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Intellectual Disability in Children with Congenital Heart Defects in Western Australia

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Introduction

Congenital heart defects (CHD) are diagnosed up to age 6 in 8-12/1,000 births annually in Western Australia. Recent improvements in management of infants with CHDs has significantly increased survival; approximately 85% of infants with CHDs live beyond childhood. However, children with CHDs may have increased risk of life-long intellectual disabilities.

Objectives and Approach

We conducted a study of 20,997 children to determine risk of intellectual disability (ID). All singleton, live born infants with CHDs born 1983-2010 were identified from the Western Australian Register for Developmental Anomalies, a statewide birth defects registry (n=6,968). Infants without CHDs born 1983-2010 were randomly selected from birth records (n=14,029). All data were linked to the Western Australia Midwives Notification System to obtain maternal and infant information. Children with ID were identified by linkage to the statewide Intellectual Disability Exploring Answers database. Risk ratios (RR) and 95% confidence intervals (CI) were calculated from multivariable logistic regression analyses.

Results

Of 20,997 children, 965 (4.6%) had an ID; 1.3% of children without CHDs and 11.2% of children with CHDs had an ID (P<0.001). 0.2% of children without CHDs and 0.4% of children with CHDs had autism. Three percent of children with CHDs had a known biomedical cause for ID (excluding trisomy 21) and 4.4% of children with CHDs had trisomy 21. Children with CHDs had 9 times the risk of ID compared to children without CHDs (RR=9.30; 95% CI: 7.91, 10.94). Children with CHDs almost had a twofold increased risk of autism compared to children without CHDs (RR=1.78; 95% CI: 1.07, 2.95). The greatest risk of ID among children with CHDs was associated with trisomy 21 (RR=166.0; 95% CI: 78.5, 350.8).

Conclusion/Implications

Children with CHDs have higher risk of ID than children without CHDs. Although the greatest risk for ID was for trisomy 21, children with CHDs still had increased risk of ID from other causes and all causes overall. Future research should elucidate the underlying etiology of ID in these children.

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