

Young children with heart disease and their families may have poorer quality of life than the general population

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A study by medical researchers from UNSW Sydney and the Sydney Children's Hospitals Network has shown that young children with heart

disease and their families may have poorer quality of life than the general population, leading to calls for routine screening to enable early intervention and better outcomes.

The paper – the largest Australian study on the quality of [life](#) in young children with complex [congenital heart disease](#) (CHD) – was published today in the *Journal of Pediatrics*.

"The findings are striking and highlight the significant challenges children with [heart](#) disease and their families face," says study author Associate Professor Nadine Kasparian from UNSW Medicine.

"Our study included young children aged 1-5 years, all of whom had undergone at least one heart operation. We examined their and their mums' physical, emotional, social and cognitive health, using a well-established quality of life measure," says Dominique Denniss, a UNSW Medicine Honours student and author on the study.

"We looked at quality of life from a multi-dimensional perspective, taking into account a whole range of factors that can influence a child's sense of wellbeing."

Emotional health

Overall, the study found that many children with complex CHD have meaningful impairments in quality of life, compared to their healthy peers – especially when it comes to their emotional health.

"Our youngest children in the study, aged between 1 and 2 years, showed functioning that was below what we might expect in the general population for almost every domain," A/Prof Kasparian says.

"For our 2-5-year olds, we found one very striking result – emotional

functioning was, on average, more than 10 points below what we might expect to see for healthy children the same age. That's an important difference."

The team identified a number of potentially modifiable factors that contributed significantly to child quality of life.

"We found that feeding difficulties and mums' level of psychological stress played an important role for children's quality of life," Ms Denniss said.

"Additional factors were having the most complex form of congenital heart disease (functional single ventricle CHD) or having another health condition in addition to heart disease."

Key factors

The results were similar for mothers, with key factors for lower health-related quality of life being difficulties in their family, psychological distress, whether their child had any additional physical conditions, and perceiving their child as having a difficult temperament.

While the study highlights profound difficulties for young children with heart [disease](#) and their families, A/Prof Kasparian says it's also really important because these factors can potentially be addressed.

"We now have a roadmap showing us what we can do to make a difference for these children and their families – we now know what avenues there are for better care and support.

"For example, if maternal psychological stress is playing a role in influencing quality of life, there are evidence-based interventions and supports we can offer that can make a difference.

"Similarly, with feeding difficulties, there are things that we can do in hospital and in the community to help our babies with feeding difficulties.

"There are also ways we can nurture the developing relationship between sick babies and their parents to improve overall quality of life."

Based on their results, the researchers call for routine screening of health-related quality of life for all children with complex CHD, so they don't continue to fall through the cracks. They also make a series of recommendations for improving clinical practice and health policy.

"When you find such significant proportions of children with difficulties in domains that are important for the rest of their lives, you need to advocate strongly – across the country – for screening, so that we're picking up our most vulnerable children and providing supports as early as possible," A/Prof Kasparian says.

"When it comes to screening, there's no 'one size fits all' approach. In some cases, it might mean starting by asking families to complete a measure of [quality](#) of life – well before their baby's discharge from hospital – and then making a plan together for accessing the supports that are needed and wanted."

Development

A/Prof Kasparian says it is important to focus on these kids because early childhood is a critical time for so many aspects of development.

"In our field, there have been very few studies focusing on [young children](#). Much of the evidence that informs our clinical decisions is based on older children, so this study sheds much-needed light on our younger [children](#)'s experiences and needs," she explains.

Congenital [heart disease](#) is any structural abnormality of the heart that babies are born with – some are diagnosed in utero, and some soon after birth. CHD affects about 1 in 100 newborns, or about 1.35 million babies each year around the world. Australia's first National Childhood Heart Disease Action Plan was announced in February this year, and is currently in public consultation phase.

More information: Need for routine screening of health-related quality of life in families of young children with complex congenital heart disease. *Journal of Pediatrics* 2018: In Press.

Provided by University of New South Wales

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