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TRANSITION TO HOME AFTER NEONATAL SURGERY FOR CONGENITAL HEART DISEASE

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Abstract

Purpose—To ascertain the primary caregiver's post discharge perceptions of infant care issues after neonatal heart surgery.

Study Design & Methods—Fifteen primary caregivers of infants who had neonatal heart surgery for complex CHD participated in this study. We conducted two focus groups, and four individual phone interviews using a structured interview guide. The topics included: parent feeding management, infant caloric intake, parental acceptance of nasogastric tube, infant feeding behaviors and issues of parenting stress. We audio recorded focus group sessions, made detailed notes and key quotes were recorded verbatim by a certified impartial focus group facilitator.

Results—Feeding problems were present in both infants who were on full oral feeds as well as infants who were dependent on supplemental feeding tubes. Mothers of infants with feeding problems expressed concern over weight gain and sleep deprivation, which largely contributed to parental stress.

Clinical Implications—In this small study of infants who experienced neonatal surgery for complex CHD, parental stress over feeding and weight gain needed to be addressed during hospitalization. Future studies are needed to address increased at-home parental support.

Keywords

Infant; Feeding; Stress; Parent; Cardiac Surgery

Introduction

Complex congenital heart disease (CHD) occurs in eight of every 1000 live births (Hoffman & Kaplan, 2002) and is reported to be the number one birth defect in newborns (American Heart Association, 2011). Similar prevalence of CHD has been reported from European pediatric cardiac centers (Dolk, Loane, & Garne, 2011; Sipek et al., 2010). Over the past three decades, pediatric open-heart surgery has shifted from performing corrective surgery in the childhood years, to performing corrective or palliative repairs in the newborn period which has led to decreased morbidity and mortality. Thus, the incidence of neonatal reparative operations is increasing (Backer & Mavroudis, 2007). With the advancement of surgical techniques and perioperative care, survival rates for all congenital heart defects are

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improving, including the most lethal defect hypoplastic left heart syndrome (HLHS) (Rychik, 2010). Given the advances in pre-natal diagnosis and medical/surgical management practices, CHD is quickly becoming the most common chronic illness in childhood (Tak & McCubbin, 2002).

Families of children with complex CHD struggle with problems that produce anxiety and distress, regardless of the severity of the heart defect (McCusker et al., 2010; Wernovsky, Shillingford, & Gaynor, 2005). The burden of caring for these challenging infants is especially high during the earliest stages of the illness because of the frequency of diagnostic procedures; complexity and multiplicity of medical and surgical interventions; as well as the emotional rollercoaster before, during, and after the neonatal heart surgery (Mussatto, 2006; Tak & McCubbin, 2002). Uncertainty about the child's survival is predominant in their minds and shown to be associated with increased parental stress (Tak & McCubbin, 2002). Beyond surgical survival, feeding problems are emerging as the number one stressor for parents as they struggle to insure adequate weight gain for their infant (Davis et al., 2008). Dysphasia (dysfunctional swallowing) is a major contributor to poor feeding skills and has been reported to occur in up to one-fifth of infants after neonatal open heart surgery (Einarson & Arthur, 2003) and 50% of infants following the Norwood procedure for HLHS (Golbus, Wojcik, Charpie, & Hirsch, 2011).

Once home, the needs of the CHD infant are demanding. Constant parental vigilance generates anxiety and stress in the mother; who is typically the primary caregiver. This stress may exact a physical and psychological toll which in turn creates an environment of both amplified stress and anxiety for these parents (Carey, Nicholson, & Fox, 2002). Specifically, mothers of chronically ill infants and children have been reported to experience both repeated and sometimes sustained physical and psychological stress from the ever-present needs of the child (Knafl & Zoeller, 2000). Caring for children with chronic illness in general (Meltzer & Mindell, 2006), specifically infants post-cardiac surgery, often requires a significant amount of work throughout the day and night, resulting in the additional stressor of sleep disruption and chronic sleep deprivation (Meltzer & Mindell, 2006). The objectives of this study were to ascertain the primary caregiver's perceptions of infant-care issues after the infant was discharged home following neonatal heart surgery.

Study Design and Methods

Research Design

We conducted two focus groups and four phone interviews using a professional focus group leader. Our in-depth interviewing of respondents was done with skill in a dynamic atmosphere of rapport, sensitivity and openness to sharing thoughts and feelings. The specific objective for our focus groups and interviews was to ascertain the primary caregiver's perceptions of infant-care issues in the first three months following neonatal heart-surgery for complex CHD. Institutional Review Board approval was obtained prior to the study, with an approval to waive written consent as the study met the criteria for exemption according to the Code of Federal Regulation 45 CFR 46.101 (b)(2).

Subjects

Primary caregivers of infants who survived neonatal open-heart surgery and were discharged home between January 1 and June 30, 2008 and lived within the tri-state area of the hospital were eligible. Non-English speaking families and families of infants having surgery for non-complex CHD (those not requiring cardiopulmonary bypass during surgery) were excluded. We contacted families by phone and identified the primary caregiver. We explained the

process and purpose of the focus groups and enrolled the subject if they were interested in participating.

Fifteen primary caregivers participated (mother = 14, grandmother = 1) in both focus groups, collectively. Their infants were between the ages of four and ten months at the time of the interview. The groups included primary caregivers of infants discharged with a feeding tube (nasogastric or gastric) (n = 4), and primary caregivers of infants discharged exclusively on oral feedings (breast or bottle) (n = 7). Additional phone interviews included four (n = 4) primary caregivers; three had infants with a feeding tube in place and were unable to attend the focus group, and one was bottle-fed. Within each focus group (tube vs. oral feeding) were mothers of infants with both single ventricular repairs (SV) (n = 6), and biventricular (BV) repairs (n = 9) (Table 1). Infants with SV physiology had palliative surgery as compared to infants with BV physiology who had reparative surgery. All but one of the primary caregivers lived with their infant's father and most were married.

Data Collection Procedures

We used an interview guide during the focus groups to assist primary caregivers to recall the first three months in which they were caring for their infant following hospital discharge. The guide was developed with open-ended questions based on current literature, our clinical experience and prior research findings (Torowicz, Irving, Sumpter, & Medoff-Cooper, 2010). Topics addressed in the guide included, 1) parent feeding management, 2) caloric intake, 3) parental acceptance of nasogastric tube, 4) infant feeding behaviors and 5) issues of parenting stress. Some examples of question type are, "At what point were you advised that your baby would need to be on an NG tube at home?" and "What were your concerns about feeding your baby enough?" The moderator, using the topics pre-identified as the areas of interest, completed an in-depth report. We audio recorded focus group sessions and phone interviews and we took detailed notes with key quotes recorded verbatim. Transcripts were examined for content as it related to the five topics.

Results

Feeding Management

Regardless of mode of feeding at discharge, all mothers tried to manage a feeding schedule every 2.5 to 3 hours, as recommended by the hospital staff. The effort of 'timing feedings' was a difficult task because some babies would either take an unusually long time or quit too soon leading to frequent bottle presentations. Several mothers were determined to hold off feeding their infant for the prescribed three hours with the intention of getting the baby genuinely hungry only to have him quit feeding after one ounce. This was particularly true for mothers who were trying to keep their infants on oral (bottle) feedings rather than to regress to tube feeding. Mothers complained that they felt they were "*always feeding*" their baby, which was exhausting.

For infants discharged on a combination of tube and bottle feeding, families were instructed to offer a bottle every 2 – 3 hours for no more than 20 minutes. Liquid left in the bottle after 20 minutes was to be given via the tube. This method worked for some and was reported as being less stressful because the mother knew her baby would get the correct amount of nutrition and calories. Some mothers found the NG tube convenient and affirmed, "*Sometimes he would be sleeping, and there's a convenience in that, you realize, 'Wow, these are efficient babies, they can sleep and eat'.*"

A number of mothers whose babies went home using a NG tube had difficulties managing regular feedings. They reported that they felt "*prepared*" to feed their child at home as long as the tube remained in place. One mother stated:

I was fine as long as the tube was in, that I knew how to do it, how to hang it [feeding bag], how to put the medicine back in, how to check the pH [for tube placement in the stomach], all that stuff...my concern was if it came out, how to put it back in.

Another mother explained when her son pulled his tube out “my husband panicked...he tried to push it back in” she screamed “No, you can’t just push it back in, you have to take it all the way out and put it all the way back in.” Even without problems, frustration, exhaustion and lack of sleep were common. We heard about nighttime feedings and the toll it took on the families; as one mother detailed:

We were up all night long, we had to set up his feeds in the middle of the night, he wasn’t gaining the right amount of weight, we were just constantly taking it down, cleaning it, setting up another feed, attaching him [to the tube], waking up on the hour to vent him, and make sure he was comfortable.

Caloric Intake Management

Despite the route of feeding, vomiting was an issue for almost every infant. There was a lengthy discussion about how frustrating they felt each time an infant vomited, or as mothers described, “the retching.” It was almost as if all their efforts to achieve an adequate caloric intake were undone with each bout of vomiting. Two mothers shared that: “Vomiting cause’s stress. It’s constant, there is no break and there is no moment to relax. You can’t go anywhere and not be prepared” and “Vomiting means he is not gaining any weight, he is over 6 months old and just 12 pounds and that stresses me out.” The frequency of vomiting was regularly followed by weight loss and the potential to delay the second surgery for the infants with SV physiology.

Feeding tube acceptance

Prior to discharge, most mothers acknowledged that they were informed that it may be necessary to use the NG tube for the first few post-operative days and if feeding difficulties arose or persisted, the baby would be sent home with the feeding tube. Although families (mainly mothers) received training on how to care for the tube, once their infant was discharged, they were still anxious about using and caring for the tube once at home alone with their babies. One mother stated, “[I was] a wreck. He had all these tubes, on top of the ataxia (lack of coordination of muscle movements) and on top of the abdominal issues that he had and on top of that we had to put a tube down his throat.” During the focus groups, mothers admitted their anxiety about tube care with the worry that they may do something that could inadvertently cause harm or injury to their baby. Additionally, moms expressed concern about the amount of time and energy involved in using the tube; feeding, cleaning and replacement of the tube should it become dislodged. Most of all, they worried about the enduring effects of how the tube may hinder or help with their baby’s long-term ability to feed normally.

Mothers also experienced a sense of embarrassment about being in public with an infant who had an indwelling NG tube in place and taped to their baby’s face for security. Although temporary, the tube was a constant reminder that their baby was not “normal”. Strangers often asked one mother what was wrong with her infant and why did he have a tube in his nose. This type of incident further added to the sense of isolation that many mothers felt, resulting in ambivalence towards the NG tube.

Additionally, for those babies who had even more difficulty feeding, vocal cord paralysis, and/or who suffered from more severe reflux, the need for placing a tube (gastrostomy tube/G-tube) was discussed and/or implemented before discharge. Mothers first resisted the

recommendation to surgically implant a feeding tube because it meant an additional surgery, a supplementary wound and another instance where their infant would have discomfort. One mother remarked, *“it was upsetting to us because we didn’t want to go through another surgery. He had a very difficult time with the open heart surgery and we were very traumatized by it.”* However, once it was explained that discharge was contingent upon adequate weight gain most families accepted the recommendations for a feeding tube.

Infant Feeding Behaviors

Several mothers commented that their infants gave neither verbal nor nonverbal cues signaling hunger or satiety and they found it stressful as they attempted to determine when their baby was hungry or full. Most of the oral fed babies cried when hungry, whereas most of the tube fed babies gave little if any cues that they were hungry and/or satiated. We heard phrases like, *“It’s not the same as a baby that gets a bottle...these kids, [with a tube] they don’t know, they don’t let me know when it’s time to eat, he would starve if I didn’t [just] feed him.”* Nighttime feedings were no different. Many of the mothers commented that during night-time hours, their babies had to be awakened to eat because they did not wake up on their own. Mothers were especially concerned that the absence of nighttime feedings meant that *“he wasn’t getting enough calories for the day”*, and *“he can’t afford not to eat.”* They expressed the anxiety they felt to *“make their baby gain weight.”* In addition to the babies not signaling when they are hungry, they also did not indicate that they were full until it was too late. This often resulted in vomiting.

Parental Stress

Mothers verbalized general feelings of stress and anxiety surrounding hospital discharge, home care and most of all feeding and weight gain. They felt ill-equipped to deal with the fears surrounding their infant’s heart condition. One mother remarked, *“I was just more worried about him turning blue and dying, so I checked on him every hour,”* and another stated that, *“In the back of your mind you are always worrying about the heart,...”*. Mothers discussed the stress of constant infant care needs without personal or respite time. As one mother explained, *“It’s hard, and today it is still hard... there [are] very few people I can leave him with to watch him, I’m with my son 24/7.”* The response that seems most revealing was when one mother was asked how she reduces her stress and her reply was, *“Medication for me and my husband...the stress was constant, there is no break, no moment to relax.”* Despite the constant vigilance, parental stress diminished over time if the infant remained stable without the need for emergency room visits or re-hospitalizations.

Receiving support from immediate and extended family members gives parents great relief. One mother brought her whole family to the hospital so that the doctor could explain her baby’s heart condition at one time. She said that she *“didn’t have to tell each person the same story over and over again. And then the family knew exactly what we were expecting so they knew to help us with [our] other child.”*

Limitations

There are several limitations to these findings. A small sample size and limited demographic descriptions reduce the generality of the data. Data from phone interviews may be qualitatively different from the in-person group experience.

Clinical Implications

The results of the focus groups provided interesting insights into the post-discharge challenges experienced by infants in the early months of their recovery from neonatal surgery for complex CHD. One of the most important messages gleaned from our study was

the need for early parental support for infant care; especially in reference to feeding. Although the decision to discharge an infant with either a nasogastric tube or a surgically implanted feeding tube is often not made until an infant demonstrates significant feeding problems, over 50% of infants are released with some supplemental feeding device (Medoff-Cooper & Irving, 2009). Advance teaching and education regarding feeding problems, along with practice in feeding infants, would be extremely beneficial.

Torowicz and colleagues reported that it was the care demands and difficulty to soothe that created the most stress for parents through the first year of life (Torowicz, et al., 2010). In contrast, this group of mothers had little discussion regarding infant difficulty; rather it was the care demands most often related to feeding issues. Lengthy feedings, infant vomiting, fears about inserting (and caring for) nasogastric tubes and the constant anxiety about weight gain were the biggest concerns. Parents attempted numerous strategies to improve daily intake and lessen vomiting. These ranged from decreasing amounts of formula at any given time and increasing frequency of feedings, to feeding infants upright and increasing caloric density. In most cases, these strategies were unsuccessful; becoming an additional source of frustration and stress.

Discomfort with feeding tubes, whether nasogastric or surgically placed gastric tubes, were universally acknowledged. Mothers whose infants were fully orally fed at the time of the focus group admitted that their biggest fear was that their infant would not gain weight, thereby leading to the need to return to device support. For mothers whose infants were dependent on some device support, the constant fear existed that the feeding tube would be dislodged. Very few of the parents (in either focus group or phone interviews) voiced any level of comfort with inserting and caring for a nasogastric tube; thereby adding another source of parental stress. While it is possible that increasing parental experiences with feeding tube placements prior to discharge may be helpful in enhancing confidence levels, parental perceptions of how much discomfort they caused their infant during the process of reinserting the nasogastric tube may be a more powerful factor.

Infant behavioral responses to feeding cannot be overlooked as a source of stress. These infants do not appear to be good informants about their feeding needs. Not being able to discern when an infant was hungry or satiated, nor being given any warning about impending explosive retching from potential overfeeding, was also found to be extremely frustrating.

Extended family involvement appeared to serve as a mediator of stress for some participants. For those without families nearby, the day in and day out demands of “24/7” care was overwhelming at times. Creating social support networks prior to release may decrease some of the early anxiety of pending discharge and the challenges of daily infant care. Social support networks could encompass internet chat groups for mothers of infants with complex CHD or virtual “home visits” from cardiac centers via Skype.

In summary, mothering infants recovering from neonatal surgery for complex CHD can be a stressful undertaking. For many infants, whether orally or device fed, daily intake and weight gain appears to be a constant struggle. Potential solutions for maternal stress management include more intensive discharge planning and home monitoring.

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Call outs

“She never showed any sign of hunger”

“We have no idea when he is hungry, I don’t think he understand the concept of hunger.”

“Vomiting causes stress. It’s constant, there is no break, and there is no moment to relax. You can’t go anywhere and not be prepared.”

“When we found out about [the need for a gastric feeding tube], it was upsetting to us because we didn’t want to go through another surgery. He had a very difficult time with the open heart surgery and we were very traumatized by it.”

Several mothers reported that the scheduled feedings were never-ending; just as they would finish feeding their child, in less than one hour they needed to start the process all over again.

Clinical Implications

- Begin parental preparation to reduce stress once discharged home immediately upon admission:
 - Set up home support by preparing other family members to care for the infant, encourage parents to seek out a family counselor for quick access if necessary following discharge.
 - Encourage parents to actively seek out a support group during the admission period and begin dialoging. Support groups can be found through their local hospital, childcare cooperatives, universities, libraries, churches, synagogues, or other religious or community organizations.
 - Web Communities:
 - ◆ Moms Club - designed for at-home mother:
<http://www.momsclub.org/>
 - ◆ Little Hearts Inc. - National Group:
<http://www.littlehearts.org/>
 - ◆ Many local support groups have Facebook and Twitter addresses
- Most mothers receive NG tube education before leaving the hospital. However, once the infant is discharged, mothers leave the hospital feeling stressed, uncomfortable and uncertain about managing or replacing the tube should it dislodge.
 - Immediately following surgery, nurses should educate the parents in hands-on feeding tube management, regardless of potential discharge feeding route. Nurses should repeat this education whenever parents are present. Doing this will give parents increased confidence in the management of the feeding tube once the infant is discharged.
- Feeding challenges include; lengthy feedings that can last up to two hours, frequent vomiting episodes, frequent feedings or bottle presentations and confusing infant hunger cues.
 - Hospitals and nurses should provide resources for GERD and NGT support groups, brochures, online chat or blog groups and medical resources prior to discharge.
 - ◆ Zero to Three: www.zerotothree.org
 - ◆ Pediatric Adolescent Gastroesophagel Reflux (PAGER) Association: www.reflux.org
- Nurse Liaison:
 - Available post discharge to the parents for triage
 - Available to re-insert NG/G-tubes when necessary

Table 1

Diagnosis and Feeding Group

	SV	Bi-V	Total
Oral feeding at hospital discharge	1	7	8
Tube feeding at hosp discharge	5 (83%)	2 (22%)	7
Total	6	9	15

Note. SV=single ventricle palliation; Bi-V = biventricular repair