

Title: Parent's perspectives on how they cope with the impact on their family of a child with heart disease

Running Head: Parental coping with child heart disease

Alun C JACKSON PhD^{1, 2, 3}

Rosemary O HIGGINS PhD^{1, 4, 5}

Erica FRYDENBERG PhD²

Rachel P-T LIANG MEdPsych^{1, 2}

Barbara M MURPHY PhD^{1, 4, 6}

¹ Australian Centre for Heart Health, Suite 8, 75-79 Chetwynd Street North Melbourne, Victoria, 3051, Australia

² Melbourne Graduate School of Education, The University of Melbourne, Grattan Street, Parkville, Victoria, 3010, Australia

³ Centre on Behavioural Health, University of Hong Kong, 2/F The Hong Kong Jockey Club Building for Interdisciplinary Research, 5 Sassoon Road, Pokfulam, Hong Kong

⁴ Deakin University, Geelong, Victoria 3217, Australia, Faculty of Health

⁵ Department of Physiotherapy, Faculty of Medicine, Dentistry and Health Sciences, The University of Melbourne, Grattan Street, Parkville, Victoria, 3010, Australia

⁶ School of Psychological Sciences, Faculty of Medicine, Dentistry and Health Sciences, The University of Melbourne, Grattan Street, Parkville, Victoria, 3010, Australia

**Corresponding author: Alun C Jackson Australian Centre for Heart Health, Suite 8, 75-79 Chetwynd Street North Melbourne, Victoria, 3051, Australia alun.jackson@australianhearthealth.org.au
Telephone: +61 3 9 326 8544**

Published as:

Jackson, A.C., Higgins, R.O, Frydenberg, E., Liang, R., Murphy, B.M. (2018). Parent's Perspectives on How They Cope with the Impact on Their Family of a Child with Heart Disease, *Journal of Pediatric Nursing*, <https://doi.org/10.1016/j.pedn.2018.01.020>

REVISION

Parent's perspectives on how they cope with the impact on their family of a child with heart disease

ABSTRACT

Purpose

Studies of familial coping with a child's chronic condition have highlighted psychological distress; family functioning; and quality of life; as issues that demand coping strategies.

There are conflicting findings on impact and coping and a paucity of information about the specific coping challenges for parents of a child with heart disease, with few qualitative studies in this area. The purpose of the study was to explore the way parents coped with their child's heart condition as it impacted on different domains of family functioning.

Design and Method

In this qualitative study, interviews were held with 17 parents attending a paediatric hospital-based family support program in 2015. Fifteen of the 17 children's conditions were classified as 'major'. Domains covered in the interviews included: coping challenges posed at different stages of the illness trajectory, parenting, condition management, transitions, psychological impact, social support and coping strategies. Interview transcripts were coded thematically.

Results

Multiple points of stress and challenges to coping were identified: coping with the diagnosis, including consideration of termination; dealing with the challenges facing their child; coping with parenting including co-parenting issues; the role of social support in coping; and identification of adaptive and maladaptive coping behaviours.

Conclusion

A large range of positive coping strategies were identified, as was the need for coping-focused psychological support throughout the parents' and children's journey.

Practice implications

The strategies identified have formed the basis of a manualised intervention for these parents.

KEY WORDS

Child heart disease; parenting; coping

INTRODUCTION

Several studies have reported that the presence of chronic conditions in children, including child heart disease (CHD), may place the well-being of the entire family at risk as the burden of care increases vulnerability to major psychological and social disturbances (Carey, Nicholson, & Fox, 2002; Hodapp, Dykens, & Masino, 1997; Martin & Nisa, 1996; Woods, Haberman, & Packard, 1993). Using a resilience and coping perspective rather than a deficit perspective, however, the majority of studies of families' response to childhood conditions suggest that overall most families adjust well (Kazak et al., 1997; Kupst et al., 1995; Kupst & Schulman, 1988; Sawyer, Antoniou, Toogood, & Rice, 1997). Nonetheless, a significant subset of parents of children with chronic conditions has difficulty coping in both the short and long term (Graf, Landolt, Mori, & Boltshauser, 2006; Kupst et al., 1995; Kupst & Schulman, 1988). This is important as parental coping has been demonstrated to be a significant predictor of coping and adjustment in children with a range of chronic conditions (Kupst et al., 1995; Kupst & Schulman, 1988; Rodenburg, Marie Meijer, Dekovic, & Aldenkamp, 2006; Sanger, Copeland, & Davidson, 1991; Thompson et al., 2003). A recent systematic review has confirmed the multi-faceted impacts on families caring for a child with heart disease, including impacts on parental distress levels, family functioning, quality of life and ways of coping (Jackson, Frydenberg, Liang, Higgins, & Murphy, 2015)

Psychological distress

Some parents of children with child heart disease (PCCHD) show a higher incidence and severity of anxiety, distress, depression, anger, hopelessness and/or somatisation of symptoms, compared to parents of healthy children or children with non-cardiac related diseases (Dale et al., 2012; Lawoko & Soares, 2002, 2006). The severity of the child's heart lesion at diagnosis has been shown to be related to parental distress levels with more severe lesions being associated with higher levels of psychological distress (Brosig, Whitstone,

Frommelt, Frisbee, & Leuthner, 2007). Higher psychological distress is also associated with poorer understanding of the diagnosis and poorer cohesiveness in the family (Doherty et al., 2009). The timing of diagnosis is important. Prenatal diagnosis, for example, has been found to be more impactful than postnatal diagnosis of CHD (Brosig, Whitstone, et al., 2007).

Family functioning

Complexity of the child's disease, as well as parents' socioeconomic status, have both been linked to higher levels of family uncertainty. For example, families of children with more severe CHD (e.g. Hypoplastic Left Heart Syndrome - HLHS) report more negative impacts than families of children with milder forms of CHD, particularly in the domains of familial burden (including more problems with siblings), social relationships, mastery, financial burden and personal strain (Almesned, Al-Akhfash, & Mesned, 2013; Brosig, Mussatto, Kuhn, & Tweddell, 2007; Connor, Kline, Mott, Harris, & Jenkins, 2010).

Quality of life

Research on the quality of life (QoL) of PCCHD has produced contrasting findings, particularly where different measurement tools have been used with different samples. Similar QoL scores were found between parents of different CHD diagnostic groups (HLHS vs. Transposition of the Great Arteries) and healthy controls using the Paediatric Quality of Life Inventory (Brosig, Mussatto, et al., 2007). Another study, however, using the Medical Outcomes Study Short Form 36 (SF-36), revealed that PCCHD reported significantly poorer QoL. The most significant differences were found in the domains of general health, vitality and physical role limitation (Arafa, Zaher, El-Dowaty, & Moneeb, 2008).

Coping

A lower degree of maternal health and adjustment has been found to be associated with maladaptive coping strategies such as avoidance/behavioural disengagement, and denial/wishful thinking but unrelated to the severity of heart defects (Davis, Brown,

Bakeman, & Campbell, 1998; Doherty et al., 2009). Perceived social support has been found to be positively related to individual parental coping with CHD (Tak & McCubbin, 2002), although not all social support offered is seen by parents as necessarily positive or relevant to the child's illness trajectory (Bruce, Lilja, & Sundin, 2014). Mothers have been shown to seek more instrumental and emotional support and avail themselves of more spiritual and religious support compared to fathers, who are significantly more likely than mothers to use alcohol to cope (Doherty et al., 2009; Spijkerboer et al., 2007) . Younger mothers report more helpful coping related to family integration, cooperation and optimism whereas for younger fathers helpful coping involves maintaining social support, self-esteem and psychological stability (Tak & McCubbin, 2002).

Generally, family cohesiveness and adaptive parental coping strategies appear to be paramount for successful parental adaptation to CHD. Additionally, achieving a balance between fearing for their child's vulnerability and celebrating their resilience within a desired backdrop of a normalised life is a major focus of coping for PCCHD (Larson, 1998; Lee & Rempel, 2011).

Study aim

While previous studies have focused on parents' styles of coping, there is a paucity of information about the specific challenges faced by PCCHDs over the trajectory of the child's illness. Moreover, there have been relatively few qualitative studies in this area. The purpose of attempting to identify these stress points and the attendant challenge to the family's coping capacity, is to guide health professionals in directing their resources to families in a timely, informed and nuanced way. The aim of this study, therefore, was to develop a deeper understanding of coping challenges and strategies from the parent's perspective as they relate to the stresses and strains characteristic of phases in the child's journey, such as diagnosis; first and subsequent surgeries; and transitions such as hospital to home, and home to school.

MATERIALS AND METHODS

Participants and procedure

Family members attending the HeartKids Family Support Program at the Royal Children's Hospital, Melbourne, Victoria were invited to participate by the Program Coordinator. In-depth interviews were conducted with parents using a semi structured interview schedule developed as a collaborative exercise between the research team and the HeartKids Family Support Workers, all of whom were parents of children with heart conditions themselves, and who formed an Expert Reference Group for the research project. This ensured that the language used was consistent with the way these parents usually discussed issues related to their child and their condition.

Ethics approval for the study was granted by the Humanities and Applied Science Ethics Committee of the University of Melbourne (Approval 1441631.1), and all parents were supplied with a plain language statement, and provided written consent to their participation, and acknowledged that they had a right of withdrawal from the study. Parents were advised that if participation in the study caused them distress, a clinical psychologist with additional training in family therapy was available for them to consult at no charge.

Inclusion criteria were that the parents were over 18, spoke English, and had a child with a heart condition. Although the research team considered excluding families with a child undergoing complex procedures or having a recently determined poor prognosis at the time of interview, the Expert Reference Group advised against these exclusions.

Data collection

Twelve of the interviews were conducted face to face (six at the hospital; five at the research centre and one at home) while five were conducted over the phone. There were no differences between these groups in terms of age, socioeconomic status and severity of their

child's condition. This is consistent with other research indicating no difference in participant response using either medium (Sturges & Hanrahan, 2004).

Using the schedule, which covered seven domains, as indicated in Figure 1, two of the authors (AJ, RH) and two research fellows (psychology and nurse-trained) conducted the 17 interviews. Within each domain, there were between one and four key questions, with probes provided for the interviewer. Under the 'parenting' domain, for example, one of the questions asked was: *Can you tell me a bit about your parenting of your child and the impact of their illness on this?* The probes for this question included: *What is a normal day like for you in parenting this child? What is your relationship like with this child? What about (name other parent)'s (name step parent)'s relationship with this child? What are some of the unique parenting challenges of having a child with a heart condition? Can you tell me a bit about how you see yourself as a parent: permissive/ nurturing / strict /structure/involved/ easy going, etc? Has having this child changed your parenting style? If so, in what way? How do your concerns about your child's health impact on the way you parent? Further probe - sibling play/supervision/sleep/discipline? What areas would you like to improve in terms of your parenting? If you got help with your parenting, what would that help /support look like? How might it be provided?*

Figure 1 about here

Data analysis

Interviews were transcribed by the research fellows. Interview transcripts were read repeatedly and subjected to content analysis by one member of the team (RH). Reliability of the analysis was enhanced through another member of the research team (AJ) independently analysing a random sample of interview records. Analysis focused on the themes and their components, related to parental coping generated by the domains included in the interview schedule. This is where this study is different from a grounded theory approach to

understanding parental coping, in that an interview schedule informed by empirical research, theory, clinical practice, and the lived experience of parents of children with a heart condition was used.

If it was thought necessary, a third member of the team (EF) was to adjudicate differences of opinion if consensus could not be reached. This option did not have to be used. The coping themes were then presented to the whole research team to ensure a common interpretation of the meaning attached to parents' responses, and the naming of the themes. The de-identified transcripts were then read by the HeartKids Family Support Program coordinator, to ensure that the research teams' interpretation of the data was accurate.

RESULTS

Demographic and clinical characteristics

The sample comprised 17 participants (15 mothers; two fathers) with a mean age of 40 for mothers and 41 for fathers. Fourteen of the 17 (82%) families had private health insurance, compared with 47% for all Australians being covered by private health insurance. Of the 17 children, 12 were female. Ages of the children ranged from: one year to five years-six children; six years to ten years-seven children; over 11 years- four children.

Of the 17 children included in the study, 15 were classified as 'major' using the CHD severity schema in Figure 2, which categorises congenital heart disease into minor, moderate and major types, based on the haemodynamic effect, the potential for damage to the heart, and mortality risk.

One additional child experienced Long QT syndrome (LQTS) and Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT). As younger age at CPVT diagnosis is a predictor of future cardiac events (Hayashi et al., 2009) and is implicated in sudden cardiac death (Pflaumer, Davis, & members of the Cardiovascular Genetic Diseases Council Writing Group Cardiac Society of Australia and New Zealand, 2011), this child's condition

was classified as 'major'. One other child was diagnosed with a 'moderate' condition: Atrioventricular septal defect (AVSD).

Figure 2 about here (Sholler, Kasparian, & Winlaw, 2011)

Themes

The themes related to coping, and the components of these themes arising from the interviews, are shown in Figure 3. The themes indicate that there were numerous challenges to parental coping and multiple points of stress for these families, of predominantly younger children. Themes identified were coping with: their child's diagnosis; the challenges facing their child; the challenges of parenting; the role of social support; and strategies for coping.

Figure 3 about here

Coping with their child's diagnosis

A range of emotions were experienced with pre-natal diagnosis including anxiety, worry, anger, guilt, relief and gratitude. These emotional reactions tended to relate mostly 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 baby were stressful and were often experienced as overwhelming. There were mixed responses in relation to communication with medical staff with parents expressing both satisfaction and dissatisfaction with the quality and content of their communication.

"I didn't enjoy my pregnancy, naturally, terrified of the whole thing."

The most contentious issue in pre-natal diagnosis was discussion about termination of the pregnancy following the diagnosis. Most of the discussions between parents and paediatricians about the possibility of termination were seen by parents as having been handled with a lack of sensitivity. Some of the parents acknowledged, however, 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. Parents acknowledged that once they had decided not to terminate, there was no further discussion about this. They suggested that they would have benefited from psychological support at this time, but no parents recalled having received such help.

“Both of our feeling was that we wanted to give him a chance, and if we only had him for a day, or we only had him for a minute, then at least he had been born and he was a person for the minute he existed, and he had a birth certificate ...”

Post-natal diagnosis was also marked by mixed views on the quality of communication with hospital staff. The more positive parent experiences of the post-natal diagnosis process were characterised by a sense of medical staff and parents being a team, involved in joint decision making:

“In intensive care I felt like I was always consulted, like they never made a decision unless they had me part of that decision, even small things ...”

Many parents found the tasks associated with understanding their child’s diagnosis challenging, and expressed a strong need for psychological support at this stage. Clear communication was valued, as was the feeling that the parents could go over the information a number of times as their understanding of the condition increased, which at times raised further questions:

“My main thing was, will this baby have a quality of life, that’s all I needed to hear. And he said this baby will never be a marathon runner, but can have a very good quality of life. And I thought well that’s all I need to hear.”

Coping with the challenges facing their child

The first challenge identified by parents was the severity of their child’s condition, and the trauma associated with fluctuations in their condition including the possibility of non-survival:

“That was the only moment ... that’s when I did say to my son, we brought him in the day before the surgery and said we need to say goodbye. That’s the only moment we thought this could be it.”

Parents identified a number of issues around the capacity of their child for self-management and the extent to which they needed to be involved in their child’s decision making and activity choices through giving age-appropriate information:

“I think it’s a very fine line, with kids, like I don’t want to say to her, look out in case you might have shortness of breath, when she’s older say 11 or 12, because then that might put panic in her too, and then every time she has shortness of breath she might be saying, you know ... I don’t want to tell her too much as she gets older either.”

Transitioning from hospital to home and transitioning from child and family-centered hospital care to adult care were seen as major challenges both for their child and for parents. While a move from intensive care to the ward, for example, was seen as positive, it also meant reduced levels of care by specialist staff and parents being responsible for more care-oriented decision making. For this cohort of parents of mainly younger children, transitioning from child to adult care was not an immediate issue, but was recognised as potentially very challenging for their child, and themselves, as they anticipated dealing with their children’s greater autonomy in their health-related decision making.

“It was daunting going home, because you had relied so much on advice, staff, guidance, and you were questioning can I let him cry for a couple of minutes, If he vomits do I just give him more formula, things like that. But it made me get my confidence in being a mum...”

Parents were aware of the challenges in growing up faced by their children, and noted how their children dealt with the challenges. These ranged from attention seeking behaviour, tantrums, anxiety disorders and socially inappropriate behaviour on the one hand, to their

children showing more empathy, maturity and energy in life compared to children their age, on the other hand. Parents noted that psychological support to help them normalise their children's behaviour should be *routinely* available to PCCHD and not necessarily subject to specialist referral.

“He actually got diagnosed, well the first time we saw the psych he thought it was Post Traumatic Stress, but they actually said no he's got Generalised Anxiety Disorder, which they think is quite common in kids who have had major surgeries and major health issues ...”

Because many of the children in this study were at the more serious end of childhood heart conditions many of the parents found it difficult to project themselves too far into the future, displaying a preference, rather, for focusing on their more immediate coping tasks.

Coping with the challenges of parenting

Following the birth of their child, many parents identified post-birth management as a significant challenge, as they attempted to connect to their child while fitting in with emergency procedures. Breastfeeding was identified as a particular challenge in this respect.

“We just got through one day at a time, and made sure we spent as much time as we could with him, we sat by his bedside basically until we were falling out of the chairs asleep.”

In this early phase of hospitalisation, parents learned to be assertive, in their desire to establish some level of control in relation to their child's management:

“I felt like an expert because I knew what it's like, I probably clocked up a year and a half of living in a hospital, so I knew, okay, I've got to ask the nurse, can you organise the dietician, can you get the lactation consultant, ..., and have an idea of all the specialists to get. And I think for parents who are just coming into the hospital, and they've never experienced hospital living, that would be good knowledge to have...”

For parents with children who are hospitalised for extensive periods, and for those parents who are uncertain about their child's prognosis, bonding is an issue, with many of the parents saying that the real bonding happens when their child comes home.

“Waving goodbye to him and playing with him before his last surgery was really full on and hard, and watching him be wheeled off was so hard, we knew what we were potentially going to lose and he was so cute ... and as he got wheeled off by the anaesthetist he looked back at us and gave us this wave and it was sort of like mum I'll be back soon and it was so cute and we thought he'll be okay.”

Although most parents recognise that they have a 'style' of parenting, they are aware that they tend to parent their child with the heart condition differently:

“We are more (helicopter parents) than we used to be...”

For some families, co-parenting challenges brought an added stress to relationships while for others it brought the parents closer together. Some parents found it difficult to see anything past their increased responsibility whilst others were able to let go a little.

Establishing clear roles through good partnerships and teamwork were seen as vital.

“I think you just focus on what you need to do and because we'd been in and out of hospital so many times... we knew what to do. I'd say we are in emergency, and he'd know what to do. His job was to look after our son, look after the business, and I could just focus on just living at the hospital and trying to sort out everything and I'd just report back to him and say this is what's happening. We knew our roles really well, and I think that helped a lot.”

An important aspect of co-parenting noted by fathers in particular was the opportunity their situation offered for re-definition of their 'father' role, triggered by a blurring of roles between the parents.

The presence of siblings posed its' own challenges for parents with issues such as how to meet the child with the heart condition's special needs while also meeting their other children's needs for parental nurturing, time and attention, as well as the issue of different rules applying to the different children. Many parents noted, however, the special relationship formed between their children, characterised by high levels of protection of, and responsiveness to, the sibling with the heart condition. There was awareness of the impact on the family of the many times that one parent, usually the mother, was absent because of staying in the hospital while their child underwent surgery. Where this happened, these periodic challenges to the apparent cohesiveness of the family unit were experienced by all members of the family.

Parents were very aware of the emotional toll that their situation had taken and reported feeling isolated, dismissing their own thoughts and feelings, difficulties with sleep, lack of self-care, and battling with their own health issues. For some parents this had led to clinical depression and suicidal ideation.

"I remember one time we'd come home, she was still in ICU and something so small happened and I just lost it and I scared the boys because I was on the floor crying."

"It's been hard, you can see how raw I am..... because you just push it aside and you go on, you know. I try not to focus on it because it's so painful."

The role of social support in coping

Parents' views on social support were mixed, with some families finding that they were well supported from health professionals, family and friends whilst others felt that more could have been done to support them. Families indicated that a more directed approach to support services would have been helpful, for example a manual or a phone app to assist in locating resources such as specialised health professionals. Others reported feeling that their psychological support needs were not well recognised by the hospital and that they could

have benefitted from this support at all stages of their journey, although one mother felt that the timing of this support was not right for her:

“They put me onto a psychologist if I needed mental support. I spoke to her a couple of times but it wasn’t working for us. We went together. It wasn’t what we needed at the time. We were overwhelmed with grief and we didn’t know what was going to happen so we were kind of grieving for the life we planned with the new baby and stuff and to think that that may not happen.”

Another mother felt that her need for relationship counseling was not well recognised and commented:

“I think even if we had relationship counseling, or been offered something like that while we were there, or once we came home, I think that could have been really helpful.”

One mother was hesitant to seek support:

“I mean I wish I was in that world where I don’t have to think, one day I might have to bury him...So it’s hard emotionally. I don’t like to talk to people about it because one it’s not fair on them to hear those sorts of things I guess, and it’s not their reality, so I kind of keep that to myself.”

Strategies for coping

Families generally showed determination to cope in the best possible way with their situations. A variety of strategies were indicated including adopting helpful ways of thinking, learning to be present in the moment, trying not to worry about the future, making a choice in how they were going to react and attempting to move forward.

“We tried to make sure that we set the tone, so even when he was in hospital we tried to set the tone of, if he was having a good day, and we didn’t want to dwell on all the negatives, because if you dwell on all the negatives you don’t get anywhere in life.”

A range of **productive coping strategies** were identified. These included identification of people to talk to, and actively working towards increasing their own health to ensure they would be around to look after their children. Some parents found that exercise was beneficial to both their mental and physical health.

“One of the things I made a decision to do was to go for a jog every morning. I had a routine, I was really aware if I was not looking after myself, that that was an important thing too, even though I spent twelve hours a day over at the hospital with her. ”

Others found that being productive either through work or a hobby was a way of coping with their situation. On another level, some families found that having a sick child in the family had given rise to positive self-growth. Some parents wanted to give back by talking to other parents who may find themselves in similar situations or by ensuring that the general public were more aware of the existence and extent of childhood heart disease. Other parents believed that they no longer took things for granted, and were thankful every day for the time they have with their children.

“Being thankful for every day to be honest. When you’ve got healthy kids you can’t imagine what it’s like, and just having a sick child changes your outlook on everything ... I think it makes you more grateful, and maybe even more compassionate, once you’ve had sick child and seen what happens at the (hospital), you don’t realise just how lucky you are when you’ve got healthy kids.

Other adaptive coping strategies included seeking spiritual help, attending to one’s self image, retaining a sense of humour and actively working to improve relationships. Working to consciously develop a different perspective on their problems was noted by some parents:

“I don’t like to think about the future. I catastrophise about it so I taught myself not to think about it. If I worry about what’s going to happen in the future, I won’t get out of bed.”

“We deal with things in three months chunks, when we found out. So we found out at 20 weeks, we deal with the next three months until he was born. And then we dealt with the next three months of being in hospital, but we never really thought past that three months.”

Others highlighted problem solving as a productive coping measure:

“I think I need facts, like we both need facts to make decisions. Like we are both emotional people but we are fairly practical”

Appropriate grieving for the child that they would not have, was also identified:

“We have really dealt with that and we’ve grieved for what we lost, well what we didn’t get, we didn’t lose it because we never had it, but we dealt with all of that and now we are good.”

as was the existential awareness that this brought on:

“I understand that everyone’s future is ..., you know you can walk outside and get hit by a bus, but you don’t know that. We actually know that it’s more than likely that we are going to outlive (him). I don’t think about that all the time, obviously I’d be a mess if I did. But it’s there. So it’s hard emotionally. “

As noted previously, parents learned to be assertive and to advocate and this should be recognised as a positive coping strategy:

“And again it was a learning curve, how to advocate for our child. Took me a long time, because you naturally assume that they are the specialists. They know the children, they know the medicine, whatever. What do we know? We are first time parents, is this normal? I don’t know. So I soon learnt to be strong.”

Parents also identified a range of **non-productive ways of coping**, including worrying:

“You are always worrying, every day it’s in the back of my mind that she’s not like other kids and when she first went to school it took me a while to adapt to her being at school, because I was worried all the time.”

Denial or blunting was noted in some parents:

“As I was walking down the road one of the neighbours came out and you could see the apprehension on her face, everything alright, I said all good, don’t worry. She said wow there was a lot of flashing lights. I went yeah, but you get used to it, one of those things. Like everything with these heart kids, you just get used to it.”

Others described becoming unwell and ‘falling in a heap’ or ‘falling to pieces’ once a crisis was over; becoming angry with medical staff for no apparent reason; becoming tearful; or coping through alcohol:

“We all drink a lot, in the darkest times... I remember one particular night I sat there and I said I’m just going to open a bottle of wine and she said you’ve already opened one, and I’m like wow, where did that go? And it’s empty, I must have drunk it.”

DISCUSSION

This group of parents of children with a heart condition confirmed the importance of the domains specified in the interview schedule, identifying key points of stress for families and identifying a large range of productive coping strategies for dealing with the impact of their child’s condition on them as parents, as couples and as a family. Overall, the parents indicated that the severity of their child's heart lesion at diagnosis was not necessarily related to their distress levels as has been found previously (Brosig, Whitstone, et al., 2007). Parents indicated that their coping capacity generally expanded to deal with the conditions they were faced with. In the absence of an objective measure of distress, and the absence of a

comparison group of parents whose children had less severe conditions, it is difficult to know if this is a general characteristic of parents of children with severe heart conditions.

The parents noted a range of tasks they had to undertake to adjust to the hospitalisation of their children, including establishing satisfactory communication with health professionals and ensuring that their information needs were met. These tasks have long been identified in relation to other hospitalised paediatric patient populations generally (Hallström, Runeson, & Elander, 2002), and in intensive care (Meyer, Snelling, & Myren-Manbeck, 1998) and oncology (Jackson et al., 2007; Shiminski-Maher, 1994). With a relatively small number of fathers interviewed, it was not possible to clearly discern the sorts of gender differences found in previous studies of parents of children with a heart condition such as mothers experiencing higher state anxiety (Vrijmoet-Wiersma, Ottenkamp, van Roozendaal, Grootenhuis, & Koopman, 2009), and greater prevalence of clinically significant psychological distress and hopelessness compared to fathers (Doherty et al., 2009; Lawoko & Soares, 2002). The study confirmed previous observations that prenatal diagnosis has been found to be more challenging than postnatal diagnosis (Brosig, Whitstone, et al., 2007) as it confronted families with coping challenges with which they were totally unfamiliar, particularly the challenge posed by making a decision on termination.

The results also support the observation that perceived social support is positively related to individual parental coping with CHD (Tak & McCubbin, 2002), but that not all social support is considered by parents as positive or relevant to their child's situation (Bruce et al., 2014). This finding on the ambivalence of parents towards social support is not new (Jackson et al., 2009; Patterson, Garwick, Bennett, & Blum, 1997), and the quality and appropriateness of parents social networks as a contribution to parental coping needs to be carefully evaluated by health professionals.

Study strengths and limitations

This study adds to the literature on familial coping with chronic conditions in children and confirms the importance of effective communication between parents and health service providers at all stages of the trajectory of the child's condition. A major strength of the study is the co-creation of the interview schedule with parents of children with heart conditions and their verification of our interpretation of the themes on coping arising from the interviews. This, and the transparency of the data collection, analysis and reporting process gives us confidence in the trustworthiness of the study using accepted criteria for qualitative studies (Elo & Kyngas, 2008; Lincoln & Guba, 1985). While the parent's perceptions of their treatment within the hospital system and the impact of this treatment on their capacity to cope may have been valid at the time the study was undertaken, a limitation of the study is that although aspects of coping over time are reported, these observations and interpretations were collected through interview with no validation through, for example, medical record checking. It should also be noted that the sample of parents was drawn from one hospital; all of the children were at the more severe end of heart conditions; the parents were part of a family support program and may have had higher levels of health literacy; and they had high levels of private health insurance. Given these characteristics these parents' views may not be fully representative of other parents' experiences.

Implications for practice

The study has shown that there are numerous possible focal points for intervention with PCCHD to assist with their coping, for example at diagnosis and at major transition points for children, such as the transition from hospital to home, and in an older group of children, the transition from child-based and family-centred care to adult care.

It is clear that psychological assistance would have been of value to these parents at all stages of their journey as PCCHDs. Provision of a psychological support service as part of a multi-disciplinary approach to working with these families is recommended. The discussion

of termination should only be held when parents have access to psychological support. It is also clear that strong communication coupled with a team approach by both medical staff and parents is vital and can promote better outcomes, and improve families' experiences during this emotional journey. This is evident when parents express their appreciation at being given the opportunity to be involved with their baby's care when in hospital. The experience is empowering and comforting for the parents to be able to care for their baby in the wards.

Combining the other studies of PCCHD cited in this paper and the systematic reviews on familial coping with CHD (Jackson et al., 2015) and parenting programs for PCCHD (Jackson, Liang, Frydenberg, Higgins, & Murphy, 2016) conducted by the present team, with the findings from the interviews with parents, a major strength of the study was the capacity to use the findings to contribute towards the design of a manualised group program for parents to enhance coping. This includes topics such as: The positive psychology of parenting; supporting health and wellbeing; adjusting to a family life with chronic illness; strengthening family's coping strategies; helping the child to express feelings in the early years; tuning in to siblings; using assertiveness to advocate for oneself and for the child; empowering the child to cope; couples working together towards improving their relationship; adjusting, accepting and healing through mindfulness; and helping the child through transitions.

CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

FUNDING

This study was funded under the Research Grant-in -Aid program of HeartKids Australia in their 2015-16 grant round.

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| Domain | Examples of domain components |
|--------------------------------|---|
| Illness trajectory | Diagnosis, commencement of treatment, post-surgery, relapse or increase in severity of condition |
| Parenting | Parenting style and parenting challenges, management of sibling relationships, family structure and cohesion, subjective distress and parent self-care, dealing with sleep issues and treatment-related trauma in their child |
| Disease management | Understanding of the condition and its treatment, level of child's self-management capacity, treatment decisions |
| Transitions | Between hospital and home, from acute condition to chronic condition, from child patient status to adult congenital heart disease (ACHD) status |
| Psychosocial impact and coping | Financial, family life and relationships, positive and negative emotional impact, family strengths, adaptive and maladaptive coping |
| Social support | Informational, instrumental, emotional, timeliness of support, formal and informal supports |
| The future | Anxiety about their child's prognosis, anxiety about further pregnancies, anxiety following changes in treatments |

Figure 1: Interview Schedule Domains for the Parents of Children with Heart Disease Project.

Categories of congenital HD severity (based on haemodynamic effect, potential for damage to the heart, and mortality risk)

Minor (little or no haemodynamic impact, or functional impact on activities of life)

Small muscular ventricular septal defect (VSD); Trivial pulmonary valve stenosis;

Bicommissural (bicuspid) aortic valve with no functional consequence; Small atrial septal defect (ASD)

Moderate (haemodynamic impact may produce medium to long-term complications, and intervention is required electively if the impact of the condition does not ameliorate)

ASD with right ventricular dilation; Coarctation of the aorta beyond the first months of life;

VSD (restrictive — ie, impedes flow through the VSD — with mild to moderate left heart dilation or associated with aortic valve distortion); Partial anomalous pulmonary venous return (some but not all pulmonary veins return to the right-sided venous compartment or right atrium. Functionally similar to ASD in most patients)

Major (major haemodynamic impact, sometimes life-threatening and often needing urgent intervention)

Functional single ventricle (eg, tricuspid atresia, hypoplastic right or left heart, etc);

Transposition of the great arteries (TGA); Tetralogy of Fallot* (and associated lesions); Large VSD

Figure 2: Clinical categories of congenital heart disease (Sholler GF, Kasparian NA and Winlaw DS., 2011)

| Coping theme | Components |
|---|---|
| Coping with their child's diagnosis | Pre-natal diagnosis; post-natal diagnosis; understanding of diagnosis; pregnancy termination discussions |
| Coping with the challenges facing their child | Severity of condition; capacity of the child for self-management; managing transitions; growing up; health monitoring; the future |
| Coping with the challenges of parenting | Post birth management; being proactive rather than reactive; parental bonding; parenting styles; co-parenting; fathering; parenting the child with a heart condition's siblings; the emotional impact of parenting; managing depression arising from the parenting role; managing general family life and relationships |
| The role of social support in coping | Professional support; informational, practical and emotional support; family support, including the hospital-based Family Support Workers; unhelpful support; gaps in resources |
| Strategies for coping | Adaptive coping; useful coping strategies such as talking, exercise, work, giving back, adopting |

| | |
|--|--|
| | a different perspective; connection; optimism; productive problem solving; maladaptive coping, e.g. worrying; denial; emotion numbing |
|--|--|

Figure 3: Themes related to coping arising from parent interviews