Published in final edited form as:

Newborn Infant Nurs Rev. 2012 December 1; 12(4): 207–213. doi:10.1053/j.nainr.2012.09.008.

Feeding Problems of NICU and PICU Graduates: Perceptions of Parents and Providers

Kristin F. Lutz, PhD, RN [Assistant Professor]

Oregon Health & Science University School of Nursing, 3455 SW U.S. Veterans Hospital Road,
Mail code: SN-6S, Portland, OR 97239-2941; Office: 503-494-5010

Kristin F. Lutz: lutzk@ohsu.edu

Abstract

There is little known about family experiences with pediatric feeding problems after NICU or PICU discharge. The study purposes were to better understand the family experiences with and consequences of feeding problems among NICU and PICU graduates after they transitioned home. Using a qualitative, descriptive design, 15 parents and 10 health professionals completed in-depth interviews. Data were analyzed using qualitative content analysis. Analysis revealed that feeding problems greatly impacted families. Education and resources were considered important, but generally insufficient. Though some parent-provider partnerships were strong, many others were not, and at-times, partnerships were fraught with conflict, communication problems, and lack of collaboration. System barriers and financial concerns escalated parents' distress, affecting their emotional responses. Parents' perceptions of discrepancies between their family situation and those of "normal" families violated their expectations. Understanding the perspectives of parents and providers regarding feeding problems common among NICU and PICU graduates is essential to developing effective interventions.

Keywords

NICU; Feeding Problems; Families; Transitional Care; Qualitative Research

Feeding problems, common in full-term, healthy infants and young children, are even more likely among high-risk infants and young children who required hospitalization in a neonatal or pediatric intensive care unit (NICU; PICU) such as those born preterm^{1–5} or with complex or severe conditions.⁶ Feeding is a complex process requiring sufficient neurodevelopmental maturation; physiologic stability; control of tone; behavioral state organization; and coordinated sucking, swallowing, and breathing.^{7,8} Thus, oral feeding depends on the interrelated factors of structure and process. Additionally, feeding occurs within the dyadic context of the infant and care provider relationship, most often the parent.⁹ Though feeding and nutrition problems are common complications experienced by high-risk infants and young children, they are often amenable to early intervention, particularly if diagnosed and treated early.^{10,11,12} However, there is little known about feeding problems of high-risk infants after NICU discharge and family consequences from the perspective of parents and health professionals.

© 2012 Elsevier Inc. All rights reserved.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Review of Literature

The growing number of infants born preterm (<37 weeks gestation) or with complex health conditions is a significant public health problem with major consequences for the infant, families, and society. Preterm infants are vulnerable to many complications, including congenital and neurological defects such as cerebral palsy and other neurological disabilities, cognitive abnormalities in early childhood and learning disabilities, behavioral disabilities, developmental delays, sensory impairment including blindness and hearing loss, compromised immune system, cardiovascular and respiratory disorders, and growth impairment.^{13–15} Because of their increased risk of immediate and long-term health problems, there is added responsibility and caregiving burden placed on parents of high-risk infants as compared to parents of full-term, healthy infants.

Evidence suggests that high-risk infants are at significantly increased risk of feeding and regulatory problems¹⁶ and have greater rates of feeding problems as compared to healthy, full-term infants.^{1–6} In the preterm infant, the ability to take in, process, digest, and absorb food is disrupted due to neurodevelopmental and physiological immaturity. The gastrointestinal tract function, feeding reflexes, and ability to coordinate the functions of sucking, swallowing or breathing, which are necessary for safe intake and sufficient oral nutrition, are not sufficiently mature in preterm infants. As a result of these multiple variables, unlike healthy infants, high-risk infants are frequently unable to begin or maintain oral intake via breast or bottle shortly after birth, requiring intervention to provide sufficient nutritional intake for growth and development. Surgeries and illness may affect feeding, while noxious stimuli such as prolonged endotracheal intubation or nasogastric tubes may also lead to the development of oral aversions causing the child to resist or be unable to tolerate oral intake.¹⁷ Moreover, persistent feeding problems continuing until school age have been found to be more common in children born preterm¹⁸ and extremely preterm¹⁹ than comparison term infants.

Though feeding problems may begin while high-risk infants are hospitalized in the NICU or the PICU, after they are discharged to their home environment feeding problems often reoccur or new problems arise, often when an infant reaches the next developmental stage.²⁰ Further, growth of high-risk infants often falters once they go home.²¹ As a result, parents may seek reassurance or assistance from health professionals. Indeed, in the first year, feeding problems are a significant cause of increased number of planned health care visits,²² as well as hospital readmissions after NICU discharge^{22–26} for preterm infants. However, rehospitalization, invasive and non-invasive procedures, illness, and disruptions in feeding routines or schedules may also interfere with established feeding patterns for fragile infants.

Once parents have brought the high-risk infant home, accessing clinicians becomes more difficult than in the NICU or PICU, and knowing which health professional to seek assistance from becomes yet another variable for parents to consider. Additionally, community-based providers, such as public health nurses, nurse practitioners, pediatricians, lactation specialists, and nutritionists are often ill-equipped or unable to adequately address the complex feeding problems faced by these high-risk infants and their parents. While this literature suggests some of the risks and challenges that parents may confront when trying to feed their child after they have transitioned home, the family experiences and consequences of pediatric feeding problems remain unclear. Thus, the purpose of this investigation was to explore the family consequences of and experiences with feeding problems among NICU and PICU graduates from the perspective of parents and health professionals.

Design and Method

This study used a qualitative descriptive design^{27,28} to 1) explore parents' and health providers' perspectives of their experiences with and family consequences of infants and young children who were NICU and PICU graduates with feeding problems and 2) identify potential family-centered interventions. This article presents data regarding the first aim. The study was approved by the University IRB.

Participants

Study participants were recruited through pediatric specialty clinics located in Southern Wisconsin and via snowball sampling. The convenience sample consisted of two groups: 1) Parents of young children under age 4 who were graduates of a NICU or PICU with feeding concerns and 2) Health professionals who care for this population. Inclusion criteria for parents were age 18 years or older, English-speaking, parent of a child under age 4 who graduated from a NICU or PICU and has feeding and nutrition issues. Inclusion criteria for health professionals included English-speaking and health care provider with experience with pediatric feeding problems. Clinic and hospital personnel provided parents who met the inclusion criteria with a study flyer. Professional participants were recruited through snowball sampling.

Following an informed consent process, in-depth, semi-structured interviews were completed by the principal investigator, a graduate research assistant, or one of the trained graduate nursing students. Parents were interviewed about the experiences and consequences of their child's medical condition and history; feeding their child; feeding strategies and nutritional goals; health professional support, care, and access; family and other relationships; and their recommendations. Professionals were interviewed about their experiences caring for children with feeding problems and their families and asked for recommendations. The audiorecorded interviews lasted approximately 30 minutes to 2.5 hours and were conducted in-person or via telephone as preferred by participants. Each participant was offered \$20 remuneration. To maintain confidentiality, all identifiers were removed and pseudonyms are used.

Data Analysis

Interviews were transcribed and analyzed using a process of conventional content analysis to identify major topics and themes.²⁹ NVivo7³⁰ was used to manage the qualitative data as well as to facilitate data analysis. Interview transcripts were analyzed by a research team comprised of the principal investigator, a graduate research assistant, along with graduate and undergraduate nursing students. Transcripts were individually read and coded by the team members. The research team then collectively reviewed codes and data analysis, discussed the coding and analysis, and revised the codes as necessary to eventually reach consensus on the salient topics and themes in the data.

Findings

The sample (N=25) consisted of parents (n=15) from eleven families and health professionals (n=10) from acute care, specialty clinic, and community practice settings in Southern Wisconsin. Parent participants included 10 mothers (66.7%) and 5 fathers (33.3%). All of the parents were white and married or partnered when their child was born. One parent was separated when interviewed. The mean age for parents was 34.2 years (range 25–43). Eighty percent (n=12) of the parents had completed college and most (n=8; 72%) had an annual household income above \$40000. Seven (64%) of the children were preterm or low birthweight, three (27%) had a congenital or genetic disorder, and one (9%) child was

preterm and had a congenital disorder. The mean age of the children was 20.7 months (range: 8–36 months).

The children's feeding problems varied considerably; many of them experienced a combination of behavioral, relational, mechanical, and physiological problems. Most children had difficulty coordinating suck-swallow-breathe or latching on, particularly when they first transitioned to home. Most of the children were described as easily distracted and as having gastroesophageal reflux and/or oral aversion. Most of the children were fed via a temporary feeding tube while in the NICU or PICU and several currently had a permanent feeding tube or placement of a permanent feeding tube was an intervention under consideration.

Professional participants consisted of nurses (n=4), nutritionists/dieticians (n=3), and occupational, physical, and speech/language therapists (n=3) with acute care and/or community experience. All of the professionals were female, 9 were white (one did not provide information about race). The mean number of years experience was 18.14 (range: 2–31). Professionals possessed experience across practice settings and often had cared for infants and children with different health conditions and varied complexity and severity of feeding problems.

Major Themes

Five salient themes were identified through content analysis: 1) Diverse and fluctuating parental responses; 2) Feeding as the focus; 3) Isolation and violated expectations; 4) Conflicting collaboration, perceptions, and communication; and 5) Barriers and challenges to accessing care.

Diverse and Fluctuating Parental Emotional Responses

After they had transitioned home and the feeding problems recurred, persisted, or worsened, parents' stress and worry intensified. Parents and professional participants described myriad parental emotions about their child's health concerns and feeding issues ranging from guilt and grief to hopefulness and gratitude. These emotions vacillated as their child's health condition changed; as their feeding progressed, stalled, or declined; as information about the child's problems evolved; with the knowledge and quality of health care providers; and/or when other stressors occurred. As one mother of a former preemie described her feelings of guilt and the questioning process she went through when her child did not gain weight as expected and they experienced difficulty feeding: "...I kept wondering does my breast milk just not have enough calories in it? Am I making, you know, thin milk or whatever? And a lot of that is just mommy guilt and mommy stress." As another mother described:

It's affecting my family quite a bit with Jacob's feeding needs and stuff; it's a struggle for everyone. It's probably more of a struggle for me because I'm the mom and I'm with him all day long. It's a struggle for my husband when he gets home and you know, I'm home with Jacob and I ask him to take at least one of his feedings. And although he works long days, it's hard for him. It's a struggle for everybody.

Stress and differing emotional responses also influenced relationships with other family members, including the parents' relationship with one other. At times, there was tension between parents because one parent felt they were carrying most of the responsibility or, less commonly, when there were disagreements about which feeding approaches or interventions to use.

Disagreements occurred mainly when invasive interventions were recommended (e.g., placement of a permanent feeding tube), the child's health worsened, or significant feeding setbacks occurred. As one mother described the stress on her marriage resulting from her child's feeding problem, "It's taking a huge toll on our personal lives, our marriage, because my husband and I disagree on the use of the g-tube." For other parents, however, their child's feeding problems, while challenging to manage, were not detrimental to their relationship. As one mother stated, "I think that we are lucky enough to have a very, very strong marriage and adversity in a lot of ways has made us an even stronger team because we truly have approached this as a team." For many parents, feeling overwhelmed, sad, and disheartened about their child's problem was balanced with hope and optimism that the feeding difficulties would resolve or the child was "growing out of it".

Feeding as the Focus

Although many parents felt confident and well-prepared to provide care for their infant at the time of hospital discharge, most were surprised and ill-prepared for the complex preparation and extended time needed for feeding. Many parents were astonished by how much of their time and energy was expended in feeding activities. Most parents described feeding their child every 2–3 hours while awake. The actual process of preparing for and administering an oral feed took parents about 30–60 minutes. Thus, there was scant time between completion of one feeding and initiation of the next. As one parent described, "Feeding schedules made us think the way to take care of a baby was by a clock. We lived by a clock." Consequently, parents expressed the need and desire for more anticipatory guidance specific to feeding, growth, and development. As one parent of a former very preterm infant explained,

...When she was discharged from the NICU, they kind of only talked about one month or so out from her discharge. It would have been helpful if someone had actually sat us down and talked about some of the typical things that preemies go through from a feeding perspective as they are growing up.... Then it wouldn't have been as much of a surprise along the way.

This was echoed by a nurse when she described what she had realized when she transitioned from working in a NICU to starting to work with families in the home or at specialty clinics:

Families have questions, and I would answer that as best I could within my, what I have learned working in the neonatal intensive care unit. Which is helpful, but only, you know, only to a certain extent, the... What the families, what children and families face once they leave the unit, particularly as the kids grow and develop is, you just can't continue to make use of what you learn in the NICU setting and only use that as you move forward kind of a thing as a child grows.

As illustrated by the previous examples, as they prepared to take their infants home, parents' knowledge about feeding was often limited. As children matured or their health conditions changed, parents had to be flexible and creative with the process, often experimenting with countless feeding techniques and diverse strategies in order to ensure adequate nutritional intake. Despite the stress associated with feeding, however, parents often viewed feeding as an opportunity to spend time with their fragile infant, particularly in the early transition period from NICU or PICU home. As one father of a former preemie explained, "We looked forward to her feedings. Even though they were so stressful, we looked forward to that interaction time. Just because she would be up and interacting with you."

Even for children with very complex medical problems and frequent health care visits, parents explained that feeding often overshadowed those other concerns because without adequate nutritional support, growth and development would suffer. As one parent

described, “Our lives basically revolve around just feeding him at this point and the other medical problems. But on a day-to-day basis it really is – everything revolves around his feeds.” Another added, “It’s definitely taken stress to a new level. It’s just one more, it seems to us like one more unnecessary thing to deal with, it’s one thing that we have to deal with on top of everything.”

As these statements illustrate, many parents were shocked that feeding and surveillance of their child’s nutritional intake had become such a stressful and time-consuming activity that family life revolved around. This was something that parents were not all prepared for. Furthermore, feeding interactions required significant parental focus, minimal external distractions, and extensive time thereby placing strict limitations on the feeding process and environment.

Isolation and Violated Expectations

Social isolation and insufficient support were described by all of the parents. The difficulties in feeding combined with the child’s vulnerable health status limited parents’ ability to engage in the social activities that they had been engaged in prior to the birth of their high-risk infant. Consequently, feeling alone, isolated, or misunderstood by other parents or their family and friends were common experiences and sentiments expressed by parents. This is exemplified in the following description from a mother of a 3-year-old daughter who was former preemie:

I felt pretty isolated for a long time. We didn’t take her out much due to immune issues. I did attend an infant massage class, but I felt shunned by the other mothers. People don’t want to hear about things going wrong.

And a father’s account:

People don’t know how to, friends don’t necessarily know how to deal with it or talk about it or I don’t talk about it much, too much at work because people don’t know what to say. And it’s not, not that they’re um, bad people or anything, so they might say things like, “Oh, maybe he’s just going to be small.”

Similarly, many of the health professionals observed that after parents took their infants home and the child’s feeding problems continued or worsened, the parents frequently felt cut off from resources. As one dietician in the community explained:

More than anything they [parents] feel isolated. They know that they have an issue...they know their children should be at a certain place because they see their peers there and they don’t know where to get the answers to their questions.

Moreover, differences between their own family’s situation around feeding and caring for their infant or young child and other families of healthy infants or young children violated parents’ expectations regarding what family life and caring for an infant or child would be like, particularly concerning feeding.

As one parent explained,

I think the rest of the world paints this picture of you start rice cereal and then boom, you have an eater in your family dinners. And toddlers are notoriously picky and you spend lots of years on macaroni and cheese and chicken fingers and voilà you’ve got eaters. And it suddenly hit us at some point that that’s not our reality and so now what do we do?

Reconciling their reality with the reality of others was often very challenging for families and contributed to their sense of isolation.

Collaboration, Perceptions, and Communication

Collaborative partnerships between parents and health professionals and among health professionals in different specialties and across settings were considered extremely important by parents and health providers. However, communication issues and lack of collaboration were frequent issues and, at times, conflicts between parents and professionals or between professionals arose, leading to frustration and distrust. Yet, health care providers who demonstrated sensitivity and empathy for what families were going through were highly appreciated by parents. Conversely, health professionals' insensitive remarks or inconsiderate behavior left parents feeling frustrated and even angry. This sentiment is exemplified by this description of health professionals from a parent of an infant with a genetic disorder,

I think the ones that have been the best are the ones that really understand how stressful it is...we have had a few who seem to be residents or fellows who don't quite get it and those are the ones that just rub you the wrong way and you're just like, "O.K., we're done with you."

Several health professionals were also concerned about other providers' lack of sensitivity when working with parents, but were confident in their own communication. As one professional explained, "I feel like I have a pretty good um, ability to empathize with the families, but I don't always know all their circumstances."

For many parents, however, the communication process was often fraught with difficulty. Parents frequently expressed the feeling that their opinions or preferences were not valued or respected by health care professionals. As expressed by the mother of a 12-month-old with a genetic disorder: "Time and time and time again they would not listen to me and 'Jack' suffered and suffered and suffered and continues to suffer because nobody will listen." Similarly, in describing her challenges with getting professionals to listen to her concerns about her son's feeding issue, a mother of a 3-year-old former preemie explained, "I felt like people weren't listening to me. I didn't get listened to. I don't know why." However, when parents felt that their child's and their own needs were being met by their providers, parents' stress and worry diminished. As one parent explained:

In the feeding clinic in [city name], I think they've done, I think they've been very effective. Um, you know he's still working through some issues, they, they haven't pulled out the magic wand and made it all go away, but they've given us a safety net you know, and in some ways – this sounds really cheesy and I don't mean it that way – but in some ways they gave us lots of our life back. We were spending so much time fighting with this child, even just drinking with a bottle and um, they're really just encouraging of having mealtime be fun and not a battle...

Professionals also described frustration with communication between providers and settings. Between "playing telephone tag" or not even knowing which health professional to communicate with, most professionals acknowledged that communication between providers and settings was not optimal. As one health professional admitted, "There's not a lot of communication to be honest with you."

Barriers and Challenges to Accessing Care

Parents and health professionals identified numerous barriers and challenges to accessing care. Among these challenges were system barriers that limited families' access to specialists or resources and numerous care providers and settings which made accessing health care services very difficult for many families. For parents of high-risk children with feeding issues, uncertainty regarding the most effective interventions to promote feeding and

nutrition was a frequent challenge. Quite simply, parents were often not sure what to do. As one professional explained:

I've heard that enough from families over the years, too, that that's something that they really value. They don't necessarily want somebody to take over and tell them what to do, but they do want access to information and someone who might think through with them what to make of it.

However, many of the parents also described "trial and error," "guesswork," and questioned the "evidence" for feeding interventions recommended by some of the health professionals. As one mother described her frustration regarding inconsistent recommendations:

They didn't talk to each other...Nobody ever offered to talk to each other. I remember going in repeatedly. I always had a list of questions when we went in. ... I remember saying, "I can't stand this. All of you are contradicting each other." I said, "Wait, so you want me to do this, she wants me to do that, you want me to do this." And it was even something like how many ounces a day does my child need? The calculation based on his weight was done differently by every person. The amount of formula to be added to the milk was done differently so I ended up averaging because I don't know what to do. ...I literally tried to make them all happy for about 3 weeks.

As reflected in this example, inconsistencies between health professionals combined with lack of evidence-based interventions left parents frustrated and uncertain about the best course of action.

Additionally, limited access to relevant services or service providers significantly impacted care for children, while financial problems, insurance co-pays, insurance limits, and health networks were also major determinants of the care families were able to access. Geographical barriers were also problematic for those participants and providers in areas without pediatric tertiary care. As exemplified by this statement by a rural community nurse, "The biggest thing is that there is no one here locally to help them deal with nutrition and feeding problems – especially for kids."

Finally, although several families had worked with a multidisciplinary feeding team, most families had not. Those families that had worked with a feeding team often had to wait several months in order to get in to the service and travel several hours for care, but they felt that their child had been well-cared for. Parents described satisfaction and relief with a coordinated team approach where professionals from different disciplines collaborated with the parents to address the feeding problem. Many of the families received care through public health services, but most often families described working with a number of professionals from different agencies in order to meet their child's needs. Parents' satisfaction with care coordination and communication varied, while health providers consistently described frustration with their inability to meet the needs of the children and families that they were caring because of health service barriers and insurance coverage limits. Overall, most parents and providers felt that the services were not meeting the families existing needs. As a community-based dietician explained: "Unfortunately because of cost constraints, I usually only see the family one time."

Discussion & Conclusions

The process of transitioning from the NICU or PICU to home and taking on the full responsibility of caregiving for the high-risk infant can be extremely challenging and stressful for parents.³¹ Undoubtedly, as described by participants in this study, complex pediatric feeding problems have a profound impact on families' daily life, are an ongoing

source of parental stress, consume a great deal of parental energy and time, and impact relationships within and external to the family. In addition to worrying about how their child's nutrition may affect their health and development, parents often are emotionally burdened by feelings that they are doing something wrong and are somehow responsible for the feeding problem. These findings underscore the distress and burden that parents of high-risk infants often experience, which may not be readily appreciated by health professionals and other sources of support.

Inadequate communication between providers across disciplines is a frequent source of frustration to parents and health professionals that can also have a negative impact on the child's treatment and family's well-being. Although health professionals may consider parents to be fairly knowledgeable about their child's problem and care, often parents did not feel respected or that their concerns were taken seriously by health professionals. Also, parents identified an important gap between the education on feeding provided in the NICU or PICU and the feeding problems experienced at home. Thus, parents could benefit not only from sensitive, respectful collaboration, but also from anticipatory guidance and pre-discharge education by nurses on such topics as developmental changes affecting feeding, pediatric nutrition needs, and specific feeding techniques and specialty items, such as nipples.

Pediatric feeding problems frequently depleted financial and insurance resources for families of NICU and PICU graduates. Health care services were often inadequate to meet the needs of families. Moreover, barriers to care such as insurance limitations or lack of access to specialists with the necessary expertise to address a child's particular feeding issue were far too common and aggravating to parents and health care providers alike. Helping families to identify resources before hospital discharge and connecting them with public health programs, such as Women, Infants, and Children (WIC) and community health nurses will help to meet important family needs.

Overall, study findings emphasize the value of a coordinated, multi-disciplinary family-centered approach to care of the NICU and PICU graduate and their family, specifically for feeding and nutrition problems. According to practice standards, parents of high-risk infants should receive anticipatory guidance prior to NICU discharge and close follow-up,³² but study findings suggest that those standards are not consistently being met. Clearly, there is an urgent need for care coordination and nurses are well-situated to help coordinate care – particularly as high-risk infants and children transition from the NICU³³ or PICU to home. As described by parents and providers, care coordination may be determined by a child's condition or problems, but it is also influenced by insurance plans or status, the location of the family's home, and available resources. Parents need assistance to identify resources, but they also want to collaborate with health professionals in developing individualized, developmentally appropriate interventions that will meet the needs of their child and their family. Importantly, nurses can serve a vital role for families by collaborating with nurses and other professionals across settings and specialties. For example, before discharge of a high-risk infant, the NICU nurse could collaborate with community nurses to establish community services for the family. The NICU nurse could also help bridge the transition with lactation services and work with nurses in primary care or specialty clinics to help facilitate the family's transition between home, intensive care, community services, and specialty services.

The study limitations must be considered when evaluating this research. The parent sample was well-educated, high socioeconomic status, white families. Further research with diverse families is needed. Additionally, research is needed to develop and test family-centered interventions, but understanding the experiences and perspectives of parents and providers is

an important first step in addressing the complex feeding problems commonly experienced by young NICU and PICU graduates and their families.

Acknowledgments

Funded by the Center for Patient-Centered Interventions (NINR; P20 NR008987, Sandra Ward, PI), University of Wisconsin-Madison School of Nursing. With deep appreciation to the participating families and professionals who generously shared their experiences and to my UW School of Nursing colleagues: Dr. Karen Pridham, Dr. Susan Riesch, Kristen Panther, MS, RN; Dr. Ann B. Harris and the interdisciplinary feeding team; and the nursing students who contributed their time and expertise to this research.

References

1. Field D, Garland M, Williams K. Correlates of specific childhood feeding problems. *Journal of Paediatrics and Child Health*. 2003; 39(4):299–304. [PubMed: 12755939]
2. Linsheid T. Behavioral treatments for pediatric feeding disorders. *Behavior Modification*. 2005; 30(1):6–23.
3. Linsheid, T.; Budd, K.; Rasnake, L. Pediatric feeding problems. In: Roberts, M., editor. *Handbook of Pediatric Psychology*. 3. New York: Guilford Press; 2003. p. 481–498.
4. Rommel N, DeMeyer A, Feenstra L, et al. The complexity of feeding problems in 700 infants and young children presenting to a tertiary care institution. *Journal of Pediatric Gastroenterology and Nutrition*. 2003; 37:75–84. [PubMed: 12827010]
5. Wood N, Costeloe K, Gibson A, et al. The EPIcure study: growth and associated problems in children born at 25 weeks of gestational age or less. *Archives of Disease in Childhood Fetal and Neonatal Edition*. 2003; 88(6):F492–500. [PubMed: 14602697]
6. Hawdon JM, Beauregard N, Slattery J, et al. Identification of neonates at risk of developing feeding problems in infancy. *Developmental Medicine & Child Neurology*. 2000; 42:235–239. [PubMed: 10795561]
7. McGrath J, Braescu A. State of the science: Feeding readiness in the preterm infant. *Journal of Perinatal and Neonatal Nursing*. 2004; 18:353–368. [PubMed: 15646306]
8. Thoyre S. Developmental transition from gavage to oral feeding in the preterm infant. *Annual Review of Nursing Research*. 2004; 21:61–92.
9. Chatoor I. Feeding disorders in infants and toddlers: diagnosis and treatment. *Child and Adolescent Psychiatric Clinics*. 2002; 11:163–183.
10. Burklow K, McGrath A, Kaul A. Management and prevention of feeding problems in young children with prematurity and very low birth weight. *Infants & Young Children*. 2002; 14(4):19–30.
11. Rider, E.; Bithoney, W. Medical assessment and management and the organization of medical services. In: Kessler, D.; Dawson, P., editors. *Failure to Thrive and Pediatric Undernutrition: A Transdisciplinary Approach*. Baltimore, MD: Brooks Publishing Company; 1999. p. 173–194.
12. Schwarz S. Feeding disorders in children with developmental disabilities. *Infants & Young Children*. 2003; 16(4):317–330.
13. Allen M. Preterm outcomes research: a critical component of neonatal intensive care. *Mental Retardation and Developmental Disabilities Research Reviews*. 2002; 8:221–233. [PubMed: 12454898]
14. Hack M, Cartar L, Schluchter M, et al. Self-perceived health, functioning and well-being of very low birth weight infants at age 20 years. *Journal of Pediatrics*. 2007; 151(6):635–641. [PubMed: 18035144]
15. Martin JA, Hamilton BE, Ventura SJ, et al. Births: final data for 2009. *National Vital Statistics Reports*. 2011; 60(1):1–72. [PubMed: 22670489]
16. Schmid G, Schreier A, Meyer R, et al. Predictors of crying, feeding and sleeping problems: a prospective study. *Child: Care, Health and Development*. 2011; 37(4):493–502.
17. Hawdon JM, Beauregard N, Slattery J, et al. Identification of neonates at risk of developing feeding problems in infancy. *Developmental Medicine & Child Neurology*. 2000; 42:235–239. [PubMed: 10795561]

18. Ostberg M, Hagelin E. Feeding and sleeping problems in infancy – a follow-up at early school age. *Child: Care, Health and Development*. 2010; 37(1):11–25.
19. Samara M, Johnson S, Lamberts K, et al. Eating problems at age 6 years in a whole population sample of extremely preterm children. *Developmental Medicine & Child Neurology*. 2010; 52(2):e16–e22. [PubMed: 19832883]
20. Pridham K, Steward D, Thoyre S, et al. Feeding skill performance in premature infants during the first year. *Early Human Development*. 2006; 14:293–305. [PubMed: 16916589]
21. Ross ES, Krebs N, Shroyer AL, et al. Early growth faltering in healthy term infants predicts longitudinal growth. *Early Human Development*. 2009; 85:583–588. [PubMed: 19608359]
22. Jackson K, Schollin J, Bodin L, et al. Utilization of healthcare by very-low birthweight infants during their first year of life. *Acta Paediatrica*. 2001; 90(2):213–217. [PubMed: 11236053]
23. Escobar GJ, Greene JD, Hulac P, et al. Rehospitalisation after birth hospitalisation: patterns among infants of all gestations. *Archives of Disease in Childhood*. 2005; 90:125–131. [PubMed: 15665162]
24. Escobar G, Joffe S, Gardner M, et al. Rehospitalization in the first two weeks after discharge from the neonatal intensive care unit. *Pediatrics*. 1999; 104:9.
25. Martens P, Derksen S, Gupta S. Predictors of hospital readmission of Manitoba newborns within six weeks postbirth discharge: a population-based study. *Pediatrics*. 2004; 114:708–713. [PubMed: 15342843]
26. DeMauro SB, Patel PR, Medoff-Cooper B, et al. Postdischarge feeding patterns in early- and late-preterm infants. *Clinical Pediatrics*. 2011; 50(20):957–962. [PubMed: 21856965]
27. Sandelowski M. Whatever happened to qualitative description? *Research in Nursing and Health*. 2000; 23:334–340. [PubMed: 10940958]
28. Sandelowski M. What's in a name? Qualitative description revisited. *Research in Nursing and Health*. 2010; 23:77–84. [PubMed: 20014004]
29. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qualitative Health Research*. 2005; 15:1277–1288. [PubMed: 16204405]
30. NVivo 7. Doncaster, Victoria, Australia: QSR International; 2006.
31. Bakewell-Sachs S, Gennaro S. Parenting the post-NICU premature infant. *MCN*. 2004; 29(6):398–403.
32. Committee on Fetus and Newborn Hospital discharge of the high-risk neonate. *Pediatrics*. 2008; 122:1119–1126. [PubMed: 18977994]
33. Griffin T, Abraham M. Transition to home from the newborn intensive care unit: Applying the principles of family-centered care to the discharge process. *Journal of Perinatal and Neonatal Nursing*. 2006; 20(3):243–249. [PubMed: 16915057]