

Title: Congenital heart disease in pregnancy and severe maternal morbidity: a distributed data network study

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Abstract

Background

Pregnant people with congenital heart disease (CHD) are a growing patient population in obstetrics, yet evidence on the risk for severe maternal morbidity (SMM) has largely been limited to studies that lack specificity for CHD (1–5). We conducted this study to demonstrate the utility of distributed data networks for obstetric research and to characterize pregnant patients with CHD and their risk of SMM.

Methods

The study included female patients aged 12–55 years who delivered between 2015 and 2026 at three U.S. academic healthcare organizations. We used a distributed data network study design by developing analytical code, executing the code locally at each organization using its electronic health record (EHR) data in a common data model (CDM), then aggregating the results. This analytical approach is rigorous, reproducible, and protects patient confidentiality by not sharing patient-level data. The Observational Medical Outcomes Partnership (OMOP) CDM was used by each organization, and we used OMOP standard concepts to identify CHD and SMM. We categorized outcomes as SMM, non-transfusion SMM, and cardiac SMM based on the CDC SMM index (6). We analyzed the incidence of the outcomes and estimated risk ratios (RRs) and Wald 95% confidence intervals (CIs) using contingency tables.

Results

The prevalence of CHD in pregnancy was 2.2% among 166,033 deliveries across three healthcare organizations. 19.3% of people with CHD had an acquired heart condition, compared to 2.1% of people without CHD. SMM occurred in 9.4% of deliveries to people with CHD compared to 4.5% among people without CHD (RR: 2.08; 95% CI: 1.88, 2.31), and non-transfusion SMM occurred in 6.7% vs 2.5% of deliveries (RR: 2.63; 95% CI: 2.33, 2.98), respectively. Cardiac SMM represented 51.8% of non-transfusion SMM among people with CHD compared to 16.2% among people without CHD.

Conclusions

Our distributed data network study using EHR data from three geographically diverse U.S. healthcare organizations found that 1 in 15 people with CHD had non-transfusion SMM compared with 1 in 39 people without CHD. This study demonstrates the feasibility and utility of distributed data networks for obstetric research and provides novel evidence on maternal outcomes for pregnant patients with CHD.

Table 1. Demographic, pre-pregnancy, and pregnancy characteristics of study population by congenital heart disease status.

	People with congenital heart disease N = 3,648 n (%)	People without congenital heart disease N = 162,385 n (%)
Race		
Asian	358 (9.81)	27,534 (16.96)
Black or African American	435 (11.92)	20,501 (12.62)
White	1,985(54.41)	71,059(43.76)
Other or Unknown	870 (23.85)	43,291 (26.66)
Hispanic or Latina/e	766 (21.00)	34,519 (21.26)
Age at delivery^a		
20-24 y	280 (7.68)	9,396 (5.79)
25-29 y	599 (16.42)	24,323 (14.98)
30-34 y	1,187 (32.54)	34,138(21.64)
35-39 y	1,061 (29.08)	50,176 (30.90)
40-44 y	382 (10.47)	15,675 (9.65)
Pre-Pregnancy Characteristics		
BMI $\geq$ 40 kg/m²	213 (5.84)	8,168 (5.03)
Preexisting diabetes	161 (4.41)	3,976 (2.45)
Asthma	456 (12.50)	14,985 (9.23)
Chronic kidney disease	78 (2.14)	1,575 (0.97)
Autoimmune or connective tissue disease	466 (12.77)	17,448 (10.74)
Chronic hypertension	464 (12.72)	12,774 (7.87)
Acquired heart condition	704 (19.30)	3,479 (2.14)
Pregnancy Characteristics		
Multiple gestation	152 (4.17)	4,753 (2.93)

Gestational diabetes	419 (11.49)	17,493 (10.77)
Preeclampsia	350 (9.59)	12,414 (7.64)
Preterm delivery	228 (6.25)	6,301 (3.88)
Cesarean delivery	1,675 (45.92)	65,361 (40.25)

^aAge not reported for 12-19 and 45-55 due to small numbers

Table 2. Prevalence of congenital heart conditions

Congenital Heart Disease Condition^a	N = 3,648	%
Ventricular septal defect	891	24.42
Atrial septal defect	549	15.05
Tetralogy of Fallot	418	11.46
Congenital insufficiency of aortic valve	271	7.43
Coarctation of aorta	268	7.35
Patent ductus arteriosus	245	6.71
Discordant ventriculoarterial connection	241	6.61
Hypoplastic left heart syndrome	186	5.10
Double outlet right ventricle	185	5.07
Patent foramen ovale	169	4.63
Congenital stenosis of pulmonary valve	155	4.24
Bicuspid aortic valve	144	3.95
Atrioventricular septal defect and common atrioventricular junction	122	3.34
Congenital stenosis of aortic valve	103	2.82
Congenital insufficiency of mitral valve	93	2.55
Congenital anomaly of aorta	87	2.38
Congenital anomaly of coronary artery	85	2.33
Congenital atresia of pulmonary valve	70	1.92
Persistent left superior vena cava	63	1.73
Congenital anomaly of pulmonary artery	59	1.62
Congenital anomaly of tricuspid valve	55	1.51
Ebstein's anomaly	52	1.43
Right aortic arch	50	1.37
Common arterial trunk (truncus arteriosus)	44	1.20
Discordant atrioventricular connection	36	0.99

^aParticipants may be represented in multiple diagnosis groups. Diagnoses with small numbers are not shown in the table.

Table 3. Risk of severe maternal morbidity among those with congenital heart disease compared to those without.

	People without congenital heart disease N = 162,385 n (%)	People with congenital heart disease N = 3,648 n (%)	Risk Ratio (95% Confidence Interval)
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Severe maternal morbidity^a	7,362 (4.53)	344 (9.43)	2.08 (1.88, 2.31)
Non-transfusion severe maternal morbidity^a	4,140 (2.55)	245 (6.72)	2.63 (2.33, 2.98)
Cardiac severe maternal morbidity^b	670 (0.41)	127 (3.48)	8.44 (7.00, 10.17)

^aFollowing CDC, SMM defined with and without blood products transfusion as an indicator

^bCardiac SMM included acute myocardial infarction, aneurysm, cardiac arrest, ventricular fibrillation, conversion of cardiac rhythm, and acute heart failure

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