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Trends in Long-Term Mortality After Congenital Heart Surgery

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ABSTRACT

BACKGROUND Congenital heart surgery has improved the survival of patients with even the most complex defects, but the long-term survival after these procedures has not been fully described.

OBJECTIVES The purpose of this study was to evaluate the long-term survival of patients (age <21 years) who were operated on for congenital heart defects (CHDs).

METHODS This study used the Pediatric Cardiac Care Consortium data, a U.S.-based, multicenter registry of pediatric cardiac surgery. Survival analysis included 35,998 patients who survived their first congenital heart surgery at <21 years of age and had adequate identifiers for linkage with the National Death Index through 2014. Survival was compared to that in the general population using standardized mortality ratios (SMRs).

RESULTS After a median follow-up of 18 years (645,806 person-years), 3,191 deaths occurred with an overall SMR of 8.3 (95% confidence interval [CI]: 8.0 to 8.7). The 15-year SMR decreased from 12.7 (95% CI: 11.9 to 13.6) in the early era (1982 to 1992) to 10.0 (95% CI: 9.3 to 10.8) in the late era (1998 to 2003). The SMR remained elevated even for mild forms of CHD such as patent ductus arteriosus (SMR 4.5) and atrial septal defects (SMR 4.9). The largest decreases in SMR occurred for patients with transposition of great arteries (early: 11.0 vs. late: 3.8; $p < 0.05$), complete atrioventricular canal (31.3 vs. 15.3; $p < 0.05$), and single ventricle (53.7 vs. 31.3; $p < 0.05$).

CONCLUSIONS In this large U.S. cohort, long-term mortality after congenital heart surgery was elevated across all forms of CHD. Survival has improved over time, particularly for severe defects with significant changes in their management strategy, but still lags behind the general population. (J Am Coll Cardiol 2018;71:2434–46)
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Congenital heart defects (CHDs) affect nearly 1% of children born in the United States (1) who, without interventions, experience significant morbidity and mortality as described by the first and second natural history studies (2,3). Surgery for CHD dramatically changed the outcomes for patients with even complex defects, and surgical mortality has significantly decreased over time (4–8). As a result, there is a continuously growing population of CHD survivors whose long-term health must be monitored (9–12). However, robust long-term outcomes after congenital heart surgery (CHS) in the United States are lacking (13).

Most data on long-term outcomes after CHS have been reported from countries with national health systems (14–19). Other sources include data from individual states (20), reports on single lesions and operative strategies collected over a short time span as part of a major center's experience (9,21–36), or population-based data lacking surgery-related information (37–39). Although valuable, these data do not adequately capture the experience across the United

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TABLE 1 Characteristics of Eligible Patients in PCCC With Adequate Identifiers for Linkage With NDI

	In-Hospital Death at First Surgery (n = 2,489)	Discharged Alive After First Surgery (n = 35,998)	Deaths Post-Discharge (n = 3,191)
Age at first surgery			
0–27 days	1,804 (72.5)	6,624 (18.4)	1,158
28–365 days	622 (25.0)	12,674 (35.2)	1,251
1–4 yrs	40 (1.6)	9,778 (27.2)	414
5–20 yrs	23 (0.9)	6,922 (19.2)	368
Median (IQR), yrs	0.0 (0.0–0.1)	0.8 (0.2–3.8)	0.2 (0.0–0.9)
Sex			
Male	1,353 (54.4)	18,713 (52.0)	1,826
Female	1,136 (45.6)	17,285 (48.0)	1,365
Race			
White	1,465 (80.5)	9,952 (81.3)	1,168
Black	307 (16.9)	1,967 (16.1)	295
Other	48 (2.6)	317 (2.6)	35
Missing	669	23,762	1,693
Ethnicity			
Not Hispanic	1,739 (93.9)	13,860 (93.2)	1,575
Hispanic	113 (6.1)	1,013 (6.8)	99
Missing	637	21,125	1,517
Type of Defect			
2V lesions			
Left-to-right shunt			
Total	270 (10.9)	15,906 (44.2)	827
PDA	20 (0.8)	2,976 (8.3)	98
ASD	27 (1.1)	6,198 (17.2)	184
VSD (simple)	64 (2.6)	4,522 (12.6)	204
CAVC (simple)	159 (6.4)	2,210 (6.1)	341
RVOTO			
Total	207 (8.3)	3,927 (10.9)	298
PS/Sub-PS	22 (0.9)	724 (2.0)	34
PA/IVS	66 (2.7)	199 (0.6)	23
TOF	119 (4.8)	3,004 (8.3)	241
LHOL			
Total	291 (11.7)	5,642 (15.7)	375
Cor-Tri	6 (0.2)	77 (0.2)	5
MS	9 (0.4)	70 (0.2)	14
AS/Sub-AS	59 (2.4)	1,284 (3.6)	92
CoA	124 (5.0)	3,899 (10.8)	215
IAA	93 (3.7)	312 (0.9)	49
APVR			
Total	118 (4.7)	1,461 (4.1)	69
TAPVR	114 (4.6)	684 (1.9)	51
PAPVR	4 (0.2)	777 (2.2)	18
TGA physiology			
d-TGA (simple)	192 (7.7)	1,554 (4.3)	113
Complete mixing			
TAC	129 (5.2)	268 (0.7)	59
Complex lesions			
Total	220 (8.8)	2,792 (7.8)	423
Complex CAVC	29 (1.2)	60 (0.2)	31
Complex d-TGA	57 (2.3)	232 (0.6)	75
Complex VSD	32 (1.3)	1,729 (4.8)	90
Complex TOF	102 (4.1)	771 (2.1)	227

Continued in the next column

States for all CHD, and, often, do not possess sufficient patient numbers or follow-up time for meaningful long-term outcome evaluation. In the absence of longitudinal registries for CHD in the United States, assessment of long-term survival in this population remains incomplete. To fill this gap, the National Center on Birth Defects at the Centers for Disease Control and Prevention outlined a public health research agenda for CHD that includes database linkage (40,41).

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In this study, we used the Pediatric Cardiac Care Consortium (PCCC), a large U.S.-based registry of

ABBREVIATIONS AND ACRONYMS

CAVC = complete atrioventricular canal

CHD = congenital heart defect

CHS = congenital heart surgery

d-TGA = dextro-transposition of the great arteries

NDI = National Death Index

PCCC = Pediatric Cardiac Care Consortium

SMR = Standardized Mortality Ratio

TABLE 1 Continued

	In-Hospital Death at First Surgery (n = 2,489)	Discharged Alive After First Surgery (n = 35,998)	Deaths Post-Discharge (n = 3,191)
Miscellaneous			
Total	73 (2.9)	2,003 (5.6)	189
l-TGA (2V)	18 (0.7)	200 (0.6)	48
MR/AI	6 (0.2)	407 (1.1)	44
TVA	13 (0.5)	160 (0.4)	28
Other	36 (1.5)	1,236 (3.4)	69
SV lesions			
Total	989 (39.7)	2,445 (6.8)	838
RV	668 (26.8)	833 (2.3)	370
LV	195 (7.8)	1,027 (2.9)	265
Other	126 (5.1)	585 (1.6)	203
Severity			
Mild	97 (3.9)	12,497 (34.7)	429
Moderate	430 (17.3)	13,590 (37.8)	957
Severe 2V	752 (30.2)	4,658 (12.9)	694
Not classifiable	221 (8.9)	2,808 (7.8)	273
Critical			
No	464 (18.6)	22,435 (62.3)	1,249
Yes	2,025 (81.4)	13,563 (37.7)	1,942
Chromosomal abnormality			
No	2,177 (87.5)	31,132 (86.5)	2,527
Yes	312 (12.5)	4,866 (13.5)	664

Values are n (%), unless otherwise indicated.

2V = 2 ventricle; APVR = abnormal pulmonary venous return; AS/Sub-AS = aortic and subaortic stenosis; ASD = atrial septal defect; CAVC = common atrioventricular canal; CoA = coarctation of the aorta; Cor-Tri = cor-triatriatum; d-TGA = dextro-transposition of the great arteries; IAA = interrupted aortic arch; l-TGA = levo-transposition of the great arteries; LHOL = left heart obstructive lesions; LV = left ventricle; MR/AI = mitral regurgitation or aortic insufficiency; MS = mitral stenosis; PA/IVS = pulmonary atresia with intact ventricular septum; PAPVR = partial anomalous pulmonary venous return; PDA = patent ductus arteriosus; PCCC = Pediatric Cardiac Care Consortium; PS/Sub PS = pulmonary and subpulmonary stenosis; RV = right ventricle; RVOTO = right ventricular outflow tract obstruction; SV = single ventricle; TAC = truncus arteriosus communis; TAPVR = total anomalous pulmonary venous return; TOF = tetralogy of Fallot; TVA = tricuspid valve anomalies; VSD = ventricular septal defect.

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