



Mortality, rehospitalizations and costs in children undergoing a cardiac procedure in their first year of life in New South Wales, Australia[☆]



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ABSTRACT

Background: Cardiac procedures are part of management for many children with congenital heart disease (CHD). Using population health data, this study explores health outcomes of children undergoing a cardiac procedure in the first year of life to better understand the impact of CHD on children, families and health services.

Methods and results: A population-based record-linkage cohort study was undertaken. Rate of cardiac procedures in the first year of life over the study period 2001–2012 in New South Wales, Australia, was steady at 2.5 children per 1000 live births, accounting for 2722 children. Excluding those with isolated closure of patent ductus arteriosus ($n = 416$), 50% required readmission in the first year of life. Over 1/5th had an additional non-cardiac congenital anomaly. Average total cost per infant for initial procedure admission was \$67,054 AUD (\$63,124–\$70,984) with a median length of stay (LOS) 13 days (IQR 8–23). Average cost per readmission in the first year of life was \$11,342 (95% CI 10,361–\$12,323) with median LOS 2 days (IQR 1–5). Mortality rate in the 30 days following initial procedure was 3.1% (72/2306). Mortality rate by age 1 year was 7.1%, and 13.8% for those who had neonatal surgery.

Conclusion: Risk of mortality in operatively-managed CHD extends beyond the immediate perioperative period. Children undergoing a cardiac procedure in their first year are often readmitted to hospital for both further planned procedures and unplanned reasons such as infection. These readmissions capture the significant impact of illness and pose substantial financial cost to the health system.

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1. Introduction

Congenital heart disease (CHD) is among the most common congenital conditions in Australia, estimated to affect up to 7 per 1000 live births [1]. A number of children with CHD will require surgical management [2], with a third requiring this or a catheter-based intervention in the first year of life [3]. CHD is known to contribute to hospital and intensive

care unit admissions, detrimentally impacting the health-related quality of life for affected children and their families [4,5,6,7,8,9,10,11], as well as the health system. In the Australian setting, the full health burden of surgically managed CHD beyond the immediate peri-operative period, including planned and unplanned hospital readmissions, associated costs and longer-term mortality is unknown.

Internationally, perioperative morbidity and mortality in children with CHD has been evaluated by disease and operation specific subgroups through retrospective database analysis and cohort study [8, 12,13,14,15,16,17]. Beyond this period, international work has identified that children with CHD are at an increased risk of emergency department presentations, hospital admissions and unplanned intensive care unit admissions [7,18,19,22,23]. There are significant costs associated with both procedure-related admissions [20,21,22] as well as other hospital admissions [22,23], particularly in children less than one year of age [22,22,23].

Mortality in surgically-managed CHD remains a significant consideration [23,24,17]. An Australian, single-centre study has identified

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overall operative mortality within 30 days of cardiac procedure in childhood as 1.9% and higher in neonates (6.8%) [8]. The risk of premature death in these children is known to extend beyond the perioperative period and initial hospital admission [8,25] however remains inexactly defined.

The first aim of this study was to quantify the number of children undergoing cardiac surgery or catheter-based intervention in the first year of life. The second aim was to describe the subsequent health outcomes including mortality, hospital readmissions and hospitalisation-associated costs for these children in the first six years of life to better clarify the current post-procedure outcomes in both the short and medium term. This information is to allow evaluation of the burden of readmissions in terms of both number and cost to the health system and to allow comparison with other developed nations.

2. Methods

2.1. Study population and data sources

The study population included all children born in NSW, Australia between 2001 and 2012. NSW is Australia's most populous state, with over 95,000 births per annum and approximately 7 million residents (representing 32% of Australia's population) [26].

A population-based record-linkage cohort study was undertaken. Data were obtained from the NSW Admitted Patient Data Collection (APDC), the NSW Perinatal Data Collection (PDC), and the Register of Births, Deaths and Marriages (RBDM). The APDC, 'hospital records', is an administrative database of all hospital admissions, including public and private hospitals. Procedures are coded according to the Australian Classification of Health Interventions and diagnoses are coded according to the International Classification of Diseases 10th Revision-Australian Modification. The PDC, 'birth records', is a population-based surveillance system of all births (≥ 20 weeks gestation or ≥ 400 g birthweight). The RBDM is a register of all deaths occurring in NSW. The three databases were linked by the NSW Centre for Health Record Linkage. The study was approved by the NSW Population and Health Services Research Ethics Committee.

Children undergoing a cardiac procedure (surgical or catheter-based intervention) in the first year of life were identified using a list of procedure codes from the Australian Classification of Health Interventions that captured procedures on the heart. The hospital records also provided information on total length of stay for the admission (including transfers), intensive care unit admissions, cardiopulmonary bypass and principal and other diagnoses. Diagnosis codes from hospital admissions in the first year of life were used to identify the underlying congenital cardiac condition present. The RBDM was used to identify deaths. The birth records provided maternal characteristics (age, country of birth, maternal smoking, medical conditions), birth outcomes (gestational age, plurality, birthweight, hospital of birth) and postcode of residence at time of birth. Socioeconomic status and rurality were identified using postcode of residence at time of birth and classification from the Australian Bureau of Statistics Socio-Economic Indexes for Areas (SEIFA) and Accessibility-Remoteness Index of Australia (ARIA). Small-for-gestational-age (SGA) was defined as <10th birthweight percentile for gestational age and infant sex [27].

2.2. Outcomes

Outcomes evaluated included mortality and morbidity. Mortality was characterised by age at death, proximity from initial cardiac procedure (<30 days or >30 days) and whether it occurred in the admission of initial cardiac procedure or subsequently. Neonatal death was defined as death of a live born infant during the first 28 days of life. Indicators of extent of health service utilisation included need for cardiopulmonary bypass, admission to ICU and need for readmission (planned and unplanned) to hospital. Number and average length of readmission was included. Children born 2001–2011 (inclusive) were followed up until age 1 year, those born 2001–2008 (inclusive) were followed up until age 6 years. Costs in Australian dollars AUD were estimated using published costings based on Australian Refined Diagnoses Related Groups (AR-DRG). Each admission is classified into an AR-DRG group based on diagnosis and procedure information. Each admission is allocated a cost weight to be multiplied by the base average cost, \$3840 as per NSW Costs of Care Standards 2009/2010 [28]. The NSW Costs of Care Standards cost per admission takes into account cost of presentation to and referral from emergency department, admissions to intensive care unit, transfers, and long stays.

2.3. Data analysis

Perinatal characteristics were compared between children with a cardiac operation and all births in NSW in study period. Incidence of study outcomes in children with a cardiac operation was tabulated. The proportion of infants who had subsequent admissions following discharge home from the initial cardiac admission were identified and average length of stay (LOS) per admission up to age 1 year and from 1 year up to age 6 years calculated. Total days in hospital for all infants undergoing a cardiac procedure were calculated and total average days per year reported. Multivariable logistic regression was used to examine perinatal and perioperative predictors of study outcomes in children who had undergone a cardiac operation.

Costs in Australian dollars were estimated using costings based on Australian Refined Diagnoses Related Groups. Average costs per initial admission were calculated for all infants. The distribution of costs are skewed as a small number of infants had a very high cost of initial admission, as such the median and interquartile ranges of the costs were also calculated. The cost per readmission was calculated up to age 1 year and from 1 to 6 years of age. The total cost of all infants per year was also calculated.

3. Results

Over the study period 2001–2012, there were approximately 1.1 million births in NSW, of which 2722 children underwent a cardiac procedure in their first year of life, a rate of 2.5 children per 1000 live births. Rate of children undergoing cardiac procedure in the first year of life was relatively unchanged over the period (Supplementary Fig. 1), as was mortality, percentage of procedures performed via percutaneous procedure and length of hospital day at first surgery admission (data not shown). Closure of ventricular septal defect was the most frequently performed principal procedure over the period (Table 1). Closure of a patent ductus arteriosus (PDA) alone was performed in 416 children (excluded from further analysis).

The infant and maternal characteristics of the remaining 2306 children undergoing a cardiac procedure in the first year of life are summarised in Table 2. Children undergoing a cardiac procedure were more likely to be male, preterm and/or small-for-gestational-age. Of the children undergoing a cardiac procedure in the first year of life, 43% (981/2306) underwent first cardiac procedure in the neonatal period. In regards to the admission associated with first cardiac procedure, cardiopulmonary bypass was utilised in over 60% (1401/2306), ICU admission occurred in 92% (2143/2306), with 35.9% (829/2306) remaining in ICU for over a week (Table 3).

Mortality rate in the first year of life was 7.1% (Table 3). The mortality rate within the first 30 days following initial procedure was 3.1% (72/2306). Of all deaths before age 1 year, 56% (92/164) occurred >30 days post-operatively. Of these children, 40% had another congenital anomaly, 59% had surgery in the first 7 days of life and 22.7% were preterm. The mortality rate in the first year of life for the 981 infants who underwent surgery in the neonatal period was 13.8% (131/981), the majority died during the hospital admission that surgery took place (8.7%, $n = 87$). There were a total 140 deaths before age 6 years for those infants born from 2001 to 2008, giving a mortality rate in the first 6 years of life for those who had a cardiac procedure in the first year of life of 9.4% (Table 3). Survival by year is shown in Fig. 1. Characteristics of initial cardiac surgery and outcomes in first year of life are summarised in Table 3.

Almost 50% of children undergoing a cardiac procedure in the first year of life who survived to discharge were readmitted to hospital at least once in their first year of life (1084/2197), accounting for 2854 hospital readmissions. The majority (65%, 1856/2854) of presentations for readmission in the first year were to one of the three tertiary children's hospitals in NSW. Readmission was most likely in the first three months following cardiac procedure. Over a third of children (35%) with one hospital readmission had three or more readmissions in their first year. Of all readmissions, 52.9% were for emergency

Table 1

Most frequent principal cardiac procedures performed in first year of life (excluding patent ductus arteriosus closure).

| Procedure | Number performed |
|--|------------------|
| Closure of ventricular septal defect | 702 |
| Repair of aorta with anastomosis | 259 |
| Creation of systemic-to-pulmonary shunt | 241 |
| Closure of atrial septal defect | 181 |
| Repair of transposition of great vessels | 171 |
| Right and left heart catheterization | 152 |
| Percutaneous balloon pulmonary valvotomy | 116 |
| Creation of cavopulmonary shunt | 106 |
| Banding of main pulmonary artery | 91 |

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