US TRENDS IN INFANT MORTALITY DUE TO SPECIFIC CRITICAL CONGENITAL HEART DEFECTS FROM 1999 TO 2017

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Background: Approximately 1% of infants are born with congenital heart disease (CHD). Patients born with critical CHD have the highest rates of mortality during the first year of life. Previous population-based studies reported declining rates of CHD-related infant mortality. US population-based CHD-specific infant mortality trends in the last decade are scarce. We aimed to report current era CHD lesion-specific mortality trends in the US.

Materials/Methods: We used 1997-2017 US Multiple Cause of Death data to calculate annual infant mortality due to overall CHD, six specific lesions, and a single ventricle (SV) composite. Mortality rates were calculated using the number of infant deaths caused by CHD specific lesions as the numerator, and the total number of live births as the denominator.

Results: Among the 77 million live births included in this study, CHD-related infant mortality rates decreased from 4.5 to 3.0 (per 10,000 live births) during the 19-year period ($p<0.001$). Overall, nearly 19% of CHD-related deaths had prematurity, an extracardiac birth defect, or a genetic syndrome listed as another contributing cause. This proportion steadily increased during the study period (15.7% to 22.5%). Notably, when those cases were excluded from the numerator, trends in CHD-related infant mortality did not change. Mortality due to transposition of the great arteries had the largest relative decrease (77.6%), from 0.16 to 0.04 per 10,000 live births. Hypoplastic left heart syndrome (HLHS) accounted for the largest proportion of infant deaths due to CHD (21.8%). HLHS made up 94% of all SV deaths, and SV deaths accounted for 35.2% of CHD deaths. Infant mortality due to HLHS decreased from 0.89 to 0.51 per 10,000 live births, although most of the decline was during the first 11 years, with a relative plateauing between 2011 and 2017. While infant mortality due to tetralogy of Fallot and truncus arteriosus also decreased, mortality due to atrioventricular septal defect and total anomalous pulmonary venous return remained relatively stable.

Conclusions: Infant mortality due to CHD from 1999 to 2017 in the US has declined with substantial variation in trends by lesion. Prematurity, extracardiac birth defects and genetic syndromes play a large contributory role in CHD-related deaths. Variation across lesion type may be related to differential screening efficacy, surgical advances, and improvements in critical care of CHDs. Additional research is needed to better elucidate underlying causes of mortality.