## Variation in Use of Pediatric Cardiology Subspecialty Care



### A Total Population Study in California, 1983 to 2011

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### ABSTRACT

**BACKGROUND** American Academy of Pediatrics guidelines emphasize regionalized systems of care for pediatric chronic illness. There remains a paucity of information on the status of regionalized systems of care for pediatric congenital heart disease (CHD).

**OBJECTIVES** This study evaluated variations in use of pediatric cardiology specialty care centers (PCSCC) for pediatric patients with CHD in California between 1983 and 2011.

**METHODS** We performed a retrospective, total population analysis of pediatric CHD patients using the California Office of Statewide Health Planning and Development unmasked database. PCSCCs were identified by California's Title V program.

**RESULTS** There were 164,310 discharges meeting inclusion criterion. Discharges from PCSCCs grew from 58% to 88% between 1983 and 2011. Regionalized care was highest for surgical (96%) versus nonsurgical (71%) admissions. Admissions with a public payer increased from 42% (1983) to 61% (2011). Total bed days nearly doubled, and median length of stay increased from 2 to 3 days (nonspecialty care) and from 4 to 5 days (specialty care). There was a decrease in the pediatric CHD in-hospital death rate from 5.1 to 2.3 per 100,000 between 1983 and 2011, and a shift toward a larger percent of deaths occurring in the newborn period.

**CONCLUSIONS** California's inpatient regionalized specialty care of pediatric CHD has increased substantially since 1983, especially for surgical CHD discharges. The death rate has decreased, the number of bed days has increased, and a large proportion of these discharges now have public payers. Health care reform efforts must consider these shifts while protecting advances in regionalization of pediatric CHD care. (J Am Coll Cardiol 2015;66:37-44) © 2015 by the American College of Cardiology Foundation.

ccess to high-quality care for children with serious chronic illness depends upon regionalized systems of care (1-3). Pediatric heart surgery has lower mortality rates at high-volume hospitals (4-7), especially for more complex cases (8), and outcomes are improved for mothers, infants,

and children with heart disease when they are cared for in a regional network of cardiac providers (9). Theoretical modeling of increased regionalized care for children with congenital heart disease (CHD) predicted a decrease in mortality from 5.3% to 4% (10). The American Academy of Pediatrics' "Guidelines

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#### ABBREVIATIONS AND ACRONYMS

CCS = California Children's Services

CHD = congenital heart disease

LOS = length of stay

**OSHPD** = Office of Statewide Health Planning and Development

**PCSCC** = pediatric cardiology specialty care centers

for Pediatric Cardiovascular Centers" states that designated centers with specific pediatric capacities should strive to participate in regional health care networks (11).

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de Pediatric CHD is a broad category encompassing a wide range of conditions, and hospital mortality rates of CHD repair vary: 1% for simple forms and up to 5% for more complex lesions (12). Indeed, in the most complex cases, mortality rates range from 26% to 36% (13) and complex lesions such as hypoplastic left heart mortality can be as high as 21% to 40% on the basis of distance to specialty care center, prenatal diagnosis, and hospital CHD volume (14).

During the last 30 years, medical and surgical advances have improved outcomes for children born with CHD, leading to an increasing number of survivors requiring an ongoing provision of services. In addition, reducing health disparities for pediatric and adult CHD is a high priority. Health disparities are described in patients with CHD (15,16), including a study revealing reduced survival among non-white children born with CHD (17). Access to care for CHD has been shown to vary between whites and non-whites (15) and on the basis of type of insurance (18).

Fundamental to many of these questions, and what remains unexamined, is how overall use of regional centers for pediatric cardiac care has evolved in the last 30 years, a period which has seen expansion of public health insurance programs and the advent of managed care models. As the United States embarks on a new era of care brought about by the Affordable Care Act, clarity in understanding the baseline of access to care for vulnerable pediatric patients is critical. Therefore, we sought to understand the use of regional pediatric cardiology specialty care centers (PCSCCs) during the last 28 years in California between 1983 and 2011.

#### METHODS

**STUDY DESIGN.** A retrospective analysis of pediatric hospitalizations for children aged 0 to 18 years in California during the period 1983 to 2011 was performed. The Institutional Review Board at Stanford University and the State of California Committee for the Protection of Human Subjects reviewed and approved this study.

**INCLUSION AND EXCLUSION CRITERIA.** The analysis included children whose discharges included codes

for pediatric congenital heart disease diagnoses (745.xx-747.xx) and/or cardiac surgical procedural codes (35.xx, 37.xx [except 37.0x], 39.0x, 39.21, 39.54, 39.59, 39.61, 39.62, 39.63, 39.64, and 36.99). If an individual had > 1 CHD or cardiac surgical procedural codes, we included up to the first 5.

We extrapolated from the work performed on categorization of CHD in adults by Warnes et al. (19), and defined CHD as either simple (i.e., isolated atrial or ventricular septal defects or valvular disease) or moderate/complex. Simple CHD was then excluded from the nonsurgical group due to the perceived low risk of morbidity and mortality after repair. Moderate to complex CHD diagnoses, along with all surgical cases, remained in the sample. We further excluded newborns who died at nonspecialty centers within the first 2 days of life and the newborns born in a nonspecialty care center who were transferred within the first 3 days of life (vaginal deliveries) and 7 days of life (Cesarean deliveries). Finally, we excluded cases with primary codes indicating admission for pregnancy, trauma, and residence in a non-California zip code, the methodology of which has been described in prior work (20-22). This generated 531,772 pediatric CHD discharges, with 164,310 meeting inclusion criteria (Figure 1).

DATA SOURCES AND DEFINITIONS. This analysis used the unmasked Patient Discharge Database from the Office of Statewide Health Planning and Development (OSHPD), which contains information on discharges from all licensed nonfederal acute care hospitals in California. Unmasked OSPHD discharge files contain age, race/ethnicity, sex, county of residence, patient zip code, insurance status, and clinical information such as discharge diagnoses, procedures, disposition of patient, external cause of injury, source of admission, and length of stay (LOS). Each discharge file documents the principal diagnosis and up to 24 secondary diagnoses, all coded according to the International Classification of Disease-9th Clinical Modification. We combined race and ethnicity variables to create categories as White non-Hispanic, Black non-Hispanic, Hispanic, Asian/Pacific Islander non-Hispanic, and other non-Hispanic categories. Payer status was categorized as public insurance (Medicare, Medi-Cal [California's Medicaid program], County Indigent Programs, State Children's Health Insurance Program [SCHIP], and Title V programs), private insurance (including private health maintenance organizations and other managed care plans), and other (self-pay and other payer).

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