Maternal & Child Nutrition

DOI: 10.1111/mcn.12302

Original Article

"I was so worried about every drop of milk" – feeding problems at home are a significant concern for parents after major heart surgery in infancy

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Abstract

Increasing numbers of operations in small infants with complex congenital heart disease are being carried out in the UK year on year, with more surviving the initial operation. However, even after successful surgery some of these infants remain fragile when they are discharged home. The aim of the study was to elicit parents' experiences of caring for a child with complex needs after major congenital heart surgery. We conducted a qualitative study involving semi-structured interviews with parents of 20 children (aged <1–5 months at hospital discharge), who had undergone open heart surgery and subsequently died or been readmitted unexpectedly to intensive care following their initial discharge home. Feeding difficulties following discharge from the specialist surgical centre emerged as one of the most significant parental concerns spontaneously raised in interviews. For some parents the impact of feeding difficulties overshadowed any other cardiac concerns. Key themes centred around feeding management (particularly the practical challenges of feeding their baby), the emotional impact of feeding for parents and the support parents received or needed after discharge with respect to feeding. Caring for a child with congenital heart disease following surgery is demanding, with feeding difficulties being one of the most significant parent stressors. Local health professionals can be a good source of support for parents provided that they are well informed about the needs of a cardiac baby and have realistic expectations of weight gain. Specialist surgical centres should consider addressing issues of parental stress around feeding and weight gain prior to hospital discharge. © 2016 Blackwell Publishing Ltd

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Introduction

Congenital heart disease (CHD) is one of the most common forms of congenital abnormality and occurs in eight of every 1000 live births (Hoffman & Kaplan 2002). CHD is a known risk factor for poor weight gain (Varan *et al*. 1999) as a result of a combination of factors, such as poor calorie intake, inefficient use of calories and increased energy expenditure (Hofner *et al*. 2000; Mcgrail 1997; Mitchell *et al*. 1995; Leitch 2000). Over a third of children with CHD require urgent care as infants, which may include open heart surgery (Marino *et al*. 2001). The physiological stresses of surgery and associated complications can also contribute to poor weight gain and failure to thrive, with gastrointestinal and feeding complications being common concerns (Boctor *et al*. 1999). Poor weight gain in the first months after congenital heart surgery is associated with greater risk of post-operative infection and longer hospital stay in survivors and has also been found to be a risk factor for death later in infancy (Eskedal *et al*. 2008).

Gastrointestinal and feeding complications, such as dysphagia, necrotizing enterocolitis and failure to thrive are common concerns in infants following congenital heart surgery, particularly those undergoing palliative procedures for univentricular heart conditions such as hypoplastic left heart syndrome (Golbus *et al*.

2011; Johnson *et al.* 2008; Davis *et al.* 2008). While these infants may be of normal or near-normal birth weight, many experience significant weight loss and failure to thrive while hospitalized for their first palliative surgery (Hehir *et al.* 2011). Post-operative gastrointestinal and feeding difficulties can have a significant impact on infants' ability to achieve optimal weight for subsequent palliative surgeries. Poor nutritional status at the time of cavopulmonary anastomosis (stage II surgery) has been associated with poorer surgical and longer-term outcomes (Anderson *et al.* 2010; Anderson *et al.* 2011), and close monitoring of weight change is recommended during the inter-stage period (Slicker *et al.* 2013). It is therefore no surprise that feeding difficulties are emerging as one of the most significant parental stressors as families struggle to ensure that their child's weight reaches optimal parameters in advance of their stage II surgery (Davis *et al.* 2008).

The move toward delivering health care to children in the community has resulted in many children being cared for at home at an earlier stage in their recovery and with this has come the need for parents to take on a greater role in their child's health care. Caring for an infant after congenital heart surgery is demanding, particularly for those with more complex conditions. Infants require round the clock care and adherence to a strict medical regimen that can involve disruption to sleep for the primary care giver, resulting in chronic sleep deprivation and high parental stress (Hartman & Medoff-Cooper 2012; Meltzer & Mindell 2006).

To understand more about parent experiences of caring for a child with complex needs after congenital heart surgery we undertook a qualitative study involving semi-structured interviews with parents. These interviews took place in the context of a wider study examining post-discharge care and support for infants following discharge from the specialist surgical centre. Feeding emerged as an important theme in parent narratives of caring for their child at home after surgery, and the findings related to feeding are the focus of this paper.

Method

Parents were invited to take part in the study if their child underwent major congenital heart surgery in their first year of life at one of three UK children's hospitals and subsequently died or were readmitted unexpectedly to intensive care following their initial discharge. This particular group of parents was selected because of the focus of the wider study on discharge processes and subsequent care of the most vulnerable infants who had undergone cardiac surgery for CHD. Parents were initially approached with information about the study by local specialist nurses who obtained consent to pass on their details to the research team. Because of the ethical issues associated with approaching bereaved families and the sensitive nature of the study, initial contact was made by a nurse who knew the family and who was aware of any particular issues for the family at the time of the study. No direct contact was made by the research team until the family had expressly said that they were willing to speak to the researcher. Separate participant information leaflets were used for bereaved and non-bereaved families so that information could

Key messages

- Poor feeding and growth failure are common in babies with complex congenital heart disease and poor weight gain in the first few months after cardiac surgery is a risk factor for early mortality and morbidity.
- Caring for an infant with congenital heart disease following surgery is demanding, with feeding difficulties being one of the most significant stressors described by parents, overshadowing all other concerns in some cases.
- Surveillance and monitoring of feeding and growth of infants after cardiac surgery in the UK are variable but local health professionals can be a good source of parental support, provided they have realistic expectations of weight gain in a cardiac baby.

be sensitively tailored to their different circumstances. The researcher conducting the interviews was a clinical psychologist with experience of family therapy and bereavement counselling, and she furthermore ensured that all parents had information about appropriate local support services.

Ethical approval was granted by the local National Research Ethics Service Committee London–Central (Reference: 12/LO/1398). All participants provided written consent.

All but one of the interviews took place in parents' own homes and were conducted face-to-face by a single female researcher (JT). Topic guides were used to provide general structure, although parents were encouraged to influence the direction of the interviews. Parents were asked to give an account of their experience of caring for their child at home following major congenital heart surgery, the particular challenges they faced and the support they received in the community. Parents were not specifically asked to provide information about feeding, other than the method of feeding at discharge, although all parents chose to elaborate. Interviews were tape-recorded and transcribed verbatim before being analysed using Framework Analysis. Framework Analysis (Srivastava & Thomson 2009) is a structured approach to managing qualitative data that allows researchers to organize and extract themes from the data more easily. It aims to reduce bias and make analysis of large data sets more manageable and involves entering qualitative data (e.g. quotes and summaries) into charts to aid interpretation, ensuring that key themes are systematically searched for across each transcript. In the development of frameworks for the present study each transcript was read by at least three members of the research team.

Results

Descriptive information

Specialist nurses contacted 25 families, 21 of whom agreed to be interviewed. One family had to be excluded because they did not meet inclusion criteria. Eleven of these families were bereaved. Fourteen interviews were conducted with the mother alone and six with both parents together. The majority of families were white British ($n = 14$), with the remainder being Asian ($n = 3$), mixed ethnicity ($n = 2$) or white European ($n = 1$). Most primary caregivers had completed secondary education with eight undertaking further education. One parent did not speak English as a first language, and two were bilingual.

All children had their index surgery between September 2009 and October 2013. Post-surgery, 12 children were discharged home directly from the specialist surgical centre and eight were discharged to their local hospital in a 'step-down' arrangement.

Half of the families interviewed brought their child home from hospital with some form of assisted feeding – in nine cases this was a nasogastric (NG) tube and one child came home with a gastrostomy. One further child was discharged to their local hospital with an NG tube but this was removed before sending the child home. Parents of 16 of the 20 infants (80%) reported feeding problems. Table 1 provides a case-by-case summary of parent reported feeding difficulties by diagnosis.

Qualitative findings

Data about feeding are presented in three main sections, corresponding to the themes identified through framework analysis. The first section describes the day-to-day aspects of feeding management with specific emphasis on the practical challenges faced by parents. The second section describes the emotional impact of feeding on parents, and the final section describes the feeding support offered to parents in the community. It is important to bear in mind that these findings relate to families of children who experienced major problems after hospital discharge and are therefore not representative of the wider CHD population.

Feeding management

Regardless of the method of feeding at discharge, 80% of families ($n = 16$) reported feeding difficulties of some kind. Although most parents expressed relief at having their child at home with them after a long period of hospitalization, several parents commented that they had not been prepared for how demanding caring for their child at home would be.

'I didn't understand until I came home and I thought, "Oh, I am home finally, great," and then my son needed

Table 1. Case-by-case summary of diagnoses, age at discharge, method of feeding at discharge, parent reported feeding difficulties and feeding support accessed

ID[a]	Diagnosis	Age at discharge (months)	Method of feeding at discharge	Parent reported feeding difficulties?	Feeding support accessed
FR01	Single ventricle disease (not HLHS)	2	NG and bottle (formula)	Yes	- Dietician- SaLT - Community nurse
FR02	HLHS	<1	NG and bottle (formula and EBM)	Yes	- Community nurse- Dietician
FB03[a]	TGA (± other features)	<1	Breastfeeding and bottle (formula and EBM)	Yes	- Dietician - Midwife
FB04[a]	HLHS	<1	NG, breastfeeding and bottle (formula and EBM)	Yes	- Health visitor- Community nurse
FB05[a]	HLHS	<1	Bottle fed (formula)	Yes	- Health visitor- Community nurse
FB06[a]	VSD + significant medical co-morbidity	3	NG, breastfeeding and bottle (formula and EBM)	Yes	- Health visitor- Community nurse- Dietician- SaLT
FR07	DILV	<1	Bottle (formula)	No	- Health visitor- Community nurse
FR08	TOF	<1	Bottle (formula)	Yes	- Health visitor
FR09	TGA + significant medical co-morbidity	1	Bottle (formula and EBM)	Yes	- Cardiac Liaison Nurse
FB10[a]	Single ventricle disease (not HLHS) and significant medical co morbidity	2	NG	No	- Community nurse
FB11[a]	HLHS	2	Bottle (formula)	Yes	- Health visitor
FB12[a]	Single ventricle disease (not HLHS)	<1	Bottle (formula)	Yes	- Health visitor
FB13[a]	HLHS	1	NG	Yes	- Health visitor- Community nurse- Dietician
FB14[a]	ALCAPA	5	NG	Yes	- Dietician- Community nurse
FR15	Single ventricle disease (not HLHS)	2	NG	Yes	- Community nurse
FR16	Single ventricle disease (not HLHS)	3	Gastrostomy	No	- Health visitor- Community nurse- SaLT- Dietician
FB17[a]	Single ventricle disease (not HLHS)	<1	Bottle (formula)	Yes	- Health visitor- Dietician
FB18[a]	Single ventricle disease (not HLHS)	<1	Bottle (formula)	Yes	- Health visitor
FR19	TGA ± other features	<1	Bottle (formula)	No	- Health visitor
FR20	TAPVD	1	NG	Yes	- Health visitor

HLHS – hypoplastic left heart syndrome; NG – nasogastric; TGA – transposition of the great arteries; EBM – expressed breast milk; VSD – ventricular septal defect; SaLT – speech and language therapist; DILV – doublet inlet left ventricle; TOF – Tetralogy of Fallot; ALCAPA – anomalous coronary artery from pulmonary artery; TAPVD – total anomalous pulmonary venous drainage.

[a] The child is deceased.

so much attention and care with expressing and the NG feeding….that was tough'. (FR20, 1 month)

Common challenges included poor weight gain and infants taking a long time to feed or taking only small amounts at a time. Some parents noted that their child did not show any signs of being hungry at all with many having to be woken in the night for their feeds. The management of feeding was often further complicated by the need to incorporate a number of different medications into every feed, and for those infants who were NG fed, the risk of the NG tube being pulled out by the child.

'*You're trying to deal with a sick baby, trying to feed him through a tube; he's pulling his tube out. You've* *got a 3-year-old and [another child]….you've got to go to all the appointments…every single feed you have to work in 3 or 4 or 5 different medicines…you've got to remember to order them…' (FR01, 2 months)*

Several mothers whose child came home with an NG tube attempted to continue with breastfeeding alongside NG and bottle feeding. However, keeping this up was very demanding and involved mothers spending protracted periods of time feeding their child.

> '*It was, for me, that was the thing that was depressing me, because you had to sit there with him half an hour feeding him that because you can't give it too fast. Then I had to breastfeed him. Then I had to express because for the feeder. So, it was every three hours my whole life was literally revolving around tube feeding, expressing and breastfeeding*'. *(FB04, <1 month)*

While most parents attempted to stick to a 3–4 hourly feeding routine, this proved challenging in many cases for the reasons mentioned previously and resulted in frequent feeding attempts and sleep deprivation that placed significant demands on parents, particularly if they had other children to care for at home.

> '*I was breastfeeding, and she would feed, but not for a very long time. It was quite stressful having a toddler and trying to breastfeed…I just kind of kept trying. She would kind of have a feed for just, like, ten minutes, and then just go to sleep. Then she'd wake up a bit unsettled, but then have another*'. *(FR19, <1 month)*

> '*[they told us] "Even if you have to offer milk 35 times a day." You just think, well, I don't know how easy your life is at home. We can try, but it's tricky*'. *(FR01, 2 months)*

Vomiting was also a significant concern and led to high levels of parental stress as parents became concerned about their child's weight gain and whether or not to administer medications again.

> '*We were struggling to keep the medicines down……. my original worry……he's been sick*, *do I give it again*?' *(FR09, 1 month)*

In some cases parents constructed their own monitoring charts in order to keep track of their child's fluid intake and medications.

> '*We were keeping all these charts and things [made themselves], about how much milk she'd had…how many ml, what time. Every single day…' (FB03,<1 month)*

While these parents took the initiative to develop their own systems of record-keeping, which they experienced as reassuring, other parents did not find rigorously monitoring their child's fluid intake as helpful. For example, a small number of parents were given fluid monitoring charts by their specialist centre to complete at home but found these stressful to complete, particularly if they struggled with numeracy.

> '*And I'm thinking I'm worried more about the paperwork than I am about my baby. At one point that's how I felt*'. *(FB05, <1 month)*

Emotional impact

For over two thirds of parents, feeding their child was one of the most stressful and demanding aspects of their post-discharge care. Words used to describe their experience of feeding reflected a wide range of emotions and included '*depressing*', '*tough*', '*a battle*', '*exhausting*', '*frustrating*', '*stressful*', '*desperate*' and '*horrendous*', with several parents going further to say that feeding became so challenging that this outstripped any other cardiac concerns.

> '*Feeding was the main thing….It [feeding] completely overshadowed any cardiac concerns, to be honest.' (FR15, 2 months)*

Several parents whose child came home with NG feeding described feeling nervous or afraid of the tube and these feelings remained throughout their child's recovery.

> *''You're terrified of the tube, as a parent, to be honest. You hate it. Even right to the end I hated it, even when I learned to feed him down it I hated it'. (FR01, 2 months)*

A number of parents said that when they brought their child home from hospital there was no plan for working toward removal of the tube, and they were not given any criteria for when it would no longer be required, leading some families to feel anxious and have concerns about whether they would ever get their child off the tube.

> '*Nothing was said about how long it would be there for….there was no plan for getting him off it…It was like this magic thing that would just suddenly be helpful and then suddenly disappear'. (FR15, 2 months)*

> '*I was panicking thinking is he ever going to be off the tube*?' (*FR01*, *2 months*)

For those families of infants with palliated circulations feeding took place in the context of high pressure to gain weight in order to meet requirements for their next surgery, which added to parents' anxiety and stress.

> '*We were desperate to have a child that was going to be the desired weight in 12 months time*, *to have the surgery. If she couldn't have the surgery, she wasn't going to survive. It's like the pressure is on*'. (*FB03*, *<1 month*)

This pressure and the demanding, and medicalized, nature of their child's day to day care resulted in some mothers saying that they felt as though they had lost some of their identity as a mother, feeling instead more like a nurse or a carer for their child. The stress of needing to get calories into their baby so that they gained enough weight to have their next operation took away the opportunity of having the time to enjoy being a parent. The following quote from a mother of a bottle-fed baby illustrates her focus on the smallest quantity of milk and its significance, at the cost of being able to enjoy being a parent:

> '*I couldn't see what else was going on with her because I was so worried about every drop of milk …because that was how they made me feel…… And it used to worry me so much and I was like* "*baby please have some more milk because you're not having enough*" *…I was being more of a nurse than a mum…*' (*FB05*, *<1 month*)

Many parents reported disruption to their sleep and sleep deprivation in order to keep up the demanding feeding routine. Some mothers were reluctant to accept offers of respite because of their fears of leaving someone else to be responsible for their child's feeding.

> '*I wouldn't let anyone else do her feeding, I had to set it up myself…..It was just me, every four hours, because I was so paranoid about it, I wouldn't trust anyone else.' (FB13, 1 month)*

Feeding support

The support parents received for feeding concerns both at the specialist centre and after discharge was variable.

> '*I had met another mum at [tertiary centre] who had come in for surgery and they'd had feeding issues, and she had said how fantastic her hospital had been with feeding. Helping her do breastfeeding and not forcing her onto the bottle, so I kind of assumed that we'd get that level of support, which was wrong to assume, because we didn't'. (FB12, <1 month)*

For many parents, their health visitor was their first point of contact and most families would have a visit from their health visitor once a week during which their child would be weighed. In general, most families were satisfied with the support they received from their health visitor, particularly in terms of the emotional support they provided, and their assistance in calculating amounts of feed if there were any difficulties. However, several parents noted that their health visitor was not well informed about issues of feeding and weight gain in cardiac babies and so some parents described their health visitor appearing 'panicked' (FB05) or 'judgmental' (FR08) about their child's difficulties with weight gain.

> '*Considering that your health visitor is the person that you have most contact with when you have a baby, it would have been better if, under the circumstances, she'd been a trained nurse…..she was not in a place to guide us because of his condition. She could only give us information that she would give to parents of a healthy baby…' (FR08, <1 month)*

Furthermore, poor communication between health professionals and lack of education of local health professionals around issues of feeding in cardiac babies sometimes led to parents receiving incorrect or conflicting information.

> '*The [local] dietician…got the wrong end of the stick and thought that I shouldn't be breastfeeding him, because she said that my milk was dangerous to him. I was like, "Well, that's not true…What they said was that before the surgery…he found it hard to feed, that I shouldn't actually breastfeed him that much, because it would tire him out, whereas after surgery he could breastfeed as much as he wanted"'. (FB06, 3 months)*

Referrals to specialists, such as speech and language therapists or dieticians, could sometimes take too long and some parents said that this support came too late. In some cases support offered to parents around their child's feeding only served to highlight the difficulties to mothers, who reported feelings of inadequacy. The following quote illustrates that it was not just in the early days after discharge that parents struggled with feeding – this particular parent talked about how stressful it was when her child was a bit older and professionals wanted her child to start on solids rather than continue with the NG feeds. While the parents described how they hated the tube they also recognized that it was the best way for their baby to gain weight:

> '*We had dieticians and SLT coming…trying to sit him up…he's still all floppy…. trying to get him to have messy play with his food and making me feel…inadequate, let's be honest….. It was either a case of, he will lose weight, you want him to lose weight before his operation? Just to get the tube out of his nose? We hate the tube, we don't want the tube in, but we know it's beneficial for him' (FR01, 2 months)*

Some mothers said that they would have liked more support to continue with breastfeeding but felt that this was not an option that was encouraged or supported.

'*It would have been nicer to have had support to have continued the breastfeeding…rather than just feeling like we had to give up on it'. (FB12, <1 month)*

For parents of children who were NG fed, a major concern was about support for the replacement of NG tubes. For the majority of families, community nursing teams were only able to attend to replace NG tubes that had been pulled out during working hours. Out-of-hours, parents had to take their child to their local Accident and Emergency department, where they sometimes had to wait for several hours to be seen, causing significant anxiety and disruption to the whole family.

'*We phoned up the community nurse, he pulled [the NG tube] out; I can't remember what time, call it ten o'clock in the morning. She couldn't get to us until seven o'clock at night. So, you're like, well, what support is that? That's no support. We had to then go to the hospital. So I have to now trundle the whole family into the car….The four-year-old [another child], it's a circus'. (FR01, 2 months)*

'*He was discharged home on Tuesday and we got home, first of all he pulled out his NG tube straight away,…..we phoned up [the community nursing team], they were like, 'Oh, we change the NG tube once a month, if he pulls it out, you have to go to your local A&E…' Within a few hours of being home ……we had to go back to hospital'. (FR20, 1 month)*

However, good practical support around replacement of NG tubes, when this was possible, and the regular delivery of equipment and specialist feeds were highly valued.

'*The dietician…at [local hospital]….ordered all the pumps and stuff, and the milks and the medicines and things like that, and then it was delivered to the local chemist and then they brought it home. Yes, so it's more practical help than anything else, really, and it's a weight off your shoulders'. (FB13, 1 month)*

Discussion

Our qualitative study aimed to understand more about parent experiences of caring for a child with complex needs after major congenital heart surgery, with a particular focus on the most vulnerable group of infants who required emergency readmission or who had died after discharge from hospital. It is important to note that this group of families was selected *specifically* because of the complications that their infant suffered (death or unexpected readmission) and that this group is not representative of the wider group of infants discharged after surgery for CHD. While not the main focus of the study, feeding difficulties emerged as one of the most significant parental concerns following discharge from the specialist surgical centre.

Regardless of the method of feeding at discharge, 80% of parents interviewed raised feeding difficulties as one of their main post-discharge concerns. Main challenges included infants taking a long time to feed, taking only small amounts at a time, and tiring quickly necessitating numerous feeding attempts over the course of a typical day and disruption to sleep. Many parents reported that their child showed little interest in feeding and gave few, if any, cues that they were hungry. Vomiting and gastrointestinal problems were also a significant stressor leading to further concerns about weight gain and whether or not to re-administer medications. While all parents of single ventricle babies in this study reported feeding difficulties, consistent with previous studies suggesting that gastrointestinal and feeding complications are more common in these children (Golbus *et al.* 2011; Hehir *et al.* 2011; Davis *et al.* 2008), parents reported that feeding difficulties were also a concern for many of the infants with bi-ventricular heart conditions. However, given the sample characteristics (i.e. all of the babies had either had an unplanned hospital readmission or died after hospital discharge) and that feeding difficulties are a known risk factor for post-surgical morbidity and mortality in CHD (Eskedal *et al.* 2008; Anderson *et al.* 2011); it is perhaps unsurprising that feeding difficulties and issues related to feeding management and the emotional impact on parents were so prevalent in this sample.

The pressure to ensure adequate weight gain, combined with a demanding care routine, sleep deprivation and, for many parents, the knowledge that their child may still be at risk of sudden death, contributed to high levels of parent reported stress and vigilance. For some parents, the impact of feeding difficulties on their family was so great that they overshadowed any other cardiac concerns, and in some cases this went as far as parents not recognizing that the feeding problems were part of the cardiac condition itself. Mothers in particular reported feelings of inadequacy and expressed concerns about whether they were doing the right things. These findings are consistent with previous studies, suggesting that caring for a child with a chronic illness is one of the most stressful experiences a family can endure (Bouma & Schweitzer 1990), and this may be particularly true for parents of children with CHD (Emery 1989; Goldberg *et al.* 1990; Lawoko & Soares 2002) with mothers being particularly affected (Lawoko & Soares 2002; Darke & Goldberg 1994). Research with both mothers and fathers of infants undergoing cardiac surgery before the age of 3 months suggests that the majority of parents experience some symptoms of trauma and that almost one third meet criteria for a diagnosis of acute stress disorder (Franich-Ray *et al.* 2013). Stress itself can affect a parent's ability to provide care for their infant and the additional challenges of feeding a 'difficult' baby can exacerbate already elevated stress levels still further. In a small qualitative study of infant care issues following neonatal heart surgery, Hartman & Medoff-Cooper found that concerns over feeding, weight gain and sleep deprivation were major contributors to maternal stress and suggested that these issues should be addressed prior to hospital discharge (Hartman & Medoff-Cooper 2012). Our results lend further support to that suggestion.

In our sample the support families received for managing feeding difficulties was variable. Many parents spoke positively about the emotional and practical support they received from their health visitor but noted that their lack of knowledge about CHD meant that they were only able to offer advice relevant to a healthy baby. Education of local health professionals was a theme across several of the interviews, and parents commented that lack of training of local health professionals sometimes led to them receiving contradictory advice and reactions, which parents experienced as being judgmental and which increased their anxiety. Overall, many parents reported receiving less support than they had anticipated particularly in relation to maintaining breastfeeding, replacement of NG tubes and access to specialist SaLT and dietician support. Parents particularly valued practical support such as organizing the delivery of prescription feeds and equipment to their home and timely replacement of NG tubes, although the latter was problematic for many families. While keeping fluid monitoring charts was reassuring for some families it was a burden for others, particularly if the primary care giver was already over-burdened or had difficulties with literacy and numeracy. It would be appropriate for health professionals to consider parent resources and coping on a case-by-case basis and consider providing additional training or support in the community if routine fluid monitoring is required.

In a recent review of nutrition and growth in children with CHD the importance of nutritional surveillance was highlighted for high-risk infants, both while the child is an inpatient and after hospital discharge (Medoff-Cooper & Ravishankar 2013). Home monitoring programmes for such infants during the interstage period between cardiac operations have been introduced in many centres in the USA, and these programmes include nutritional surveillance and management. Families are provided with weighing scales, among other equipment, and are trained to weigh their babies daily and call the treating centre if certain criteria related to weight loss, failure to gain weight or insufficient daily enteral intake are breached. When families call, conclusions related to probable causes are reached by the team and, if indicated, adjustments to the nutritional plan made. Recent evaluation of babies on one home monitoring programme revealed that the structured nutritional programme had resulted in growth patterns of infants with univentricular heart conditions paralleling the growth of healthy infants (Hehir *et al.* 2012). A further review demonstrated that growth was better in babies treated at centres which used a feeding evaluation before discharge and closely monitored weight during the interstage period compared with the growth of babies treated at centres which did not have such procedures in place (Anderson *et al.* 2012). Home monitoring programmes were not commonplace in centres in the UK when the current study was undertaken, but it is evident from the interview data that the knowledge, education and support that such programmes can offer parents would have been beneficial not only in terms of improving infant nutrition but also for reducing parental stress. As is clear from the families in our study, follow-up for high-risk infants varied considerably. While we specifically selected families of babies who had poor outcomes in terms of death or unplanned readmission to hospital, it is probable that some of these outcomes may have been improved with better surveillance and follow-up. Since this study was conducted some centres in the UK have introduced some elements of home monitoring, with hospital-based clinical nurse specialists and cardiac liaison nurses having a key role in supporting families after discharge. Follow-up by paediatricians is inconsistent – some children are seen by paediatricians with a special interest in cardiology, while other children may not have a paediatrician at all. Similarly, community nursing and health visitor input can vary enormously. Evidence of the use of home monitoring outside the US is patchy – for example, there is some limited evidence of its implementation in some parts of Europe (Hansen *et al.* 2012), but programmes differ and not all include monitoring of weight (Ohman *et al.* 2013).

Our study has a number of limitations. Firstly, discussion about feeding difficulties took place in the context of a wider interview covering all aspects of post-discharge support in the community. This is of less concern in qualitative studies as an important consideration of qualitative research methods is to describe, rather than quantify, the views held by a population of interest. As families were not specifically asked about feeding difficulties it could be argued that their drive to volunteer this information serves to underline the impact that feeding difficulties had on the lives of these families. A second limitation is that while we attempted to achieve diversity within our sample, our sample included parents of predominantly White British children. We also struggled to recruit parents whose first language was not English despite offering access to interpretation. It is therefore possible that these parents face additional challenges, particularly in terms of access to support, that are not captured by this study. Finally, as mentioned previously, it is important to recognize that our sample included only parents of children who had unplanned readmissions or died, thus limiting the generalizability of the findings to the wider population of babies with CHD discharged after surgery.

Caring for a child after major congenital heart surgery is demanding. In our study feeding difficulties emerged as an important parental concern following discharge from the specialist surgical centre causing significant parental stress in the context of variable professional support. Our findings have implications for clinical practice in terms of supporting parents and ensuring non-specialist health professionals receive adequate training and information about the specific feeding issues faced by babies after cardiac surgery. Specialist surgical centres need to consider parental resources together with other potential challenges for parents, such as meeting the needs of healthy siblings, and address issues of parental stress around feeding and weight gain prior to hospital discharge. Local health professionals, particularly health visitors and community nurses, are an important source of support for parents but it is essential that they are well informed about the specific needs of a cardiac baby and have realistic expectations of weight gain. More intensive discharge planning, improved education for health professionals in primary and secondary care and the use of a structured home monitoring programme are potential solutions for supporting parents, reducing parental stress, optimizing infant weight gain and, potentially, improving infant outcome.

Acknowledgements

We would like to thank Nurse Specialists Helen Silk, Liz Smith, Christie Fox and Kay Dyer for their assistance with recruitment and all of the parents who kindly agreed to be interviewed for the study.

Conflict of interest

The authors declare that they have no conflicts of interest.

Funding

This project was funded by the National Institute for Health Research Health Services and Delivery Research programme (Project No: 10/2002/29). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NIHR HS&DR programme or the Department of Health.

Author contribution statement

All authors contributed to the study design, analysis and preparation of the manuscript. JT conducted the interviews. All authors have seen and approved the final manuscript.

References

Anderson J.B., Beekman R.H., 3rd, Eghtesady P., Kalkwarf H. J., Uzark K., Kehl J.E. *et al.* (2010) Predictors of poor weight gain in infants with a single ventricle. *Journal of Pediatrics* **157**, 407–13 413 e1.

Anderson J.B., Iyer S.B., Schidlow D.N., Williams R., Varadarajan K., Horsley M. *et al.* (2012) Variation in growth of infants with a single ventricle. *Journal of Pediatrics* **161**, 16–21 e1; quiz 21 e2-3.

Anderson J.B., Kalkwarf H.J., Kehl J.E., Eghtesady P. & Marino B.S. (2011) Low weight-for-age z-score and infection risk after the Fontan procedure. *Annals of Thoracic Surgery* **91**, 1460–6.

Boctor D., Pillo-Blocka F. & Mccrindle B.W. (1999) Nutrition after cardiac surgery for infants with congenital heart disease. *Nutrition in Clinical Practice* **14**, 111–115.

Bouma R. & Schweitzer R. (1990) The impact of chronic childhood illness on family stress: a comparison between autism and cystic fibrosis. *Journal of Clinical Psychology* **46**, 722–30.

Darke P.R. & Goldberg S. (1994) Father-infant interaction and parent stress with healthy and medically compromised infants. *Infant Behavior and Development* **17**, 3–14.

Davis D., Davis S., Cotman K., Worley S., Londrico D., Kenny D. *et al.* (2008) Feeding difficulties and growth delay in children with hypoplastic left heart syndrome versus d-transposition of the great arteries. *Pediatric Cardiology* **29**, 328–33.

Emery J.L. (1989) Families with congenital heart disease. *Archives of Disease in Childhood* **64**, 150–4.

Eskedal L.T., Hagemo P.S., Seem E., Eskild A., Cvancarova M., Seiler S. *et al.* (2008) Impaired weight gain predicts risk of late death after surgery for congenital heart defects. *Archives of Disease in Childhood* **93**, 495–501.

Franich-Ray C., Bright M.A., Anderson V., Northam E., Cochrane A., Menahem S. *et al.* (2013) Trauma reactions in mothers and fathers after their infant's cardiac surgery. *Journal of Pediatric Psychology* **38**, 494–505.

Golbus J.R., Wojcik B.M., Charpie J.R. & Hirsch J.C. (2011) Feeding complications in hypoplastic left heart syndrome after the Norwood procedure: a systematic review of the literature. *Pediatric Cardiology* **32**, 539–52.

Goldberg S., Morris P., Simmons R.J., Fowler R.S. & Levison H. (1990) Chronic illness in infancy and parenting stress: a comparison of three groups of parents. *Journal of Pediatric Psychology* **15**, 347–58.

Hansen J.H., Furck A.K., Petko C., Buchholz-Berdau R., Voges I., Scheewe J. *et al.* (2012) Use of surveillance criteria reduces interstage mortality after the Norwood operation for hypoplastic left heart syndrome. *European Journal of Cardio-Thoracic Surgery* **41**, 1013–8.

Hartman D.M. & Medoff-Cooper B. (2012) Transition to home after neonatal surgery for congenital heart disease. *MCN: The American Journal of Maternal/Child Nursing* **37**, 95–100.

Hehir D.A., Cooper D.S., Walters E.M. & Ghanayem N.S. (2011) Feeding, growth, nutrition, and optimal interstage surveillance for infants with hypoplastic left heart syndrome. *Cardiology in the Young* **21** (Suppl 2), 59–64.

Hehir D.A., Rudd N., Slicker J., Mussatto K.A., Simpson P., Li S.H. *et al.* (2012) Normal interstage growth after the Norwood operation associated with interstage home monitoring. *Pediatric Cardiology* **33**, 1315–22.

Hoffman J.I. & Kaplan S. (2002) The incidence of congenital heart disease. *Journal of the American College of Cardiology* **39**, 1890–900.

Hofner G., Behrens R., Koch A., Singer H. & Hofbeck M. (2000) Enteral nutritional support by percutaneous endoscopic gastrostomy in children with congenital heart disease. *Pediatric Cardiology* **21**, 341–6.

Johnson B.A., Mussatto K., Uhing M.R., Zimmerman H., Tweddell J. & Ghanayem N. (2008) Variability in the preoperative management of infants with hypoplastic left heart syndrome. *Pediatric Cardiology* **29**, 515–20.

Lawoko S. & Soares J.J. (2002) Distress and hopelessness among parents of children with congenital heart disease, parents of children with other diseases, and parents of healthy children. *Journal of Psychosomatic Research* **52**, 193–208.

Leitch C.A. (2000) Growth, nutrition and energy expenditure in pediatric heart failure. *Progress in Pediatric Cardiology* **11**, 195–202.

Marino B.S., Bird G.L. & Wernovsky G. (2001) Diagnosis and management of the newborn with suspected congenital heart disease. *Clinics in Perinatology* **28**, 91–136.

Mcgrail K. (1997) Nutritional considerations for infants and children with congenital heart disease. *Topics in Clinical Nutrition* **13**, 62–68.

Medoff-Cooper B. & Ravishankar C. (2013) Nutrition and growth in congenital heart disease: a challenge in children. *Current Opinion in Cardiology* **28**, 122–9.

Meltzer L.J. & Mindell J.A. (2006) Impact of a child's chronic illness on maternal sleep and daytime functioning. *AMA Archives of Internal Medicine* **166**, 1749–55.

Mitchell I.M., Logan R.W., Pollock J.C. & Jamieson M.P. (1995) Nutritional status of children with congenital heart disease. *British Heart Journal* **73**, 277–83.

Ohman A., Stromvall-Larsson E., Nilsson B. & Mellander M. (2013) Pulse oximetry home monitoring in infants with single-ventricle physiology and a surgical shunt as the only source of pulmonary blood flow. *Cardiology in the Young* **23**, 75–81.

Slicker J., Hehir D.A., Horsley M., Monczka J., Stern K.W., Roman B. *et al.* (2013) Nutrition algorithms for infants with hypoplastic left heart syndrome; birth through the first interstage period. *Congenital Heart Disease* **8**, 89–102.

Srivastava A. & Thomson S.B. (2009) Framework Analysis: a qualitative methodology for applied policy research. *Journal of Administration and Governance* **4**, 72–79.

Varan B., Tokel K. & Yilmaz G. (1999) Malnutrition and growth failure in cyanotic and acyanotic congenital heart disease with and without pulmonary hypertension. *Archives of Disease in Childhood* **81**, 49–52.