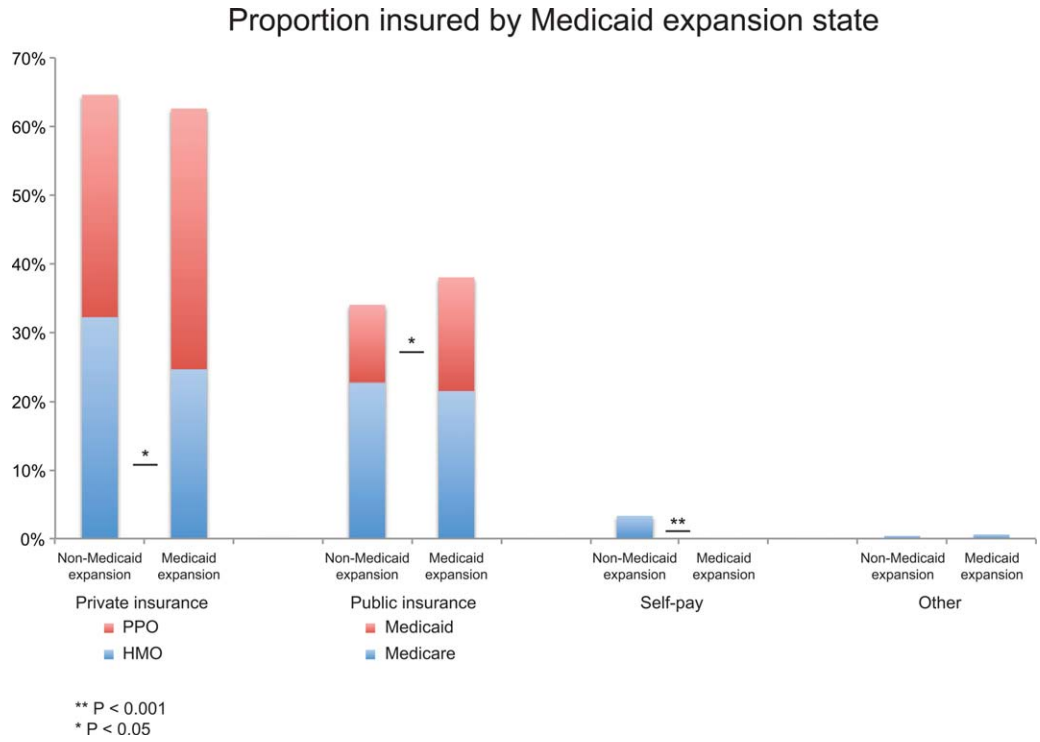

FIGURE 4 Proportion insured by Medicaid expansion state. Bar graphs indicate percentages of patients with different types of primary insurance among ACHD patients residing in states with Medicaid expansion or those without. $^{**}P < .001$; $^{*}P < .05$. Abbreviations: HMO, health maintenance organization. PPO, preferred provider organization

them with those in non-ACHD patients in the ACA era. The strength of this study is the inclusion of contemporary and representative ACHD populations, as well as the direct comparison with an age-matched non-ACHD cardiology patient cohort. We included a major urban academic teaching hospital as well as a suburban clinic staffed by the same cardiology group. The geographical location of our center allowed us to investigate insurance profiles in states with and without Medicaid expansion.

Health insurance is critical for access to medical care. ACHD patients may face distinct challenges in daily life, such as educational

TABLE 4 Logistic regression model

Type of insurance	Variable	Odds ratio	95% CI	*P*value
HMO	ACHD	0.76	(0.62, 0.94)	.010
	Age (per 5-year increase)	0.91	(0.87, 0.94)	<.001
	Median income (per $10 000 increase)	1.17	(1.11, 1.23)	<.001
	Medicaid expansion state	0.73	(0.59, 0.91)	.006
PPO	ACHD	1.35	(1.09, 1.68)	.006
	Age (per 5-year increase)	0.92	(0.89, 0.96)	<.001
	Median income (per $10 000 increase)	1.14	(1.09, 1.20)	<.001
	Medicaid expansion state	1.48	(1.19, 1.84)	<.001
Medicare	ACHD	1.48	(1.15, 1.90)	.003
	Age (per 5-year increase)	1.37	(1.31, 1.44)	<.001
	Median income (per $10 000 increase)	0.91	(0.85, 0.97)	.003
	Medicaid expansion state	0.99	(0.75, 1.31)	.96
Medicaid	ACHD	0.69	(0.52, 0.93)	.013
	Age (per 5-year increase)	0.85	(0.80, 0.90)	<.001
	Median income (per $10 000 increase)	0.56	(0.50, 0.64)	<.001
	Medicaid expansion state	1.29	(0.95, 1.74)	.10
Self-pay	ACHD	0.67	(0.36, 1.24)	.20
	Age (per 5-year increase)	0.97	(0.87, 1.08)	.54
	Median income (per $10 000 increase)	0.77	(0.64, 0.93)	.006
	Medicaid expansion state	0.09	(0.02, 0.36)	<.001

achievement, employment,[7] and personal relationships, despite having a healthier lifestyle.[11] Their reduced participation in the workforce may negatively impact insurance coverage.[7] Studies from the 1990s indicated that up to 20% of ACHD patients were uninsured, and those with insurance had more costly individual plans rather than group policies.[5] Other studies suggest ACHD patients are significantly more likely to encounter difficulty acquiring insurance irrespective of lesion severity.[12] Therefore, it is plausible that ACHD patients have reduced insurance coverage, hence access to medical care, compared to the general population. In this study, we used a contemporary database in the ACA era to address these preconceptions. We found that, in the age-matched cohort, 63% of ACHD patients have private insurance, while another 35.5% have public insurance as primary coverage. Only 2.1% of ACHD patients self-pay. These findings are in sharp contrast to the 20% uninsured rate reported in the 1990s.[13] A recent study described 70% private insurance and 26% public insurance rates in ACHD patients in the United States.[14] This single-center, survey-based study excluded patients previously seen by other ACHD specialists and those who could not complete questionnaires. It reported a higher public insurance rate compared to the national average.[14] Compared to this study, our inclusion of all ACHD and non-ACHD cardiology patients increased sample size by more than 10-fold, reduced potential biases associated with questionnaires,[15] and provided direct comparison to a representative, comparable, and age-matched non-ACHD cardiology patient cohort. The age-matched non-ACHD cohort, with 547 (68%) patients having diagnoses requiring longitudinal cardiology care (eg, status post heart transplant, cardiomyopathy, presence of defibrillator/pacemaker, status post valve replacement, stable ischemic heart disease, etc), represents a mix fairly similar to the ACHD population in terms of complexity and acuity, hence a reasonable comparator population. Comparing ACHD with non-ACHD patients, no difference could be found in the proportion of private insurance, public insurance, and self-pay. Therefore, our study provides strong evidence to refute the notion that ACHD patients are underinsured compared to the non-ACHD population.

Socioeconomic and demographic factors may impact individual options and choices for insurance and healthcare access.[16] We did not find a difference in economic status, assessed by residential ZIP code as a surrogate, between ACHD and non-ACHD patients. Our finding is in contrast to a recent study that demonstrated lower income in ACHD patients compared to the national median household income.[14] Although our use of age-matched cohorts avoids age-related bias in income, our use of ZIP code median income, rather than individual-level income data, may account for the lack of difference in income between ACHD and non-ACHD patients in our study.

The private insurance coverage in ACHD patients cannot be explained by eligibility for coverage as dependents under their parental plans. Under the ACA, patients may stay under parents' employment-based private insurance plans until the age of 26. In ACHD patients 26 years of age or older, there was no significant difference in private insurance coverage compared to those below the age of 26. Furthermore, ACHD complexity did not impact insurance coverage, regardless of eligibility for coverage on parental plans. Although we do not have individual-level employment information, our finding implies that subsets of ACHD patients of different severity may have similar employability that drives their insurability.

In the United States, patients may be eligible for Medicare if over age 65 or permanently disabled. Medicaid eligibility varies across states but in general it is obtained when there is lower-than-threshold income. In the age-matched cohort there were more ACHD patients, compared to non-ACHD patients, with Medicare coverage. Among ACHD patients, a higher percentage of Medicare coverage was observed in those 26 years of age or above, compared to those below 26. It is possible that ACHD status is associated with increased likelihood of being disabled (and hence Medicare eligible), with increasing age. Among the 605 pairs of patients between 26 and 64 years of age, 129 (21.3%) ACHD patients and 91 (15%) non-ACHD patients used Medicare as primary insurance, most likely due to disability. By contrast, there were fewer ACHD patients with Medicaid compared to non-ACHD patients. In ACHD patients, those age 26 or above were less likely to have Medicaid primary coverage compared to those below age 26. It is possible that some ACHD patients who qualified for Medicaid also qualified for Medicare and preferentially choose the latter, but validation of this hypothesis requires additional studies.

The ACA enacted Medicaid expansion, but individual states may choose whether or not to participate.[9] Our medical center is located in a state without Medicaid expansion (Missouri) and is geographically close to one with Medicaid expansion (Illinois). Our dataset thus provides an opportunity to examine the effects of Medicaid expansion with regard to insurance coverage in ACHD patients. We found that a higher proportion of ACHD patients from states with Medicaid expansion have Medicaid coverage. By contrast, they have less HMO as primary coverage. Importantly, in our sample no patients from Medicaid expansion states are self-pay. This finding suggests that expanded Medicaid coverage increased insurance access to ACHD patients, consistent with a recent Department of Health and Human Services report that indicated Medicaid expansion reduced uninsured adults in the United States.[17] Furthermore, ACA regulations prevent insurers from refusing coverage to patients with preexisting conditions, including congenital heart diseases,[10] which may help increase insurance coverage for ACHD patients. Together, our findings indicate that governmental policy has substantial effects on individual-level choice and access to insurance.

There are several important limitations to this study. The single-center and retrospective nature of the study rendered it susceptible to bias due to patient self-selection. There may be other confounding variables not included in our analysis that may affect comparisons between ACHD and non-ACHD patients. Our use of primary payer as dependent variable does not capture patients' secondary co-insurance. The proportion of ACHD patients unable or unwilling to be seen in our clinics is unknown. It is possible that some ACHD patients are not captured in this study due to lack of insurance, leading to underestimation of the true uninsured rate. However, as our center has the only Adult Congenital Heart Association (ACHA) ACHD-accredited comprehensive care center and the largest safety-net hospital system in the St. Louis metropolitan area, we believe it is unlikely that there are a large number of uninsured

patients who obtain their care elsewhere in the region. In this patient population, there is heavy representation from the St. Louis metropolitan area, Missouri, and the Midwest. Different Medicare and Medicaid policies in other states and regions of the country may limit the generalizability of the conclusions drawn from this study.

In conclusion, we report in a large, contemporary ACHD cohort that ACHD patients have comparable insurance coverage to non-ACHD cardiology patients in the Affordable Care Act era. The high rates of insurance coverage in ACHD patients cannot be explained by coverage as dependents under their parental plans. Residence in states with Medicaid expansion favorably affects insurance coverage in ACHD patients.

ACKNOWLEDGMENT

The authors thank Dr. Douglas L. Mann for critical review of the manuscript.

CONFLICT OF INTEREST

None.

AUTHOR CONTRIBUTIONS

All authors participated in revising and editing the paper.
Institutional Board Review approval: Lin
Data acquisition: Lin
Statistical analyses: Lin, Novak
Conceived the idea: Billadello
Mentorship: Billadello
Provided mentorship: Lin
Oversaw the conduct of the project: Rich, Billadello
Drafted the manuscript: Lin

ORCID

Chien-Jung Lin MD, PhD http://orcid.org/0000-0002-1702-9411

REFERENCES

[1] Benjamin EJ, Blaha MJ, Chiuve SE, et al. Heart disease and stroke statistics-2017 update: a report from the American Heart Association. *Circulation.* 2017;135(10):e146–e603.

[2] Avila P, Mercier LA, Dore A, et al. Adult congenital heart disease: a growing epidemic. *Can J Cardiol.* 2014;30(12 suppl):S410–S419.

[3] Vonder Muhll I, Cumming G, Gatzoulis MA. Risky business: insuring adults with congenital heart disease. *Eur Heart J.* 2003;24(17):1595–1600.

[4] Khairy P, Ionescu-Ittu R, Mackie AS, Abrahamowicz M, Pilote L, Marelli AJ. Changing mortality in congenital heart disease. *J Am Coll Cardiol.* 2010;56(14):1149–1157.

[5] Warnes CA, Williams RG, Bashore TM, et al. ACC/AHA 2008 guidelines for the management of adults with congenital heart disease: a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (writing committee to develop guidelines on the management of adults with congenital heart disease). *Circulation.* 2008;118:e714–e833.

[6] Mylotte D, Pilote L, Ionescu-Ittu R, et al. Specialized adult congenital heart disease care: the impact of policy on mortality. *Circulation.* 2014;129(18):1804–1812.

[7] Celermajer DS, Deanfield JE. Employment and insurance for young adults with congenital heart disease. *Br Heart J.* 1993;69(6):539–543.

[8] Miller S, Wherry LR. Health and access to care during the first 2 years of the ACA medicaid expansions. *N Engl J Med.* 2017;376(10):947–956.

[9] Sommers BD, Baicker K, Epstein AM. Mortality and access to care among adults after state Medicaid expansions. *N Engl J Med.* 2012;367(11):1025–1034.

[10] Blumenthal D, Abrams M, Nuzum R. The affordable care act at 5 years. *N Engl J Med.* 2015;372(25):2451–2458.

[11] Zomer AC, Vaartjes I, Uiterwaal CS, et al. Social burden and lifestyle in adults with congenital heart disease. *Am J Cardiol.* 2012;109(11):1657–1663.

[12] Crossland DS, Jackson SP, Lyall R, et al. Life insurance and mortgage application in adults with congenital heart disease. *Eur J Cardiothorac Surg.* 2004;25(6):931–934.

[13] Truesdell SC, Clark EB. Health insurance status in a cohort of children and young adults with congenital cardiac diagnoses. (abstract). *Circulation.* 1991;844(suppl II):1991386.

[14] Brown NM, Maul TM, Reed H, Clayton S, Cook SC. Obstacles encountered in developing an adult congenital heart disease program. *Am J Cardiol.* 2013;112(12):1953–1957.

[15] Choi BC, Pak AW. A catalog of biases in questionnaires. *Prev Chronic Dis.* 2005;2(1):A13.

[16] Braveman P, Gottlieb L. The social determinants of health: it's time to consider the causes of the causes. *Public Health Rep.* 2014;129(suppl 2):19–31.

[17] NIH. Medicaid expansion impacts on insurance coverage and access to care. ASPE Issue Brief. Washington, DC: NIH; 2017.

How to cite this article: Lin C-J, Novak E, Rich MW, Billadello JJ. Insurance access in adults with congenital heart disease in the Affordable Care Act era. *Congenital Heart Disease.* 2018;13:383–391. https://doi.org/10.1111/chd.12582