Parent's Perspectives on How They Cope With the Impact on Their Family of a Child With Heart Disease

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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 ways parents cope with their child’s heart condition and as it impacted on different domains of family functioning.

Design and Method: In this qualitative study, interviews were held with 17 parents attending a pediatric 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.

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

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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 Jr. et al., 2003). A recent systematic review has confirmed the multifaceted 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 Pediatric 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 (Arafah, 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 fear 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 & Hannahan, 2004).

Using the schedule, which covered seven domains, as indicated in Fig. 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 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
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