

Parental Coping After Their Baby's Diagnosis of Congenital Heart Disease

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Statement of Originality

*This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to this copy of my thesis, when deposited in the University Library**, being made available for loan and photocopying subject to the provisions of the Copyright Act 1968.*

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Acknowledgement of Collaboration

I hereby certify that the work embodied in this thesis has been done in collaboration with other researchers including Dr Nadine Kasparian, Associate Professor Gary Sholler, Associate Professor Edwin Kirk, Associate Professor Bryanne Barnett and Associate Professor David Winlaw and was carried out within the Sydney Children's Hospitals Network (Westmead and Randwick). Other researchers included:

Dr Nadine Kasparian, PhD, Head of Psychological care at the Heart Centre for Children, The Sydney Children's Hospitals Network (Westmead and Randwick) and Senior Research Fellow (Paediatrics) at the School of Women's and Children's Health, UNSW Medicine, The University of New South Wales, Randwick, New South Wales. Dr Kasparian is the principal investigator on this project and is responsible for all aspects of the study. She has acted as principal supervisor for this thesis.

Associate Professor Gary Sholler, MBBS (Hons I) FRACP, is Director of The Sydney Children's Hospitals Network Cardiac Service (Westmead and Randwick) and Associate Professor (Paediatrics) at Discipline of Paediatrics and Child Health, Sydney Medical School, The University of Sydney. Dr Sholler has overseen and provided critical support in the clinical aspects of complex congenital heart disease.

Dr Edwin Kirk, MB BS, FRACP, PhD, is Staff Specialist in Medical Genetics in Sydney Children's Hospital and Conjoint Lecturer in Paediatrics at the University of New South Wales. Dr Kirk played a crucial role in the development of the principal research project and has overseen all components of the project ranging from recruitment to manuscript preparation.

Professor Bryanne Barnett, MB ChB, FRANZCP, MD, AM, is an expert in the field of perinatal and infant mental health. She is currently the Director of Clinical

Services and Chairman of the Board of Directors at Karitane in Sydney South West Area Health Services, as well as Conjoint Professor of Psychiatry at the University of New South Wales. Professor Barnett played an integral role in the development of the project and the interview guides utilised with parents as well as assisting in the preparation of manuscripts for publication.

Associate Professor David Winlaw, MB BS (Hons), MD, FRACS, is Head of Kids Heart Research at The Children's Hospital Westmead. Dr Winlaw has provided invaluable input regarding the surgical aspects of the project.

I have included as part of the thesis a statement clearly outlining the extent of collaboration, with whom and under what auspices.

Signed:

Date:

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Structured Abstract

Scope and Purpose

Receiving a diagnosis of complex congenital heart disease (CHD) for one's baby is a highly stressful and potentially traumatic experience for parents and has the potential to have significant and long-lasting psychological effects (Rychik et al., 2013). Due to recent technological advancements it is now possible for mothers and fathers to receive a diagnosis during pregnancy (fetal¹ diagnosis) or postpartum (postnatal diagnosis). Currently, the literature is limited in the exploration of the similarities and differences in psychological outcomes and experiences amongst parents as a result of time of diagnosis and gender. Further, little is known about the coping strategies employed by mothers and fathers as they attempt to cope with such a diagnosis. Consequently, the present study had three main aims. First, to determine whether the stress and coping model proposed by Lazarus and Folkman (1984) can be applied to gain an understanding of parental coping in response to receiving their baby's diagnosis of complex CHD. Second, to explore thematic similarities and differences in the coping strategies employed by parents who received a fetal diagnosis with parents who received a postnatal diagnosis. Third, to explore thematic similarities and differences in the coping strategies utilised by mothers compared with fathers.

Methodology

A cross-sectional, mixed methods study design was utilised and data was taken from a larger study, previously conducted. Participants included mothers and fathers of a baby diagnosed with complex CHD during pregnancy (fetal diagnosis) or within

¹ This spelling of 'fetal' has been utilised throughout this thesis; as opposed to 'foetal', as it has been deemed to be the more accurate term in the literature (Boyd & Hamilton, 1967).

the first six months of life (postnatal diagnosis). Participants were identified through the cardiology databases of the Sydney Children's Hospital Network, including the Children's Hospital at Westmead and the Sydney Children's Hospital, Randwick. In this sub-study, parents who completed their interview after the birth of their baby and before their infant reached 6 months of age were included.

Participants were first required to complete a semi-structured interview with Dr Nadine Kasparian, which was audio-recorded and transcribed verbatim. Two weeks after completing the interview, participants were then asked to complete a brief self-report questionnaire, from which, this study accessed demographic and medical information. Transcripts were coded utilising a modified analytic induction approach with the assistance of the qualitative data analysis software, *QSR NVivo10*.

Results

In total, twenty-five parents of fifteen babies completed twenty-two semi-structured interviews, with three couples choosing to complete the interview together. The sample consisted of six mothers and six fathers who received a fetal diagnosis and nine mothers and four fathers who received a postnatal diagnosis. After applying Lazarus and Folkman's model of stress and coping (1984), each of the three types of coping proposed (problem-focused, emotion-focused, meaning-focused) were evident within the narratives of participants. One main theme identified that could not be categorised within the model was parental pride and focus on the baby.

In the exploration of differences based on time of diagnosis it was found that parents who received a fetal diagnosis differed from parents who received a postnatal diagnosis in their level of preparedness, the nature and quality of distancing, meaning-focused coping and sources of reassurance. In comparing mothers and

fathers, differences arose in the use of confrontive coping, as mothers more frequently reported fighting to be close to their baby, and in the application of emotion-focused coping, as mothers more frequently reported using emotion-focused coping such as drawing upon social support. A larger proportion of mothers than fathers were also found to engage in meaning-focused coping, finding the benefit in the stressful situation that was their baby's condition.

General Conclusions and Implications

Parental coping with a diagnosis of complex CHD in their baby can be broadly categorised by the model of stress and coping proposed by Lazarus and Folkman (1984) with the exception of parental pride and focus on the baby. This finding suggests that while the model may be beneficial in guiding clinicians' generally in understanding the coping strategies employed by parents within this setting, it is limited in its ability to capture the importance of the relationship between parent and baby in coping with the difficulties resulting from a diagnosis.

The identified differences in coping strategies between diagnostic groups highlights the need for medical staff to help parents to feel better prepared for the birth and treatment of their baby. This will likely involve assisting parents in gathering information as problem-focused coping was identified as an important strategy employed by both mothers and fathers. Medical staff also have a role to play in helping parents to strengthen their attachment with their baby and find ways to separate their baby from their diagnosis of complex CHD. As a result of these findings, recommendations for further research include the use of quantitative measures, larger sample sizes and targeted exploration of the various forms of meaning-focused coping, emotion-focused coping and sources of reassurance utilised by parents.

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Critical Literature Review: Parents' experiences of fetal or early postnatal diagnosis of congenital abnormality: A systematic literature review

Abstract

Receiving a diagnosis of congenital anomaly in your baby can be a highly stressful and potentially traumatic experience for mothers and fathers. This systematic review was conducted with two aims in mind. First, to identify if the time a parent receives a diagnosis of a congenital anomaly in their baby has a significant impact upon their psychological response and psychosocial needs (fetal or postnatal). Second, to determine if psychological response and psychosocial needs vary between mothers and fathers.

A total of fifteen studies were identified via a systematic search of electronic databases containing international peer-reviewed journals from January 1806 to June 2014. Results across the fifteen studies were inconsistent. Five of the nine studies measuring the short-term impact of a diagnosis reported significant differences as a result of timing of diagnosis although two reported improved psychological outcomes for the postnatal diagnostic group and three improved psychological outcomes for the fetal diagnostic group. Six months after diagnosis, one study reported better outcomes for parents who received a postnatal diagnosis while two studies reported no differences as a result of timing of diagnosis. Only two studies were found that considered the long term impact of diagnosis, one study reported better outcomes after receiving a postnatal diagnosis while one study found no differences between the two groups.

In total, nine of the identified articles explicitly compared the experiences of mothers with fathers, with seven out of nine reporting mothers experienced greater

psychological distress and stronger emotional response. These findings emphasise a significant gap in the literature particularly due to the conflicting results presented.

Keywords: Fetal diagnosis, postnatal diagnosis, congenital anomalies, psychological stress, coping, parents, infant.