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

Link to publication record in Manchester Research Explorer

Citation for published version (APA):

Citing this paper
Please note that where the full-text provided on Manchester Research Explorer is the Author Accepted Manuscript or Proof version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version.

General rights
Copyright and moral rights for the publications made accessible in the Research Explorer are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

Takedown policy
If you believe that this document breaches copyright please refer to the University of Manchester’s Takedown Procedures [http://man.ac.uk/04Y6Bo] or contact uml.scholarlycommunications@manchester.ac.uk providing relevant details, so we can investigate your claim.
Children with single ventricle congenital heart defects: considering the parent experience

Dr Midori Lumsden, Dr Debbie Smith, Dr Emma Twigg, Dr Rafael Guerrero & Dr Anja Wittkowski
Contact: anja.wittkowski@manchester.ac.uk

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

“Super Parents”
- Becoming experts
- Hypervigilance
- Managing emotional impact
- Parental responsibility

“Striving for Normality”
- Integrating CHD into lives
- Treating child as siblings/peers
- Celebrating achievements
- Recognising limitations
- Practical challenges to normality

“The Parent Experience”
- Management of CHD
- Hidden condition
- ‘wouldn’t change a thing’
- Timing of diagnosis
- Letting go of responsibility
- Need for support

“Accepting CHD and their Role”
- “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

“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.

Acknowledgements: The authors would like to thank all the participating parents who openly and kindly shared their experiences of living with a child with CHD and the cardiac team at Alder Hey Children’s Hospital for support with recruitment.