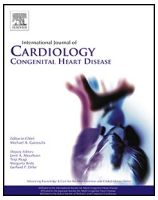
International Journal of Cardiology Congenital Heart Disease 18 (2024) 100543

Contents lists available at ScienceDirect

International Journal of Cardiology Congenital Heart Disease

journal homepage: www.journals.elsevier.com/international-journal-of-cardiology-congenital-heart-disease



Association between insurance type, clinical characteristics, and healthcare use in adults with congenital heart disease☆

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A B S T R A C T

Introduction: Adults with congenital heart disease (CHD) represent a heterogeneous and growing population with high healthcare utilization. We sought to understand the association between insurance type, healthcare use, and outcomes among adults with CHD in Oregon.

Methods: The Oregon All Payers All Claims database from 2010 to 2017 was queried for adults aged 18–65 in 2014 with ICD-9 or 10 codes consistent with CHD; patient demographics, comorbidities, healthcare use, and disease severity were identified. Insurance type was categorized as either public (Medicare and Medicaid) or private (commercial). Descriptive statistics were used to compare groups. Use rates and odds ratios were calculated representing probability of at least one event per person-year using logistic regression with clustering on patients.

Results: Of 13,792 adults with CHD, 48 % had a form of public insurance. More publicly insured patients had moderate or severe anatomic complexity (29.5 % vs. 23.0 %; $p < 0.0001$), treatment for drug and alcohol use (25.0 % vs. 7.2 %; $p < 0.0001$), and mental health diagnoses (66.6 % vs. 51.0 %; $p < 0.0001$). They were more likely to reside in a rural area (24.5 % vs. 16.1 %; $p < 0.0001$). Adjusted for age and CHD severity, publicly insured patients were less likely to access overall ambulatory care (aOR 0.72, 99 % CI 0.66 to 0.80) but more likely to access emergency (aOR 3.86, 99 % CI 3.62 to 4.12) and inpatient (aOR 3.06, 99 % CI 2.81 to 3.33) care, as shown in Fig. 1. Length of hospital stay (5.7 vs. 4.4 days, $p < 0.0001$) and rates of 30-day readmission (17.1 % vs. 11.0 %, $p < 0.001$) were higher in those with public insurance. However, individuals with public insurance were significantly more likely to undergo their annual guideline-indicated echocardiogram (aOR 1.49, 99 % CI 1.23 to 1.80) and attend their annual ACHD visits (aOR 1.62, 99 % CI 1.40 to 1.87).

Conclusions: Our study shows that publicly insured adults with CHD in Oregon have more anatomically complex disease, more comorbidities, and higher healthcare use. While they were more likely to receive guideline-indicated ACHD care, they were also higher utilizers of emergency room and inpatient resources, implying that they may benefit from targeted interventions to improve outcomes and decrease unplanned healthcare use.

1. Introduction

Advances in the diagnosis and treatment of congenital heart disease (CHD) have significantly improved survival, such that the adult CHD (ACHD) population in the United States currently numbers >1.4 million people [1]. As the lifespan of adults with CHD increases, it is essential to understand the full breadth of factors, including socioeconomic and systems factors, which impact long-term outcomes in this population. Adults with CHD comprise a heterogeneous patient population whose unique anatomical variants typically necessitate lifelong, comprehensive, specialized medical care as recommended by practice guidelines [2].Fig. 1.

The cumulative impact of ACHD healthcare utilization over the lifespan is significant, as those with CHD have been noted to be higher utilizers of healthcare than the general population [3]. As ACHD clinicians and health systems attempt to identify strategies to optimize healthcare delivery and outcomes for their ACHD patients, it is important to understand the factors that contribute to healthcare utilization in this population, including factors that may drive variability in utilization between patients.

As is the case with the general population, social determinants of health such as low socioeconomic status (SES) and inadequate health insurance coverage have been established as significant risk factors for adverse health outcomes in CHD. For instance, lack of insurance has been identified as a risk factor for emergency care utilization in adults with CHD, and financial hardship has been linked to delays in care among children with CHD in the United States [4,5].

When studying the relationship between a patient's financial status and healthcare outcomes in the United States, it is important to acknowledge the country's status as the only high-income,

☆ The authors of this manuscript have no disclosures.

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https://doi.org/10.1016/j.ijcchd.2024.100543
Received 21 May 2024; Received in revised form 8 September 2024; Accepted 14 September 2024
Available online 19 September 2024

industrialized nation without universal health insurance. The United States is also known to have much higher healthcare costs than other developed countries. In fact, health expenditures per capita in the United States exceed twice the average of other developed nations [6]. These steep costs often translate to issues in accessing and affording healthcare. The American health insurance system involves a mixed model of private and public insurance types. The major public models include Medicare and Medicaid. Medicare is primarily for adults 65 years of age and older but is also accessed by younger individuals with certain disabilities. Medicaid access is primarily contingent on low-income status, but qualifications vary based on state [7]. Between these public models and the numerous private insurance programs, many gaps in coverage persist in the United States.

While the Affordable Care Act in 2010 led to significantly higher insurance rates among those with CHD [8], we know that insurance attainment does not erase the impact of SES on cardiovascular outcomes [9]. We postulate that SES and health insurance type influence healthcare utilization in ACHD and that understanding the relationship between these factors may inform the development of systems of care that better support individuals with CHD. We also postulate that access to health care is modulated by patient costs, and that paradoxically, low SES individuals on Medicaid may have better access to care due to lower personal healthcare costs (e.g. copays) than those on commercial insurance.

In this study, we examined the association between insurance type and healthcare utilization in Oregon, which is a Medicaid expansion state with low levels of uninsurance compared to many other states [10]. The goal of the study was to determine how insurance status, SES, and rural home location impact healthcare use among adults with CHD in Oregon.

2. Methods

2.1. CHD diagnosis

The Oregon All Payers All Claims (APAC) database from 2010 to 2017 was queried for adults aged 18–64 years with International Classification of Diseases-9 and 10 (ICD-9 and ICD-10) codes consistent with CHD (codes 745–747, Q20-Q25, I27.83) (Supplementary Table S2). Using a hierarchal algorithm validated in prior studies, patients with ICD codes associated with low sensitivity and specificity were excluded, as were those with non-specific codes like "other congenital heart disease" (746.9, 745.9, 746.89) [1]. In total, 13,792 patients were studied and further classified into thirteen major defect subgroups based on ICD codes. Based on the 2008 AHA/ACC guideline on CHD anatomic complexity, the subgroups were graded on the level of disease complexity, ranging from mild to moderate or severe. For consistency with our prior work, we applied the 2008 AHA/ACC guideline for the management of adults with CHD, as we collected our data prior to the 2018 AHA/ACC guideline updates. This is important to point out given that we classify bicuspid aortic valve (BAV) as a lesion of mild disease complexity per the 2008 guideline, while the 2018 guideline has reclassified BAV as moderate disease complexity [11].

2.2. Patient risk factors

Patients' ZIP codes of residence were classified as urban or rural/frontier using definitions published by the Oregon Office of Rural Health. In the APAC database, the ZIP code is the most recent on record with a given payer. Distance from the ACHD center was calculated as the drive time from the ZIP code centroid to the hospital address using queries with a Google Maps application programming interface (API) executed during off-peak driving hours. Patient comorbidities were determined using the Statistical Analysis Software (SAS) version of

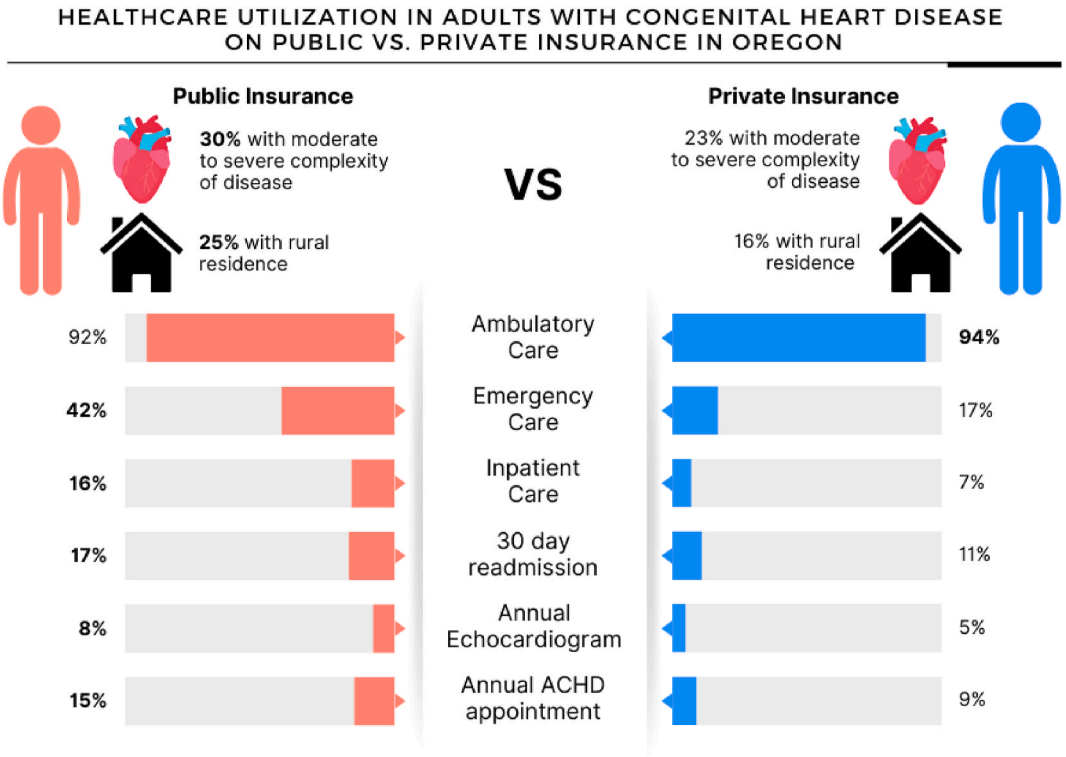

Fig. 1. HEALTHCARE UTILIZATION IN ADULTS WITH CONGENITAL HEART DISEASE ON PUBLIC VS PRIVATE INSURANCE IN OREGON. This figure captures patterns of healthcare utilization across patients with public and private insurance living in Oregon, as displayed in side-by-side bar graphs. When comparing the different rates of utilization, the greater of the two percentages is bolded. This figure also displays demographic data for each population, including their relative rates of moderate to severe complexity of disease and rates of rural residence.

Clinical Classifications Software (CCS; Agency for Healthcare Research and Quality, Rockville, MD) (Supplementary Table S5).

In patient-level summaries, patients were counted as having public insurance if they had claims with Medicaid or Medicare payers in any calendar year, even if they also had private coverage at another time; similarly, person-years were counted as having public insurance if any Medicaid or Medicare claims were filed in the calendar year. A person classified in the public insurance group could contribute year-level observations for both public and private insurance.

2.3. Utilization

Primary diagnosis associated with emergency department (ED) and hospital visits was determined by the primary diagnosis code (Supplementary Table S7); if that field contained a code for CHD, then the second diagnosis code was used. ED, hospital, and office visits were identified using APAC's health care grouper (HCG). Of note, we were unable to accurately identify the beginning and end of pregnancy in the dataset. Therefore, we were unable to distinguish utilization related specifically to pregnancy or the postpartum state from other types of healthcare utilization in the ambulatory setting.

A single inpatient episode was defined by consecutive days with inpatient claims, excluding pregnancy and perinatal conditions, along with other potentially planned procedures (organ transplants, joint replacements, etc.). For these exclusions, we used APAC's HCG and the Healthcare Effectiveness Data and Information Set (HEDIS) definitions. Procedures were identified using procedure billing codes (Supplementary Table 4 S4) [12].

2.4. Statistical analysis

Demographics were summarized as counts and percentages of unique patients. Because only claims records were available (that is, not all enrollees, but only those with claims), a person-year was defined as a calendar year with at least one claim. Utilization burden was summarized as the number and percent of people per year with given types of claims. Odds ratios and their 99 % confidence intervals were calculated using logistic regression with cluster-robust standard errors to account for multiple person-years contributed by the same patient. Inpatient utilization was summarized with episodes as the unit of analysis using cluster-robust standard errors. Differences in emergency department (ED) utilization were calculated as incidence rate ratios (IRRs) using person-year as the unit of analysis and the count of ED days as the outcome in a negative binomial regression model with cluster-robust standard errors; counts were winsorized by substituting the 99th percentile for (outlier) values greater than the 99th percentile. Because of the large sample and number of estimates, we presented 99 % confidence intervals.

3. Results

3.1. Demographic data

Our study included 13,792 adults with ICD codes consistent with CHD. The most prevalent ACHD diagnoses were shunts (N = 6,156, 44.6 %) and bicuspid aortic valve (N = 3,605, 26.1 %) (Table 1). Most patients had mild complexity CHD (N = 10,183, 73.8 %); 26.2 % (N = 3609) had moderate or severe complexity CHD. Moderate or severe CHD was more common among those with public insurance (N = 1,966, 29.5 %) than in those with private insurance (N = 1,643, 23.0 %) ($p < 0.0001$) (Table 2).

Among patients studied, 6656 had public insurance, most of whom had Medicaid (N = 4,707, 70.7 %). Our study did not include patients older than 65 years of age, but among those with public insurance, 723 had Medicare (10.9 %) and 1226 patients had dual Medicaid + Medicare coverage (18.4 %). A total of 7136 patients had private insurance only. The age distribution of study participants is shown in Table 2. Those with public insurance were more likely to be at the younger (aged 18–24 years) or older (aged 55–64 years) ends of the age spectrum. The most common comorbid conditions were mental health diagnoses (N = 8,074, 58.5 %), followed by rhythm disorders (N = 7,734, 56.1 %), hypertension (N = 6,478, 47.0 %), and hyperlipidemia (N = 6,044, 43.8 %) (Table 2). Mental health disorders, rhythm disorders, and hypertension were more prevalent among publicly insured patients. For instance, 66.6 % (N = 4435) of those with public insurance had an underlying mental health diagnosis vs. 51.0 % (N = 3639) of those with private insurance ($p < 0.0001$).

Home location was also examined, as distance to care can impact access to and utilization of healthcare. 20.2 % (N = 2781) of patients lived in rural areas, with the remainder living in or around metropolitan areas. A higher proportion of patients with private insurance lived in the metropolitan Portland area (N = 3,957, 55.5 %) as compared to those with public insurance (N = 2,936, 44.1 %) ($p < 0.0001$). As adults with CHD are often advised to seek medical care at a specialized ACHD center, proximity to an ACHD center was also evaluated. Most patients lived within 1 h's distance from the state's only accredited ACHD center

Table 1
Prevalence of ACHD diagnoses and person-years in claims, 2010–2017 (N = 13,792 unique patients and 70,683 person-years).

ACHD diagnosis	Moderate or severe				Mild			
	Unique patients	% of sample	No. person years	% with public coverage	Unique patients	% of sample	No. person years	% with public coverage
Eisenmenger/Cyanosis	68	(0.49)	345	(73.6)	–	–	–	–
Single ventricle/Fontan	275	(1.99)	1351	(53.1)	–	–	–	–
Transposition of the great arteries	389	(2.82)	1928	(49.5)	–	–	–	–
Conotruncal	742	(5.38)	3794	(52.9)	–	–	–	–
Coarctation of the aorta	764	(5.54)	3701	(36.9)	–	–	–	–
Atrioventricular septal defect	214	(1.55)	1146	(63.4)	–	–	–	–
Pulmonary valve disease	–	–	–	–	422	(3.06)	2012	(44.6)
Ebstein anomaly	122	(0.88)	617	(38.1)	–	–	–	–
Anomalous pulmonary venous return	111	(0.80)	570	(42.5)	–	–	–	–
Shunts	–	–	–	–	6156	(44.6)	32,032	(39.4)
Subaortic stenosis	194	(1.41)	987	(41.0)	–	–	–	–
Anomalous coronary artery	730	(5.29)	3859	(39.6)	–	–	–	–
Bicuspid aortic valve	–	–	–	–	3605	(26.1)	18,341	(27.6)
Total	**3609**	**(26.2)**	**18,298**	**(46.1)**	**10,183**	**(73.8)**	**52,385**	**(35.5)**

Note: Patients may have multiple diagnoses but are classified in the first row that they match in the table. For example, if a patient is counted in row 4, that means that no codes consistent with rows 1 to 3 were found in that person's claims, but possibly rows 5 and lower were.

Table 2
Demographic and clinical characteristics of the study sample, by insurance type.

	Overall		Public		Private only		% Difference	p-value
	N	(%)	N	(%)	N	(%)	–	
Total	13,792	(100.0)	6656	(100.0)	7136	(100.0)	–	
Healthcare coverage type							–	
Medicaid	4707	(34.1)	4707	(70.7)	–	(0.0)	–	
Medicare	723	(5.2)	723	(10.9)	–	(0.0)	–	
Dual eligible (Medicaid and Medicare)	1226	(8.9)	1226	(18.4)	–	(0.0)	–	
Private (in at least one calendar year)	9494	(68.8)	2358	(35.4)	7136	(100.0)	–	
Female	7131	(51.7)	3665	(55.1)	3466	(48.6)	6.5	<0.0001
Age (first observed 2010 to 2017)								
18 to 24	2814	(20.4)	1659	(24.9)	1155	(16.2)	8.7	<0.0001
25 to 34	2550	(18.5)	1240	(18.6)	1310	(18.4)	0.3	
35 to 44	2276	(16.5)	928	(13.9)	1348	(18.9)	−4.9	
45 to 54	3023	(21.9)	1248	(18.8)	1775	(24.9)	−6.1	
55 to 64	3129	(22.7)	1581	(23.8)	1548	(21.7)	2.1	
CHD complexity								
Moderate or severe	3609	(26.2)	1966	(29.5)	1643	(23.0)	6.5	<0.0001
Mild	10,183	(73.8)	4690	(70.5)	5493	(77.0)	−6.5	
Comorbid conditions								
Rhythm disorders	7734	(56.1)	4042	(60.7)	3692	(51.7)	9.0	<0.0001
Hypertension	6478	(47.0)	3445	(51.8)	3033	(42.5)	9.3	<0.0001
Hyperlipidemia	6044	(43.8)	2911	(43.7)	3133	(43.9)	−0.2	0.841
Diabetes	4104	(29.8)	2362	(35.5)	1742	(24.4)	11.1	<0.0001
Coronary artery disease	3303	(23.9)	1950	(29.3)	1353	(19.0)	10.3	<0.0001
Stroke	2851	(20.7)	1592	(23.9)	1259	(17.6)	6.3	<0.0001
Heart failure	2375	(17.2)	1585	(23.8)	790	(11.1)	12.7	<0.0001
Liver disease	2871	(20.8)	1711	(25.7)	1160	(16.3)	9.5	<0.0001
Chronic kidney disease	1039	(7.5)	725	(10.9)	314	(4.4)	6.5	<0.0001
Substance use disorder (including alcohol abuse)	2176	(15.8)	1662	(25.0)	514	(7.2)	17.8	<0.0001
Tobacco use	2593	(18.8)	1960	(29.4)	633	(8.9)	20.6	<0.0001
Mental health diagnoses	8074	(58.5)	4435	(66.6)	3639	(51.0)	15.6	<0.0001
Home geographic area								
Portland metropolitan area	6893	(50.0)	2936	(44.1)	3957	(55.5)	−11.3	<0.0001
Other metropolitan area in Oregon	4118	(29.9)	2088	(31.4)	2030	(28.4)	2.9	
Non-metropolitan areas (rural)	2781	(20.2)	1632	(24.5)	1149	(16.1)	8.4	
Distance from ACHD center, % (N)								
<1 h	7163	(51.9)	3130	(47.0)	4033	(56.5)	−9.5	<0.0001
1–4 h	5170	(37.5)	2673	(40.2)	2497	(35.0)	5.2	
>4 h	1459	(10.6)	853	(12.8)	606	(8.5)	4.3	
ACHD center patient at any time 2010 to 2017, % (N)	1716	(12.4)	1054	(15.8)	662	(9.3)	6.6	<0.0001

Note: The sum of patients listed across healthcare coverage types exceeds the total number of unique patients (N = 13,792). This is because patients may have had multiple types of insurance coverage over the study period.

(N = 7,163, 51.9 %), with close proximity being more common among patients with private insurance (N = 4,033, 56.5 %) than public insurance (N = 3,130, 47.0 %) (p < 0.0001). On the other hand, 1459 (10.6 %) of all patients lived greater than 4 h away from an ACHD center, 853 of whom had public insurance (12.8 % of those with public insurance) vs. 606 patients on private insurance (8.5 % of those with private insurance alone). (Table 2).

3.2. Healthcare utilization and outcomes by insurance type

The likelihood of a hospital admission over the study period was greater among those with public insurance, numbering 551 patients with at least one hospital admission per year (16.3 %) vs. 386 of those with private insurance (7.1 %) (age-adjusted odds ratio (aOR) 3.06, 99 % Confidence Interval (CI) 2.81 to 3.33) (Table 3). Heart failure or cardiomyopathy was the primary hospital diagnosis most strongly associated with public insurance status (aOR 5.65, 99 % CI 4.07 to 7.85), followed by pulmonary hypertension (aOR 5.38, 99 % CI 2.15 to 13.48) (Table 3). Publicly insured patients had longer hospital stays (mean 5.7 days) than did those with private insurance (mean 4.4 days) (p < 0.0001) (Table 4). Patients with public insurance were more likely than those with private insurance to discharge to hospice (N = 56, 1.2 % vs. N = 11, 0.3 %) (p < 0.001) or to another facility (N = 1,038, 22.1 % vs. N = 453, 11.5 %) (p < 0.0001) and less likely to discharge home (N = 3,513, 74.9 % vs. N = 3,522, 89.1 %) (p < 0.0001). They were also more likely to leave the hospital against medical advice (N = 119, 2.5 % vs. N = 10, 0.3 %) (p < 0.0001) and were re-hospitalized by 30 days at higher rates (N = 1,213, 17.1 % vs. N = 443, 11.0 %) (p < 0.001) (Table 4). Patients with public insurance were also more likely to die while hospitalized, with the difference in rates of inpatient mortality nearing significance but not reaching it (N = 92, 2 % vs. N = 59, 1.5 %) (p < 0.066).

Emergency department (ED) utilization was greater among those with public vs. private insurance, with 42.3 % of those on public insurance having an ED visit in a given year (N = 1428) vs. 15.9 % (N = 870) of those with private coverage only (aOR 3.86, 99 % CI 3.62 to 4.12) (Table 3). The presenting diagnoses most significantly associated with public insurance status were substance use disorders (OR 8.55, 99 % CI 6.47 to 11.28) and mental health disorders (OR 5.43, 99 % CI 4.64 to 6.34). With respect to ambulatory care, publicly insured patients were less likely to attend an office visit, with a mean of 3097 patients per year with at least one ambulatory visit vs. 5148 patients per year among those with private insurance (OR 0.72, 99 % CI 0.66 to 0.80).

Individuals with public insurance were more likely to have cardiac procedures and/or cardiac imaging, even in analyses restricted to those with moderate or severe disease. Rates of echocardiography among those with moderate or severe disease were 36.8 % in those with public insurance and 29.3 % in those with private insurance (aOR 1.33, 99 % CI 1.19 to 1.50) (Supplementary Table S1). When analyses were restricted to those with guideline-indicated annual echocardiography, the rate was 55.6 % in those with public insurance and 46.4 % in those with private insurance, although the difference was not significant (aOR 1.14, 99 %

Table 3
Healthcare utilization in the overall cohort, by insurance type.

	Public		Private		Age-adjusted OR	
N patients	6234		9089			
N person-years	27,027		43,656			
Mean N patients per year	3378		5457			
	N/year	**%**	**N/year**	**%**	**aOR**	**(99 % CI)**
Office visit	3097	(91.7)	5148	(94.3)	0.72	(0.66–0.80)
ED visit	1428	(42.3)	870	(15.9)	3.86	(3.62–4.12)
Cardiac visit	361	(10.7)	223	(4.1)	3.10	(2.78–3.44)
with chest pain	259	(7.7)	147	(2.7)	3.10	(2.75–3.49)
with endocarditis	6	(0.16)	3	(0.06)	2.63	(1.35–5.14)
with SUD	96	(2.8)	19	(0.3)	8.55	(6.47–11.28)
with mental health treated	251	(7.4)	78	(1.4)	5.43	(4.64–6.34)
Hospital admission	551	(16.3)	386	(7.1)	3.06	(2.81–3.33)
from ED visit	61	(1.82)	36	(0.66)	3.18	(2.58–3.93)
with cardiac contributor	357	(10.6)	271	(5.0)	2.72	(2.48–2.99)
cardiac primary diagnosis	173	(5.1)	167	(3.1)	2.03	(1.81–2.29)
Primary diagnosis						
Heart failure or cardiomyopathy	42	(1.25)	15	(0.27)	5.65	(4.07–7.85)
Coronary artery disease	33	(0.97)	31	(0.56)	2.23	(1.73–2.86)
Endocarditis	7	(0.21)	5	(0.09)	2.38	(1.37–4.15)
Cardiac arrest	2	(0.07)	3	(0.05)	1.33	(0.56–3.15)
Cardiogenic shock	10	(0.28)	4	(0.07)	4.65	(2.52–8.57)
Pulmonary hypertension	5	(0.16)	2	(0.03)	5.38	(2.15–13.48)
Arrhythmia	30	(0.89)	29	(0.53)	1.97	(1.48–2.64)
Pericarditis	4	(0.11)	5	(0.09)	1.37	(0.71–2.65)
Stroke	27	(0.78)	26	(0.48)	1.95	(1.49–2.56)
Valve disease	19	(0.57)	36	(0.65)	1.07	(0.82–1.39)
ACHD	14	(0.43)	26	(0.47)	0.91	(0.67–1.23)
Interventions						
Catheterization	45	(1.34)	36	(0.66)	1.93	(1.51–2.46)
EP study/ablation	15	(0.45)	31	(0.56)	0.88	(0.65–1.20)
Pacemaker/ICD	17	(0.49)	20	(0.36)	1.52	(1.12–2.07)
Echocardiography	1071	(31.7)	1492	(27.3)	1.24	(1.17–1.31)
Electrocardiography	1426	(42.2)	1658	(30.4)	1.86	(1.76–1.97)
Guideline-indicated annual echocardiogram	270	(8.0)	260	(4.8)	1.49	(1.23–1.80)
Guideline-indicated echo, any year	101	(37.3)	87	(33.4)	1.14	(0.88–1.48)
Guideline-indicated echo/EKG, any year	150	(55.6)	121	(46.4)	1.45	(1.12–1.87)
Guideline-indicated annual ACHD visit	521	(15.4)	484	(8.9)	1.62	(1.40–1.87)
Guideline-indicated ACHD visit, any year	124	(23.7)	60	(12.4)	2.19	(1.64–2.93)

Table 4
Inpatient utilization and outcomes by insurance type.

	Public		Private		
N unique patients	2489		2298		
N inpatient admissions	7109		4023		
Length of stay days, mean (SD)	**N**	**Mean ± SD**	**N**	**Mean ± SD**	**p**
All cause admission	7109	5.7 ± 8.2	4023	4.4 ± 7.1	<0.0001
Cardiac primary admission	1794	5.9 ± 8.4	1518	4.8 ± 9.2	0.0003
Cardiac primary or contributing	4151	6.1 ± 9.3	2636	4.7 ± 7.3	<0.0001
Discharge disposition, N (%)	**N**	**%**	**N**	**%**	**p**
Hospice	56	(1.2)	11	(0.3)	<0.0001
Another facility	1038	(22.1)	453	(11.5)	<0.0001
Home	3513	(74.9)	3522	(89.1)	<0.0001
Left AMA	119	(2.5)	10	(0.3)	<0.0001
Inpatient mortality	92	(2.0)	59	(1.5)	0.066
30-day re-hospitalization	1213	(17.1)	443	(11.0)	<0.0001

CI 0.88 to 1.48). Adherence to a guideline-indicated annual ACHD visit was higher in those with public than private insurance (public: 23.7 % vs. private 12.4 %; aOR 2.19, 99 % CI 1.64 to 2.93).

3.3. Healthcare utilization in patients with moderate or severe complexity of CHD, by insurance type

The findings were similar in analyses limited only to those with moderate or severe complexity CHD (Supplementary Table S1). Those with public insurance had lower likelihood of seeking outpatient care (aOR 0.72, 99 % CI 0.60 to 0.87). They were more likely to present to the ED (aOR 3.68, 99 % CI 3.24 to 4.19) and to be admitted to the hospital (aOR 3.12, 99 % CI 2.62 to 3.72). As with the entire sample, heart failure or cardiomyopathy were the primary diagnoses most associated with public insurance (aOR 5.98, 99 % CI 3.40 to 10.49), followed by cardiogenic shock (aOR 5.75, 99 % CI 1.55 to 21.30).

3.4. Emergency department utilization by region and insurance type

Emergency department utilization by home location and insurance type was also evaluated (Table 5). Rural patients had higher rates of ED visits, averaging 0.65 ED visits per year, compared to 0.50 in Portland and other metropolitan areas (unadjusted IRR 1.32; 99 % CI 1.19 to 1.47). The estimated IRR did not change when controlling for patient age or calendar year of claims but was attenuated after adjusting for Medicaid and Medicare coverage types (adjusted IRR 1.09 [0.99 to 1.20]). After accounting for other factors, patients in urban areas other than Portland had lower rates of ED use (IRR 0.90 [0.83 to 0.98]). Patients on Medicare had 1.93 times as many ED visits (99 % CI 1.63 to 2.29), on average, as those without, while those on Medicaid had 3.67 times as many ED visits (99 % CI 3.40 to 3.96) compared to non-Medicaid patients.

Table 5
Emergency department utilization by region in Oregon and insurance type, 2010 to 2017 (N = 13,777 unique patients). Excludes N = 296 patients without MSA data. IRR: Incidence rate ratio from negative binomial regression model with cluster robust standard errors.

Variable			Unadjusted		Year- and age-adjusted		Full model	
Region by Metropolitan Statistical Area (MSA)	Person-years	Mean (SD) ED visits/year	IRR	(99 % CI)	IRR	(99 % CI)	IRR	(99 % CI)
Metropolitan Portland	34,361	0.50 (1.25)	[ref]		[ref]		[ref]	
Oregon other metropolitan	21,282	0.50 (1.17)	1.00	(0.91–1.11)	0.99	(0.90–1.09)	0.90	(0.83–0.98)
Rural	14,551	0.65 (1.36)	1.32	(1.19–1.47)	1.32	(1.19–1.47)	1.09	(0.99–1.20)
Calendar year					1.06	(1.05–1.08)	1.03	(1.02–1.04)
Age (10-year increase over age 18)					0.91	(0.89–0.94)	0.98	(0.95–1.01)
Medicaid	24,941	1.00 (1.72)					3.67	(3.40–3.96)
Medicare	3607	1.01 (1.72)					1.93	(1.63–2.29)

Note: Table 5 excludes N = 296 patients without MSA data. IRR: Incidence rate ratio from negative binomial regression model with cluster robust standard errors.

4. Discussion

Our study contributes further to the understanding of the association between insurance type and healthcare utilization in adults with CHD. The major findings of this study are fourfold. First, patients with public insurance are more medically complex, as demonstrated by a higher prevalence of medical comorbidities, including substance use. Second, publicly insured patients are more likely to utilize ED and inpatient care and less likely to utilize overall ambulatory services as compared to those with private insurance. Third, patients with public insurance have worse medical outcomes, as demonstrated by longer hospital stays and higher rates of discharge to another medical facility or hospice as opposed to home. Individuals with public insurance are also more likely to have a 30-day readmission to the hospital, an important quality metric. Fourth, we found that despite lower overall usage of ambulatory care, individuals with public insurance were more likely to receive guideline-indicated echocardiography and ACHD follow-up. While the exact reason for this is unknown, it could be that individuals with public insurance have more overall contact with the healthcare system, increasing the probability that they will receive an echocardiogram or get referred to an ACHD center. Alternately, individuals with private insurance may be disincentivized to pursue echocardiography or referral to a tertiary center due to co-pays and other healthcare costs, which do not exist for those with public insurance. Taken in aggregate, these findings demonstrate that publicly insured adults with CHD comprise a complex, high-risk population with high healthcare utilization who may benefit from focused interventions to decrease their risk of adverse medical outcomes and lessen their need for inpatient hospitalization and ED utilization.

Our findings suggest that public insurance status is an independent risk factor for emergency care utilization in adults with CHD. It has previously been shown that, in the general population, public health insurance status is associated with higher ED utilization and fewer outpatient office visits as compared to private insurance [13]. We examined several subgroups of particular interest. Since ICD codes for some types of CHD are non-specific, there is the concern that they may also capture individuals without true CHD [1]. Because of this, we performed our analyses in a sample limited to those with moderate or complex CHD (for which the ICD codes are more specific) and found that our findings were not significantly changed.

We also examined rural dwelling individuals, as rural home location has been associated with adverse cardiovascular outcomes in non-congenital populations, including those with newly diagnosed heart failure [14]. Rural home location may also make it more difficult for adults with CHD to access specialized care, which is most commonly located in tertiary care centers in urban locations. In our study, we found that those adults with CHD living in rural areas were more likely to utilize the ED than urban-dwelling patients. One plausible reason for this finding is the lack of access to primary care providers and cardiologists in rural areas, which may cause patients to utilize the ED for care instead [15,16]. Importantly, individuals in rural areas were more likely to be publicly insured, suggesting that low SES may present an additional health challenge in this population.

Differences in healthcare utilization and outcomes between those with public and private insurance are likely driven by both pathophysiologic and socioeconomic differences between the two populations. In our study, we found that moderate or severe CHD was more common in those with public insurance than with private insurance. Since Medicaid enrollment is dependent on income, it is considered a strong proxy for SES, specifically poverty or near-poverty. SES is recognized as a social determinant of health and an important risk factor in the development of cardiovascular disease (CVD) [17]. Previous work has also demonstrated an association between income level and CHD complexity, suggesting that lower income populations may be more likely to have complex CHD [18]. Another study found that lower maternal education, a factor linked to SES, is significantly associated with more complex CHD [19]. One proposed explanation for this association is that there are lower rates of elective termination for severe deformities among those with low income, possibly due to challenges in accessing care [20]. Others have postulated that patients of higher SES are more likely to be diagnosed with less complex CHD lesions such as patent ductus arteriosus (PDA) because of better access to higher quality diagnostic imaging [19].

Another potential cause for the association between CHD complexity and insurance type is the inverse association between a patient's CHD complexity and their educational attainment or employment [21]. One reason for this is the higher rate of coinciding neurodevelopmental disorders among those with more complex CHD [22]. Additionally, students with CHD have more medical needs, which has been shown to result in more interruptions in schooling and employment as compared to their healthy counterparts; this is likely amplified in those with more complex disease [23].

Patients with public insurance status and lower SES were disproportionately affected by the majority of medical comorbidities that we examined. Unsurprisingly, low income is associated with social factors that impact a patient's ability to access healthcare and achieve desired health outcomes. It is well-recognized that low income is associated with traditional risk factors for CVD, including hypertension, diabetes, and tobacco use [24]. In fact, low SES alone is recognized as a non-traditional risk factor for CVD [25]. We now understand that adults with moderate or complex CHD may be especially vulnerable to cardiovascular decline in the face of acquired CVD because of their abnormal functional and anatomical baselines. The high rates of CVD risk factors in the patients in this study, especially among those with public insurance, is an area of significant concern, as it portends a high risk of acquired heart disease as these patients age [26].

Among the comorbidities we studied, coexisting mental health diagnoses had the strongest association with public insurance, in addition to being the most common comorbid condition observed, affecting over half of all study participants. This is also seen in the general population where mental health problems are more prevalent among people living in poverty than those above the poverty line [27]. The high rate of psychiatric diagnoses seen in our cohort of ACHD patients is mirrored in the literature. In fact, the literature suggests that adults with CHD are up

to five times more likely to be affected by depression, anxiety, bipolar disorder, psychosis, ADHD and autism spectrum than their peers who do not have CHD [28]. Psychiatric conditions like depression and anxiety are associated with higher medical costs in this patient population, as well as higher morbidity and mortality [29]. The reasons that those with CHD are disproportionately affected by psychiatric conditions are many, and potential risk factors span from the prenatal period to adulthood [29]. Our findings further underscore the importance of recognizing the unique psychological needs of this patient population and creating pathways to resources and treatment.

We also observed higher rates of hospitalization among patients with public insurance. Increased medical complexity, in the form of more severe CHD and more medical comorbidities, coupled with less consistent non-ACHD outpatient medical follow-up, may predispose these patients to progression of disease and complications of their CHD. This is one explanation for the association between public insurance and more frequent hospital admissions and readmissions among adults with CHD in our study; others have been offered by other authors [30].

Less frequent overall outpatient follow-up among those with public insurance can occur for a variety of reasons, including both patient factors (distrust in the healthcare system, inability to take time off work, no transportation, etc.) and systems factors (lack of local providers, especially in rural areas, inability to find a provider taking new Medicaid patients, etc.). Interestingly, in our study we found that publicly insured patients attended guideline-indicated ACHD clinic appointments at higher rates. While we are unable to determine what explains this from administrative data, we suspect that this is related to the fact that there is no insurance or financial barrier to being seen at our academic center (in comparison to some individuals with private insurance, who may need to pay a higher percentage of healthcare costs to be seen at our center outside of their insurance network) and the fact that systems factors may encourage providers to refer Medicaid patients to the academic center, as opposed to retaining them within their own practice. The finding that patients on Medicaid are more likely to access preventative health care has been noted in larger datasets, and paradoxically, may not be associated with improved physical health outcomes [31].

There are several limitations to our study. We were unable to investigate the interplay between race or ethnicity and healthcare utilization because of the high percentage of individuals in our database with missing race and ethnicity data (>60 %). We were also unable to reliably identify pregnancies in the dataset. ICD codes have known limitations, and we were unable to validate the accuracy of CHD diagnoses in this database. It is well established that ICD code-based analyses may underestimate the prevalence of CHD (when there is undercoding) or overestimate the prevalence of CHD (when there is miscoding of non-congenital diagnoses). Therefore, the numbers of individuals identified in this study should not be used to estimate population prevalence, and likely do not reflect the true size of the adult CHD population in Oregon. The number of procedures such as catheterization that we were able to identify in the dataset is also lower than expected. The reason for this is unknown, and the findings related to these outcomes should be considered only hypothesis-generating.

Importantly, we used Medicaid insurance as a proxy for SES but were unable to directly measure income in this population. Lastly, it is important to note that our study is a single state analysis in a large, predominantly white Western state with a significant proportion of rural dwelling individuals. To further contextualize the demographics of our study participants, we turned to the 2010 and 2020 Oregon Census reports, which capture population data at the beginning and near-end of our own study. To illustrate the evolution in Oregon's demographic breakdown, the 2010 and 2020 Census reports the following breakdown in race/ethnicity, respectively (using the same terminology from the Census): 83.6 %–74.8 % White alone; Black or African American alone 1.8 %–2.0 %; Hispanic or Latino 11.7 %–13.9 %; Asian alone 3.7 %–4.6 %; American Indian and Alaska Native alone 1.4 %–1.5 %; Native Hawaiian and Other Pacific Islander alone 0.3 %–0.5 %; Some Other Race alone 5.3 %–6.3 %; Two or More Races 3.8 %–10.5 %. Applying this data, based on the 2020 Census, Oregon's Diversity Index is 46.1 % compared to a national average of 61.1 %, ranking it as 30th of the 51 states in racial/ethnic diversity, an increase from the 32nd ranking in 2010 [32,33].

Perhaps even more representative of our study population is demographic data from Oregon Health Authority reflecting the population enrolled in Oregon Health Plan (the state equivalent of Medicaid). Including people with Medicare co-enrollment, in June 2024, the aggregate demographic data revealed that 49 % of those enrolled identified as White, 22 % as Hispanic or Latino/a/x/e, 5.2 % as Asian, 5.0 % as American Indian and Alaska Native, 5.0 % as Black/African American, 1.4 % as Native Hawaiian and Pacific Islander, 0.9 % as Middle Eastern/North African, 1.9 % as Other Race not listed, <0.01 % as Multiracial [34]. Further research is needed to study the relationship between patient race or ethnicity on healthcare utilization, as these data may influence initiatives to address race-based disparities in access to care and health outcomes within ACHD.

Also of relevance to our study, approximately 35 % of the state's population live in rural or frontier communities per the Oregon Office of Rural Health [35]. This demographic data is especially valuable when considering rurality as a risk factor for decreased healthcare access and utilization. Whether or not these findings would also hold true in other populations is unknown.

Recognizing the significant relationship insurance type has on many different health outcomes in this patient population, an interesting future direction would be to retrospectively collect data on a patient's insurance type earlier in life, while in the care of their pediatric cardiologist, to see how this may predict future outcomes. If a significant association was identified, this finding may inform efforts to employ safety nets for at-risk populations during transitions of care.

In conclusion, we examined the association between insurance type, dwelling status, and healthcare utilization in adults with CHD. Our results suggest that individuals with either public insurance or rural dwelling location have differential patterns of healthcare utilization, with a heavier reliance on ED services for care. Further research is needed to understand what drives these differences and to identify ways to better care for patients who may be at increased risk of high healthcare utilization and adverse clinical outcomes.

CRediT authorship contribution statement

Julia Claire Cambron: Writing – review & editing, Writing – original draft. **Evan F. Shalen:** Writing – review & editing. **Lidija B. McGrath:** Writing – review & editing. **Katrina Ramsey:** Software, Formal analysis. **Abigail Khan:** Writing – review & editing, Supervision, Methodology, Formal analysis, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijcchd.2024.100543.

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