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Children with single ventricle congenital heart defects: considering the parent experience

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Background

• About 1% of children are born with congenital heart defects (CHD) worldwide.
• CHD impacts parents’ psychological health and family life and heightens their stress compared to the wellbeing of parents with typically developed children.
• In-depth understanding of the shared experiences of parents is currently lacking.
• The aim of this study was to explore the lived experiences of parents who have children with a diagnosis of single ventricle CHD, from diagnosis through to their childhood and adolescence.

Method

• Qualitative interviews with 12 parents, recruited from a children’s hospital.
• The children were diagnosed either antenatally or postnatally and had completed the Fontan surgery at least six months prior to the start of recruitment.
• Semi-structured interviews explored parent experiences from the point of diagnosis, the process of multiple surgeries, caring for a child with a cardiac condition, family relationships, impact on life and experience of support throughout their child’s life.
• Interpretative Phenomenological Analysis was applied.

Results

“We know nothing. I don’t know how to deal with a cardiac child. It’s bad enough a kid, keeping it alive, I’ve got a cardiac that’s even, double the trouble!”
- Parent 10

“I never left him. He wasn’t left alone. Where normally you can go and put the kettle on, he was getting carried with me, so I could keep an eye on his lips, his fingers.”
- Parent 10

“He’s a normal child, his problem is inside, it’s not outside, and not visual, so we thought, no, why should we send him to a special needs school?”
- Parent 1

“I’m desperately trying, I would love for him to become independent and it’s like trying to shove a chick out of the nest, because he’s got so used to the fact that I’m always there, will always support him.”
- Parent 6

Clinical implications

• Healthcare professionals should promote emotional wellbeing and provide support to families with a diagnosis of CHD at significant time points during the patient journey.

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