



Managing Uncertainty in Prenatal Diagnosis of Congenital Heart Disease

Alun C. Jackson, PhD

Reviews of the effect of congenital heart disease (CHD) in children on parents and families and the ways they cope have highlighted a range of mental health effects in these parents, such as posttraumatic stress, anxiety, depression, worry and concern, and adjustment problems.¹ Even with greater life expectancy through surgical advances, such as the Fontan procedure for children born with a single ventricle, fear of death and uncertainty around quality and quantity of life contribute to high levels of anxiety and distress in these parents.² For these reasons, there are increasing calls for the better integration of psychosocial support services with pediatric cardiology services.^{1,3-5}

Prenatal diagnosis of CHD is recognized as a particularly difficult time for parents as they struggle with a range of emotions, including anger and guilt, as well as the expected emotions of anxiety and fear. These emotional reactions tend to relate to parents not knowing what to expect, the decision-making process surrounding their baby, and thoughts about the future. Parents' fear of the unknown and wanting to make the best decisions for their child are stressful and often experienced as overwhelming.

The article by Harris and colleagues captures well this sense of uncertainty.⁶ The authors report on a qualitative study of 27 individuals from 17 families who participated in telephone interviews conducted after the initial prenatal consultation and again at a follow-up prenatal cardiology visit. Although the study is described as longitudinal, both interviews were within the prenatal period; however, the larger project of which this study is a part includes postnatal interviews.

The study identified immediate, concrete logistical concerns for the families about how to manage the implications of the diagnosis and, in some cases, how to deal with a lack of a definitive diagnosis. This lack of a diagnosis creates more uncertainty around the severity of the condition and long-term effects on their child. Interestingly, there is no report in the article about parents having a discussion with the pediatric cardiologist or other health professional about termination. In another qualitative study of parents coping with their child's heart condition, the most contentious issue in prenatal diagnosis was discussion about termination of the pregnancy.⁷ Parents acknowledged that there was no easy way to broach this subject and that it was one that highlighted their vulnerability and sense of responsibility for their child. The parents in that study suggested that they would have benefited from psychological support at that time.

Harris and colleagues' article suggests that the incorporation of learnings from the palliative care field may better equip pediatric cardiologists to deal with the issues facing families, particularly the central issue of uncertainty. The authors raise a number of other important points. They note that post diagnosis, families need to work on creating a new identity as a family dealing with a chronic condition in a vulnerable family member. This identity construction challenges existing coping patterns, but, as we know from numerous studies, most families cope well. Nonetheless, we need to be aware of the factors associated with difficulties in coping, such as preexisting mental health issues in the primary caregiver and lack of social support.²

The authors highlight the importance of communication, particularly in relation to terminology. Having their child's condition described as a "heart difference" rather than a "heart defect" was important in the families' construction of their personal and family narrative. This reflects an orientation to hope and positive adaptation.

Also highlighted is the need felt by some parents to have assistance in negotiating complex health care systems, and the suggestion by one participant of the usefulness of a patient navigator is well made. Patient navigators are used in oncology, mental health care, and for complex conditions.

+ Related article

Author affiliations and article information are listed at the end of this article.

Open Access. This is an open access article distributed under the terms of the CC-BY License.

This article has as its primary focus the role of the pediatric cardiologist in managing the uncertainty around families dealing with a heart difference. It is important to recognize, however, that there are multiple other stress points for families with a prenatal diagnosis that could benefit not just from a palliative care-informed pediatric cardiologist but also from a multidisciplinary approach. This approach could include coping with transitions, such as from hospital to home and the system-wide communication with health professionals that this entails, and the development and maintenance of appropriate social support.

ARTICLE INFORMATION

Published: May 5, 2020. doi:[10.1001/jamanetworkopen.2020.4353](https://doi.org/10.1001/jamanetworkopen.2020.4353)

Open Access: This is an open access article distributed under the terms of the [CC-BY License](https://creativecommons.org/licenses/by/4.0/). © 2020 Jackson AC. *JAMA Network Open*.

Corresponding Author: Alun C. Jackson, PhD, Australian Centre for Heart Health, Ste 8, 75-79 Chetwynd St, North Melbourne, Victoria 3051, Australia (alun.jackson@australianhearthealth.org.au).

Author Affiliations: Australian Centre for Heart Health, Melbourne, Victoria, Australia; Faculty of Health, Deakin University, Geelong, Victoria, Australia.

Conflict of Interest Disclosures: None reported.

REFERENCES

1. Woolf-King SE, Anger A, Arnold EA, et al. Mental health among parents of children with critical congenital heart defects: a systematic review. *J Am Heart Assoc*. 2017;6(2):e004862. doi:[10.1161/JAHA.116.004862](https://doi.org/10.1161/JAHA.116.004862)
2. Jackson AC, Frydenberg E, Liang RP, Higgins RO, Murphy BM. Familial impact and coping with child heart disease: a systematic review. *Pediatr Cardiol*. 2015;36(4):695-712. doi:[10.1007/s00246-015-1121-9](https://doi.org/10.1007/s00246-015-1121-9)
3. Woolf-King SE, Arnold E, Weiss S, Teitel D. "There's no acknowledgement of what this does to people": a qualitative exploration of mental health among parents of children with critical congenital heart defects. *J Clin Nurs*. 2018;27(13-14):2785-2794. doi:[10.1111/jocn.14275](https://doi.org/10.1111/jocn.14275)
4. Caleshu C, Kasparian NA, Edwards KS, et al. Interdisciplinary psychosocial care for families with inherited cardiovascular diseases. *Trends Cardiovasc Med*. 2016;26(7):647-653. doi:[10.1016/j.tcm.2016.04.010](https://doi.org/10.1016/j.tcm.2016.04.010)
5. Utens EMWJ, Callus E, Levert EM, Groote K, Casey F. Multidisciplinary family-centered psychosocial care for patients with CHD: consensus recommendations from the AEPC Psychosocial Working Group. *Cardiol Young*. 2018;28(2):192-198. doi:[10.1017/S1047951117001378](https://doi.org/10.1017/S1047951117001378)
6. Harris KW, Brelsford KM, Kavanaugh-McHugh A, et al. Uncertainty of prenatally diagnosed congenital heart disease: a qualitative study. *JAMA Netw Open*. 2020;3(5):e204082. doi:[10.1001/jamanetworkopen.2020.4082](https://doi.org/10.1001/jamanetworkopen.2020.4082)
7. Jackson AC, Higgins RO, Frydenberg E, Liang RP, Murphy BM. Parent's perspectives on how they cope with the impact on their family of a child with heart disease. *J Pediatr Nurs*. 2018;40:e9-e17. doi:[10.1016/j.pedn.2018.01.020](https://doi.org/10.1016/j.pedn.2018.01.020)