

Parental experiences of their infant's hospitalization for cardiac surgery

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Abstract

Background Parents are increasingly recognized as important partners in children's health care. Despite their involvement in care, parental experiences of their child's hospitalization have received little research attention. In this study we explored parents' perceptions of what they found difficult, what they would like to be different and what they found to be helpful during their infant's hospitalization and surgery for the treatment of congenital heart disease.

Methods Structured interviews were conducted with 154 parents (91 mothers, 63 fathers) whose infant underwent cardiac surgery (at <3 months of age) 1 month post discharge from hospital. Thematic and frequency analyses were performed.

Results Parents reported a range of difficulties from dealing with their baby's unfolding illness, surgery and recovery to the structural and systemic issues associated with the broader context of their experiences. In an effort to be near their baby, parents struggled to obtain the necessities for daily living at the hospital and negotiate transitions between their hospital and home lives throughout the admission. Domains parents identified for change included the availability of facilities and resources and the quantity and quality of information and emotional support. Parents reported relationships with hospital staff as the most common source of support during this challenging time.

Conclusions Opportunities to improve parents' experiences when their infant is in hospital exist at an organizational level as well as at the clinical level. The significance of parents' relationship with hospital staff indicates the potential for each professional to impact on families' experiences on a daily basis. The range of challenges indicates the scope and need for allied health services.

Keywords

cardiac surgery,
hospitalization, infant,
parental experience,
qualitative methods

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Introduction

Involving and supporting parents is increasingly recognized as an important component to providing holistic paediatric care. The stress reported by parents when their infant is hospitalized has driven qualitative inquiry into the experience of parents of critically ill infants during this time. Many of these studies have looked at parents (primarily mothers) of preterm or very low birth weight infants (Hurst 2001; Obeidat *et al.* 2009; Schenk & Kelley 2010; Hollywood & Hollywood 2011; Garten *et al.* 2012) or, more generally, infants in the neonatal intensive care units (Higgins & Dullow 2003; Hall 2005; Wigert *et al.* 2006; Gavey 2007; Arockiasamy *et al.* 2008; Cleveland 2008). However, parents of infants who have undergone surgery have received less attention.

Congenital heart disease (CHD) affects 8 out of every 1000 children, making it the most common group of birth defects both in Australia (Chew *et al.* 2007), the location of the current study, and internationally (Lissauer & Clayden 2012). With moderate-to-severe cases typically requiring surgery in the first few weeks of life, these infants are a significant population of surgical cases in tertiary paediatric centres. As with other illnesses, the hospitalization of a child for surgical treatment of CHD has been shown to be a very stressful experience for parents (Utens *et al.* 2000; Hearps *et al.* 2014) particularly if the child is an infant (Franck *et al.* 2010), with some experiencing trauma symptoms consistent with an acute stress disorder (Franich-Ray *et al.* 2013; Re *et al.* 2013).

Relatively recent advances in surgery and treatment have transformed CHD from a terminal condition to a chronic illness, thus encouraging medical, nursing and psychosocial research on outcomes for children (Chen *et al.* 2004; Curtis & Stuart 2005; Majnemer *et al.* 2009) and parents (Wray & Maynard 2005; Lawoko & Soares 2006; Brosig *et al.* 2007; Dale *et al.* 2012). Studies have examined parents' experience of the diagnosis (Clark & Miles 1999; Fernandes 2005), and parenting a child with CHD (Rempel & Harrison 2007; Rempel *et al.* 2013), yet there has been little focus on the experiences of these parents during their infants' hospitalization and surgery. One study of eight mothers of infants with CHD described the effort made at 'mothering through it all' during the hospitalization. Challenges included dealing with the unknown; navigating the medical world; feeling intense, fluctuating emotions; finding meaning and spiritual connection; and facing the possibility of their baby dying (Harvey *et al.* 2013).

The purpose of this study was to explore parental experiences of their infant's hospitalization for cardiac surgery and to identify factors that may be targeted in the future to alleviate sources of parental distress. The research questions were: (1) What did parents find difficult? (2) What would they have liked to be different? and (3) What did they find helpful during their hospital experience?

Methods

Design and setting

The qualitative data from this study are part of a larger mixed methods longitudinal study examining the impact of infant cardiac surgery on infants and parental adjustment. The study was conducted at the Royal Children's Hospital, Melbourne, a large tertiary paediatric hospital and one of the main centres for paediatric cardiac surgery in Australia. At the time the participating families were in hospital, social work services and infant mental health services on referral (by health professionals or self-referral) as well as chaplaincy were offered. Ethical approval of the study was granted by the relevant Hospital Human Research Ethics Committee.

Participants

Parents whose infants underwent cardiac surgery (either open or closed) for the correction of CHD prior to 3 months of age were recruited consecutively between 2005 and 2006. Parents were eligible to participate if their infant was medically stable following surgery, they resided in Australia and were fluent in English.

Eligible infants and their families were identified by the medical team and referred to the study consistent with local privacy legislation. Written informed consent was obtained from participating mothers and fathers by the research assistant.

Data collection

At approximately 1 month following their infant's discharge, consenting parents were offered the option of telephone or face-to-face interviews. Several parents were also accommodated in requests for joint (mother and father) versus individual interviews. Demographic information was gathered via questionnaires as well as during the interview. All interviews were conducted by a graduate psychologist and a structured

interview guide was used with the sequence and wording of questions standardized. Some of the questions were not within the scope of this paper and have been reported elsewhere (Bright *et al.* 2013; Jordan *et al.* 2013a,b). The interviews were manually recorded and transcribed verbatim.

Data analysis

The three research questions were addressed by five of the questions in the interview: What did you find difficult about the surgery and hospital experience? What helped you deal with the emotional impact of your baby's surgery and hospitalization? Did the hospital provide enough help for you in dealing with the emotional impact of this experience? Is there anything else that would have been helpful? and What would you have liked to be different about the hospitalization?

Interview responses were analysed using thematic analysis (Braun & Clarke 2006). Demographic data including participant gender were removed from the transcripts so that data analysis was blinded. The transcripts were read thoroughly line by line and segmented into meaningful units that were then assigned a label or 'code' (Rice & Ezzy 1999). Following the initial reading of the transcripts for familiarity, the coding was organized according to the three research questions due to overlapping discussions. The codes were then inductively grouped into categories or 'themes' based on shared properties (Braun & Clarke 2006; Corbin & Strauss 2008). Arranging the codes into categories was conducted through a series of consultations between two of the investigators: LK and BJ. NVivo10 (QSR International, Melbourne, Victoria, Australia) software was used to facilitate the organization of data throughout coding as well as maintaining an audit trail and tracking memos and annotations that strengthened the integrity of the process.

The large number of participants and structured interview design enabled the use of frequency statistics in addition to the thematic analysis to further identify and describe patterns. The unit of analysis was the number of parents whose response or any part thereof was coded to each category (n , %).

Although a comparative gender analysis was not within the scope of this study, to avoid bias in using the term 'parents' where the sample includes more mothers, a two-sample chi-squared test for comparing proportions was used to determine any significant differences between the categories mentioned by mothers and fathers (who were interviewed individually). Gender differences will be discussed only in cases where statistical significance ($P < 0.05$) was found.

Results

Sample characteristics

During the recruitment period 198 infants aged <3 month underwent cardiac surgery, 115 of which met the eligibility criteria and were available to be approached. Seventeen families declined to participate with being 'too busy' the main reason offered. One infant died after the family was approached. A total of 154 parents from 97 families participated in the study. In every family where a father participated ($n = 63$), the mother also participated. In families where the mother was the only participant ($n = 28$), the main reason for non-participation offered by fathers was 'too busy'. Table 1 provides the parents' demographic details. Table 2 provides demographic and illness details for the infants.

Parental experiences

The analysis of parents' interview responses yielded categories that reflect different domains of the experience. Table 3 displays the categories organized by prevalence for each research question to show the domains where parents reported difficulties, what they would like to see change and what they found helped during their infant's hospitalization. Frequencies and percentages reported in this table are not repeated in the text.

Figure 1 shows the subcategories that outline specific difficulties, changes and aids discussed by the parents.

Baby

More than half of the parents reported aspects of the experience that were related directly to their baby's illness as being difficult, e.g. the uncertain and unfolding nature of the diagnoses and surgery. In terms of what they would have liked to be different, the most prevalent subcategory was *medical course* as parents reported that they wish they had not had to go through it at all.

Context

Structural and systemic issues of the greater context of the experience featured prominently in the number of parents who found this an area of difficulty. It was also the most commonly reported area that parents wanted to be different. Issues ranged

Table 1. Parents' demographic characteristics

Demographic variable	n (%)
Gender	
Female	91 (59)
Male	63 (41)
Residence	
Local†	56 (36)
Rural	46 (30)
Interstate	52 (34)
Language spoken at home‡	
English	110 (96)
Other	4 (4)
Level of education§	
Did not complete high school	17 (18)
High school	19 (20)
Trade qualification	9 (10)
Tertiary qualification	48 (52)
Employment status¶	
Full time	43 (37)
Part time	10 (9)
Maternity/paternity leave	34 (30)
Home duties	25 (22)
Unemployed	3 (3)
Marital status	
Single	3 (2)
Married/defacto	150 (97)
Separated/divorced	1 (1)
Birth order (of infant in study) by parent**	
First child	63 (41)
Second child	52 (34)
Later born	37 (24)
	Mean (SD)
Age	
Mothers	32 (4.7)
Fathers	35 (6.1)

†Melbourne, Victoria, Australia.

‡n = 114.

§n = 93.

¶n = 115.

**n = 152.

SD, standard deviation.

from the micro-environment on the ward (e.g. from physical furnishings to ward policies such as wanting shorter visiting hours) to negotiating macro-environment issues of availability and accessibility of facilities and resources (e.g. nearby accommodation, food venues, parking). Parent responses detailed the process of navigating and obtaining the resources they needed to meet their daily living needs at the hospital (or as nearby as possible) to enable them to be near their baby. This included wanting onsite access to services to meet their own health and well-being needs (identified as an area of difficulty). Also challenging was negotiating travel from the hospital to their home lives during the admission particularly with other children or

Table 2. Infants' demographic details

Demographic variable	n (%)
Gender	
Male	43 (47)
Female	48 (53)
Prenatal diagnosis	42 (46)
Diagnosis	
Coarctation of the aorta	16 (18)
Hypoplastic left heart syndrome/Norwood procedure	14 (15)
Ventricular septal defect	11 (12)
Transposition of the great arteries, complex	12 (13)
Tetralogy of Fallot/Pulmonary atresia with ventricular septal defect	9 (10)
Transposition, intact ventricular septum	7 (8)
Interrupted aortic arch	5 (6)
Total anomalous pulmonary venous drainage	3 (3)
Patent ductus arteriosus	3 (3)
Tricuspid atresia	1 (1)
Other	5 (6)
	Median (IQR)
Age at discharge (days)	37 (23–70)
Length of hospital stay (days)	25 (13–44)

IQR, interquartile range.

work demands. The parents who were able to address some of these needs, e.g. affordable acceptable accommodation, reported this as being helpful.

Relationships

The *hospital–family interface* was the most frequently reported relationship for each research question and overall was reported by most parents [$n = 94$, 72%; Joint Interview (JI) = 12] as helpful. Parents described specific actions or behaviours that they found helpful such as providing information and answering questions, providing emotional support, and providing practical assistance. Staff attributes were appreciated, including what parents perceived as extra effort (e.g. frequently updating parents on progress during surgery and answering any questions) and being 'nice', 'understanding' and 'supportive'. Aspects related to the quality of care were appreciated including availability, 'helpful' communication styles and ensuring parents felt looked after.

Challenges included unhelpful communication styles (e.g. wanting more 'sensitivity'), problems with staff availability and accessibility, inconsistency (differing opinions and information or treatment approaches among clinicians), feeling excluded from decision making, wanting multidisciplinary professionals to initiate engagement, not knowing who (i.e. which discipline)

Table 3. Categories identified through analysis of parents responses by research question

What was difficult			What would parents like to be different			What helped		
Category	n (%)	Jl	Category	n (%)	Jl	Category	n (%)	Jl
Baby	76 (58)	10	Context	79 (61)	11	Relationships	120 (92)	12
Context	70 (54)	10	Relationships	48 (37)	8	Individual coping strategies	38 (28)	4
Relationships	60 (46)	6	Baby	43 (33)	4	Context	31 (24)	5
Parent health and well-being	37 (28)	5	Information	29 (22)	4	Knowledge/knowing†	18 (14)	3
Waiting	31 (24)	5	Waiting	6 (5)	0	Baby	12 (9)	4
The unknown	20 (25)	1	Vicarious trauma	2 (2)	0	Spirituality	4 (3)	1
Information	12 (9)	5						
Other	7 (5)	0						

Note. *n* indicates the number of parents (interviewed individually) who mentioned a given category (where *n* = 130). *Jl* indicates the number of joint interviews where at least one of the parents mentioned a given category (where *n* = 12).

†This category is similar to *Information*; however, the nomenclature reflects parents' word use.

to approach for particular issues, wanting more emotional support for parents and needing to have courage to ask for support.

Social networks were another area of relationships many parents reported to be helpful (*n* = 53, 41%; *Jl* = 5), with extended family, friends, other parents at the hospital and church communities reported as sources of support. Conversely, parents who were away from their social networks due to distance or spending so much time at the hospital reported the separation from these usual supports as particularly difficult. Interestingly, several parents (*n* = 5, 4%; *Jl* = 0) also mentioned aspects of their social interactions that were seen as burdensome (e.g. managing flow of information to family and friends, finding retelling difficult and feeling that it lead to 'reliving the experience'). Some parents (*n* = 4, 3%; *Jl* = 1) mentioned strategies to manage these burdens as being helpful (e.g. have friends and family ask questions directly of health professionals and preferring cards or text messages to visiting).

Information

Challenges related to information included amount (most parents wanted more, one father found it too much), timing, wanting to receive information from a particular source (e.g. medical information from a doctor or surgeon rather than solely from nurses), understanding what was provided, the effort of obtaining information and wanting more individualized information. These difficulties aligned with what parents reported wanting to be different in relation to information. The types of information parents referred to were updates and feedback on the progress of their infant, medical information, orientation and parent entitlements within the hospital, and on caring for their infant at home. Information on orientation and

entitlements related to the sense of living at the hospital was described under *context*, with parents wanting to know where things were and what they were allowed to do (e.g. confirmation that the coffee in the parent's room was for them, or whether they are allowed to change their other children's diapers on the ward).

Similar sentiments were also reflected in parents' responses that 'knowledge' was helpful and under *relationships* parents' reported valuing staff who volunteered information or who reinforced the acceptability of families asking questions.

Waiting

Difficulties were also expressed regarding waiting, and parents wished it was something they had not had to go through. Waiting related primarily to the surgical aspect of the experience as parents reported waiting during surgery, for the surgery to occur and for their infant's recovery.

Individual coping strategies

A diversity of unique strategies were described by parents to deal with the experience, primarily relating to *baby* or *waiting*. For example, parents described cognitive strategies (including pacing/staging; e.g. 'taking it one-tube-at-a-time'), engaging in parenting behaviours (e.g. reading a book to their baby), emotional (e.g. letting it all out) and activities for distraction (e.g. working on their car, going surfing).

Discussion

Parents of infants hospitalized for surgical treatment of CHD reported difficulties relating to the uncertain and unfolding

	What was difficult	What would parents have liked to be different	What helped
Baby	Medical course Mortality ^a Baby experience Feeding ^b Vulnerability	Medical course Baby experience	Medical course (recovery) Baby attribute
Relationships	Hospital–family interface Other children/siblings With baby Social network Partner	Hospital–family interface With baby Social network Partner	Hospital–family interface Social network ^c Partner With baby Other children/siblings
Context	Hospital context Family life over two campuses Distance	Hospital context Facilities and resources Hassles of daily living	Facilities and resources Work leave
Information (knowledge and knowing)	Volume (not enough) Source Timing Difficulty understanding Had to seek	Volume Timing Quality Source	Available sources Knowledge of (e.g. the medical condition; the procedures) Normalizing Confidence Being oblivious
Waiting	During surgery For surgery For transport Waiting (non-specific) Post surgery	For surgery Waiting (non-specific)	
Parental health and well-being	Emotional response Maternal post-natal care Sleep Vicarious trauma		
Individual coping strategies			Cognitive Activities Self (got self through it) Emotional Fuel (to get by) Parenting behaviors
Spirituality			Religion Faith

Figure 1. Subcategories developed from parental descriptions. Note. The categories The Unknown and Other were excluded from this table as they did not have descriptive subcategories.

^aMore fathers ($n = 13$; 25%) than mothers ($n = 8$; 10%) mentioned their infant's mortality in their descriptions of what was difficult, to a level of statistical significance $X^2(1) = 4.16, P = 0.04$.

^bMore mothers ($n = 15$; 19%) than fathers ($n = 0$; 0%) mentioned feeding issues in their descriptions of what was difficult to a level of statistical significance $X^2(1) = 9.17, P = 0.003$.

^cWithin the category of social networks, more mothers ($n = 14$; 18%) than fathers ($n = 2$; 4%) mentioned 'other parents' as being helpful to a level that was statistically significant: $X^2(1) = 4.35, P = 0.04$.

nature of their baby's illness, surgery and recovery. The next most prevalent domain of difficulty was the structural and systemic issues of the broader context. Many of the issues parents discussed are potentially modifiable, e.g. aspects of the hospital experience either on a policy level (e.g. provision of services) or at the clinical level of care (e.g. professionals' communication with families). The large number of parents who identified aspects of their relationship with hospital staff as being helpful is indicative of the potential for positive impact of engagement and intervention with these parents on a clinical level in everyday interactions. Although the full range of difficulties described by parents may not be within the scope of practice for medical professionals, there is significant opportunity for allied health professionals, such as social work, to assist families. Psychosocial support can assist parents to cope with and adapt to aspects of the experience that are not amenable to change such as adjusting to the diagnosis, dealing with the unknown and finding ways to endure waiting, identifying and strengthening individual coping styles, and managing a range of diverse demands.

Many of our findings are consistent with previous research examining parents' experiences of neonatal intensive care more broadly. For example, the challenges involved with the parents' relationship with their baby include needing to be near and watch over their infant (Hurst 2001; Wigert *et al.* 2006; Gavey 2007; Arockiasamy *et al.* 2008; Cleveland 2008; Schenk & Kelley 2010; Hollywood & Hollywood 2011; Harvey *et al.* 2013), the importance of information (Hurst 2001; Auslander *et al.* 2003; Gavey 2007; Arockiasamy *et al.* 2008; Cleveland 2008; Hollywood & Hollywood 2011) and parents' relationship with hospital staff as both helpful and a source of difficulty (Hurst 2001; Auslander *et al.* 2003; Wigert *et al.* 2006; Gavey 2007; Arockiasamy *et al.* 2008; Cleveland 2008; Schenk & Kelley 2010; Hollywood & Hollywood 2011; Harvey *et al.* 2013). There are several aspects of parents' experiences in this study that stand out due to the surgical nature of the population, such as parents' struggle with waiting, the changing and unpredictable medical course, as well timing and source of information.

What parents reported they would have liked to be different provides an indication of the areas of difficulty they would like to see addressed. Here, the most reported area is context perhaps because parents recognize that many aspects of baby (such as medical course) were not amenable to change. What is apparent across all three research questions is that the service context provided particular challenges for parents with a new infant in hospital. In an effort to attend to their baby, parents needed to be at the hospital for lengthy periods of time and essentially establish a second campus for their lives. Parents

temporarily moved to the hospital which involved obtaining the necessities for living including accommodation, food, meeting parental health and emotional well-being needs, and child care for their other children. Many felt physically distant from the support of their usual social networks. Parents also had to manage their 'regular' lives that continued outside of the hospital from work to the daily tasks and care of their other children, as well as informing and managing their social networks, essentially negotiating the interactions and transitions between the two. This challenge is an aspect of the experience often less apparent in more phenomenological studies that tend to present a focus on 'inner world' issues (Harms 2010).

The hospital does have (and did offer at the time of data collection) social work services, infant mental health, chaplaincy, pre-hospital tours for parents with a prenatal diagnosis and support such as discounted parking as well as facilities nearby including Ronald MacDonald House for accommodation. Information about many of the services and facilities, as well as about certain medical conditions, hospital policies and procedures, was available on the hospital website. However, the findings from this study indicate that the responsibility on parents to navigate the service environment (including those for their own health and well-being needs), while they are trying to focus on their baby, can be distressing. Reducing the demands on parents of navigating the many services within the hospital or health system context will likely require the attention of hospital administrators. It also raises the question about the degree to which issues such as this are the responsibility of hospitals, although alleviating such sources of distress could increase parents' ability to be emotionally available and meaningfully participate in their child's care (particularly important with models such as family-centred care). Future research could explore systemic ways of reducing the demand placed on parents and the degree to which reducing the stress from the health context could improve parents' capacity to engage with the demands of their child's care.

Study findings identified specific barriers to services that include parents not knowing who to talk to, being unsure what certain services do, the timing of information and challenges with organization and planning given the unpredictable nature of their infants medical course. Services need to be (1) accessible, e.g. service scope and referral pathways should be clear to parents as well as clinical staff and (2) available, i.e. have adequate capacity to meet family needs. If psychosocial services have sufficient capacity, they can assist parents in navigating other services while more systemic solutions are sought.

This study benefited from the participation of a substantial number of fathers ($n = 63$). A comprehensive comparative

gender analysis was not completed; however, the frequency analysis did indicate a couple of areas in which mothers' and fathers' responses differed. Although previous research has indicated that mothers experience higher levels of stress than fathers prior to infant cardiac surgery (Utens *et al.* 2000), the current study found similarities in terms of the number and types of difficulties reported by mothers and fathers. Therefore, supports offered to parents should be equally accessible to fathers. This continues to be an important area for future research as fathers are often underrepresented in paediatric research.

Although this study benefits from a large sample size particularly for a qualitative study, as a single site study, caution should be used when considering these findings in relation to other centres. Also, English fluency was an eligibility criterion for our study as is the case in the majority of studies in this field. Future studies would benefit from focusing on the experience of non-English-speaking families as all hospital–family interactions (formal and informal) are transacted in English, even if interpreting services are used. Parents who declined to participate frequently gave the reason as 'too busy'; such parents may have provided further insight into the complexity and multiplicity of difficulties, and it is possible they were the parents most in need of psychosocial support. Furthermore, parents whose infant was too medically unstable to be invited to participate may have provided an additional perspective.

Although the frequency analysis is useful for identifying trends and minimizes some of the biases of singularly qualitative designs (Denscombe 2008; Maxwell 2010), being cognizant of the heterogeneity of experience remains important. For example, the potential burden of social networks or the single parent who was overwhelmed by too much information highlight the ongoing necessity for sensitivity to the unique experience and needs of each individual.

Conclusion

Although technological advances have achieved great improvements in treatment of CHD over recent decades, hospitalization for treatment remains a challenging time for parents. This study provides insights into what parents find difficult, what they would like to see changed and what helped them during the hospitalization. Parents' experiences are affected not only by their infant's diagnosis and the physical environment of the hospital but also by the way in which services to support families are organized as parents are required to navigate the service context in order to meet their needs. There are clearly organizational implications for service delivery to improve

families' experiences, but while systemic solutions are sought there is a significant role for individual clinicians to ameliorate parental distress.

Key messages

- Difficulties encountered by parents range from the emotional challenge of their infant's illness to systemic obstacles.
- Hospital admission requires negotiating multiple interfaces to maintain everyday life and manage daily transitions from home life to hospital.
- Incidental exchanges as well as the establishment of positive ongoing relationships with hospital staff are a critical source of support for parents.

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