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“It’s a Long-Term Process”: Description of Daily Family Life When a Child Has a Feeding Disorder

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Abstract

Pediatric feeding problems occur in 25% of the general pediatric population and up to 80% of those who have developmental delays. When feeding problems place the child at nutritional risk, families are typically encouraged to increase their child’s intake. Family mealtime can become a battle, which further reinforces problematic feeding behaviors from the child and intensifies well-intentioned but unguided parental mealtime efforts. Family has an essential influence on feeding; however, studies to date neglect to address the family context of feeding difficulty. In this study we describe, in the context of everyday life, family management of feeding when a child had a significant feeding problem. Parents of children with feeding problems were interviewed with the Family Management Style Framework components as a guide. Twelve parents participated, representing nine families of children with feeding disorder. Description of family management of feeding provides a foundation for development of family feeding interventions.

Keywords

Failure to thrive; family management; feeding problem

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INTRODUCTION

Pediatric feeding problems occur when an infant or young child cannot, or will not, eat enough (Kedesdy & Budd, 1998; Kerwin, 1999). Feeding problems early in life are linked to developmental impairments, malnutrition, and poor growth. Because children with feeding problems often have multiple comorbidities (Sharp, Jaquess, Morton, & Herzinger, 2010), it is critically important that their nutritional status support optimal neurodevelopment. Because restricted diet is a major attribute of pediatric feeding problems (Estrem, Pados, Park, Knafl, & Thoyre, 2017), optimal nutrition is a major challenge for this group of children.

Critical first behaviors during infancy indicate hunger and fullness to the caregiver and guide the caregiver's approach to feeding (Arvedson & Brodsky, 2002). However, research has shown that some children (e.g., those with autism spectrum disorder and failure-to-thrive [FTT]) may not be able to show cues of hunger or fullness (Keen, 2008). Therefore, when feeding problems exist, the roles of both the child and caregivers are altered. Families are thought to share common responses to management of feeding a child with feeding problems regardless of the child's particular background conditions (Mason, Harris, & Blissett, 2005; Sharp et al., 2010; Williams, Field, & Seiverling, 2010). Treatment for feeding disorder is often reactive and quantity driven rather than proactive and family centered (Mason et al., 2005; Williams et al., 2010). Child development is transactional, and feeding is a dynamic process (Thoyre et al., 2014; Humphry & Wakeford, 2008). There is a reciprocal relationship between feeding disorder and both child and family outcomes (Berlin, Davies, Lobato, & Silverman, 2009). Development of feeding behaviors and skills is dependent both on functioning of the child's body and the body's ability to manage various types and quantities of food and on the reciprocal and dynamic family environment, which provides both food and feedback during the meals. Nonetheless, family-centered research of feeding a child with feeding problems has been neglected. Because most child feeding occurs in the family setting, it is essential that we understand how families approach feeding when their child has significant feeding problems.

This study aimed to describe parent perspectives of their child's eating and of feeding management and to identify themes of feeding management in the context of everyday family life. Full description of family feeding management and perceptions of the child diagnosed with feeding problems will provide a foundation for developing family interventions.

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FAMILY MANAGEMENT STYLE FRAMEWORK

This study was guided by the Family Management Style Framework (FMSF; Knafl & Deatrick, 2003; Knafl, Deatrick, & Havill, 2012). The FMSF was developed to explore family management of childhood chronic conditions; it originated with conceptual work on family normalization of childhood chronic illness (Knafl & Deatrick, 2006) and research to identify patterns of family management (Knafl, Breitmayer, Gallo, & Zoeller, 1996). Within

the FMSF, individuals in the family contribute to developing a family management style or pattern, which can influence both individual and family outcomes. Major components of the framework (contextual influences, definition of the situation, management approach, and perceived consequences) were subsequently validated and refined (Knafl & Deatrick, 2003; Knafl, Deatrick, & Havill, 2012). The FMSF was the conceptual basis for the Family Management Measure (FaMM; Knafl & Deatrick, 2006; Knafl et al., 2011). The current study used the six scales from the FaMM to conceptualize family management.

METHODS

Design

This descriptive study used directed content analysis of interview transcripts for a within-and-across family case analysis. Parents completed a semistructured interview and a demographic form. We used *family* as the unit of analysis; this provided understanding of the particulars and exploration of what is common between families as they adapt and seek sustainable family feeding practices (Weisner, 2002). To refine the interview guide, we piloted it with three families.

Setting and Sample

The primary study recruitment setting was a Southeastern U.S. regional medical center children's specialty clinic; additional recruitment came via a flyer sent to local early intervention providers and via parent-to-parent word of mouth. English-speaking parents (aged at least 18 years) of children between the ages of 6 months and 5 years receiving professional care for feeding disorder were recruited. Feeding problems were deemed significant if the child was in specialty feeding care and parents self-identified as having a child with a feeding problem (i.e., child had inappropriate mealtime behaviors and selective or restrictive intake). The minimum 6-month child age is a time of developmental change in eating, when an infant is typically expected to transition in part to solid foods (Clayton, Li, Perrine, & Scanlon, 2013) and when feeding problems often become clinically apparent (Aldridge, Dovey, Martin, & Meyer, 2010; Williams et al., 2010). Inclusion up to age 5 years captured most clinically significant feeding problems (Aldridge et al., 2010).

Recruitment had a goal of providing a thick description of feeding views and approaches (Miles & Huberman, 1994; Patton, 2002). Although recruitment sought to include both mother and father figures, a higher rate of participation from mothers was expected (Sullivan-Bolyai et al., 2007). Families were defined as one adult or two partnered adults in a parental role who live in the same household with the child. Single and partnered parents were recruited for maximum variation sampling on family structure (Patton, 2002).

Measures

Data were collected from semistructured interviews with individual parents. One parent from each family completed a demographic family information form. The semistructured, open-ended interview guide was based on six FaMM scales (Knafl et al., 2011), which are grounded in the FMSF. These included questions about the child's daily life related to eating and mealtime, family's feeding management ability, family's feeding management effort,

family life difficulty due to the feeding problem, view of the feeding problem impact, and parent mutuality on management of feeding. Parents were encouraged to elaborate on their feeding experiences and introduce topics as needed.

Procedures

Institutional review board approval was obtained. Parents were informed before the time of the interview that the goal of the study is to learn from them what it is like to manage their child's feeding on a day-to-day basis. Interviews were conducted either at the family's home or over the telephone.

Analysis

All interviews were recorded and transcribed verbatim and checked for accuracy against the taped interview by the first author or a research assistant. All transcripts were coded by the first and second coder using a start list of codes reflecting the FaMM scales and then supplemented with codes derived from the interview data. The start list of codes and definitions are in the Table.

The first two interviews coded by each coder were reviewed by a second coder. Discrepancies in coding were resolved with discussion and consensus. Atlas.ti 7 data analysis software (Scientific Software Development GmbH, Berlin, Germany) was used to access and systematically organize the coded data. Analysis entailed inspection of all data related to a single code or subset of codes and was based on the principles of constant comparison (Miles & Huberman, 1994; Sandelowski, 2011b). The analysis of interview data then focused on developing a thematic summary of each parent's interview (Ayres, Kavanaugh, & Knafl, 2003; Sandelowski, 2011a). To balance the inherently reductionist nature of coding, the second analytic strategy was to complete narrative family case profiles to provide a contextual description of family management experience (Ayres, Kavanaugh, & Knafl, 2003; Knafl & Deatrick, 2003). Next, comparisons were made across all families' thematic summaries. The last analytic step entailed comparison across family profiles to look for varying themes of family management.

RESULTS

The participants were 12 parents (nine mothers and three fathers) representing nine families of children who were receiving outpatient therapy for feeding problems. The children's ages at the time of the parent interview ranged from 14 months to 4.5 years (mean = 2.3 years). All nine of the young children were reliant on oral intake for nutrition at the time of the interview, although two had previously had gastrostomy tubes that were removed before the study. Although these two children had their feeding tubes removed, they were still receiving professional treatment for feeding. Tube removal meant that they were able to maintain nutrition and hydration orally but did not mean the child ate as their typically developing peers did.

To preserve anonymity, further details for the sample will be presented in aggregate rather than by case. One child had feeding delay as a single issue and was otherwise typically developing and healthy. The other eight children had multiple diagnoses along with their

feeding problem; these included conditions of gastrointestinal function (reflux, constipation, poor motility, delayed gastric emptying), dysphagia, colic, food allergy, and other conditions (autism spectrum disorder, hemiplegia, Fragile $\times$ syndrome, William syndrome, vision impairment, and unspecified developmental delay). Three of the nine children were born prematurely. Three of the younger children were in the process of being tested for conditions to explain their trouble with feeding. Parents of six children first noticed a feeding problem in the newborn period, and the other three children had first issues at the transition to solids from breastfeeding or bottle-feeding. When parents first noticed their infant had a feeding problem in the newborn period, they also reported spending months to years seeking confirmation of the problem and specialized feeding help. One child and family in this study had been to an out-of-state intensive feeding treatment program. Another family was slated to attend an intensive program. Two were scheduled to receive gastric feeding tubes within the next month.

Annual household incomes ranged from the range of \$20,000–\$29,000 to greater than \$100,000. Children were identified as White ($n = 5$), Black/White ($n = 1$), Hispanic/White ($n = 2$), and Native American/White ($n = 1$). Seven of the family structures were married ($n = 6$) or partnered ($n = 1$) parent households, and two families were single parent (mother). Child names in quotation marks have pseudonym substitutions.

Child's Daily Life and Identity as an Eater

Child's daily life and identity as an eater are the extent to which parents saw their child's everyday life as being normal despite also having a feeding problem. Regardless of when the feeding problem started, the normalcy and routine of the child's daily life was dictated largely by feeding and the exceptional requirements needed to make feeding as successful as possible.

Defined by the differences—Parents most often described their child as an eater in terms of what and how they were eating, and how that was different from what you would typically expect a same-age peer to eat. Most (six of nine) children ate infant-level textures such as purees or subsisted mostly on formula from bottles. One father of a 30-month-old child who would eat only when seated in a highchair and spoon-fed pureed food in a specific way, stated, “Feeding her right now ... like feeding a 6-month-old or a 7-month-old in that, there's purees, ... we're doing a lot of the work. You know, as far as putting it into her mouth and stuff.”

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Two children ate a combination of purees and toddler foods. A mother of one of the children eating this combination of toddler foods and purees noticed that even sitting up in a highchair was difficult for her son. “For him, it takes a lot of energy for him to do anything. And so if he's having to sit on his own, he may get tired from that and he can't eat.” Only one child in this study was eating only age-appropriate foods that required some chewing, and that was a recent accomplishment.

When describing their child as a feeder, parents would often use comparisons to other children through casual observations of children of friends, those at daycare, and siblings. These contrasts in eating with same-age peers made a child's feeding problems more apparent. The following quotation is from a mother of a 2½-year-old boy who was doing much better with eating at the time of the interview, but when her child was an infant, she could see differences in eating from her friends' children: "It started out very frustrating, I thought, [sigh] all my other friends have babies who are eating everything" Another mother's 14-month-old child had been recently diagnosed with FTT. She remarked on seeing the difference between her daughter's abilities compared with the other children at daycare.

From what I've seen at daycare ... they're much more advanced on the types of foods that they're eating. They're more advanced on how they're taking their fluids, out of cups and sippy cups.

Defined by the (un)predictability in feeding success—Three families anticipated the need for a more intensive feeding program intervention or feeding tube placement; they reported greater (un)predictability with feeding success. One mother described her child by saying, "He is so rollercoaster" that she felt she could never say when he would be successful with feeding. Two families were planning for a gastric feeding tube placement. One of these mothers saw her son as being very rigid as to when he would even possibly accept food and very unpredictable in how much he would eat at those times, often not eating all he needed.

Intertwined with other conditions—Parents of eight of the nine children saw the concurrent conditions their child has as being highly related to the feeding problem; in other words, they saw their child's feeding problem as a functional manifestation of the concurrent condition. For the mother of a child with hemiplegia, she said tearfully of her child, "... still for what is normal for a lot of kids usually is work for her. But the food part has been the hardest." It was the feeding difficulties that they experienced that continued to be something they had to manage several times per day.

Feeding Management Ability

Parental perceptions of their ability to manage their child's feeding were discussed in terms of strengths and weaknesses. Main themes were parents knowing their child, knowing their own strengths, and knowing their partner's strengths.

Knowing their child—Several parents, when asked what they felt they managed well with feeding, said they felt able to watch for and recognize hunger cues from their child, or cues of fullness, or of impending refusal. These parents believed that the knowledge they had developed of how their child responded to foods and feeding schedules was a strength that helped them manage: "I've come to know what's, what he does.... I know what limit I can push him to.... And so I will, just to get the food in him." Knowing which seating and supports work for their child to eat at mealtime was important to seven families. Eight parents believed they knew which foods their child liked, and this would often be a food that did not need to be chewed, and/or easily melted once chewed minimally.

He won't eat anything green, he won't even try it. It could be a green cookie. He, if it's green, I'm not going to touch it [Laugh]. He used to eat the peas out of the jar, he loved them. Now, you can mash them up, you can do whatever, he's not gonna touch those peas.

When a food that a child had accepted previously was later was refused by the child, it was disconcerting to parents. For the children in this sample, this was usually because the number of accepted and preferred foods was already limited.

Parents knowing their own strengths and partner's strengths—There was a recurring theme of parents identifying their own strengths and abilities in feeding management. Also, partnered parents often identified strengths their partner brought to feeding management.

One mother believed that she was very able to be consistent and give breaks (take extra time) with her daughter when feeding. Some parents felt less able to push to advance to new foods or more complex food textures. Four parents cited following directions and advice from feeding care providers, and two of these also felt confident in their ability to modify those recommendations to do what worked best for their child and family. One mother believed that she was very able to track what was eaten and then to calculate what her child needed calorically. Although she felt unable to get all those needed calories into her child, she believed that tracking it would show others that she was trying.

Nearly half of the partnered parents who felt less able to advance foods or textures mentioned that this was a strength that their partner had. Also, one mother in particular praised her husband's skills at keeping detailed charts and graphs for tracking their daughter's intake and growth.

Finding the easy way and identifying the "harder stuff"—Families reported working toward adaptation of a routine in management of feeding their child. They felt less able to manage when a routine could not be established or if established routines were disrupted in some way. One family had a highly skilled nanny who fed their child multiple meals every day. They believed that daycare personnel would not have the skills or time to complete their child's feedings successfully (their daughter had been at a daycare when an infant, but children were expected to be able to self-feed when moved to toddler-age rooms), so when the nanny needed time off, the parent stayed home from work for a week instead of having to spend days training someone else to feed her.

The parents of the young girl who had already been to an intensive feeding program identified the protocol they learned for feeding at the program as being the easy, established way of feeding their daughter, and said this regarding moving ahead while at home:

I guess that it is still hard to make yourself do the hard things. It's great that we know how to put the food in her mouth, but working on the lateral placement, trying to make her eat crumbs three times a day, it's ... it is stressful because it's new and, that's the hard part ... is us finding the discipline to do the hard stuff, not just stay with the easy reliable stuff.

This shows how even after a child's feeding tube is removed, and after intensive feeding program treatment, the child still had a significant feeding problem to manage. Overall feeding (often of pureed table foods) may be more successful and the child more healthy, but feeding challenges still exist with food type, variety, texture, and self-feeding.

Feeding Management Effort

Feeding management effort was the time and work parents perceived themselves devoting to management of their child's feeding. Management efforts of feeding by parents were extraordinary and often extremely time consuming. If parents were not feeding or preparing foods, they were often thinking of feeding or how to manage and coordinate the best possible care for their child. Themes for feeding management effort were mealtime efforts, food preparation, efforts to seek extraordinary help, and care coordination.

Mealtime efforts—Feeding could take a long time for some of the children, upward of 45 minutes per meal for two of the children. Part of this was because the act of feeding had become a struggle, either working to have the child accept the first bite or working to keep the child eating until he/she had eaten enough.

Food preparation effort—Food preparation was time consuming for many parents, especially those whose child ate pureed foods (six of nine families). One mother started out making her child's purees but had to stop because it was too time consuming. Encouraging the child to try different foods to increase variety or texture was frequently challenging and was sometimes a "battle."

Efforts to seek extraordinary help—One family had already gone to an out-of-state intensive feeding program for their child and lived there for 6 weeks. Another family was planning to attend an intensive feeding program in the near future. In these programs, parents will typically feed their child a meal to show what feeding has been like at home, and then parents observe therapists feeding their child for a time. Gradually, over the weeks of the program, parents are taught how to feed their child in a way that is more successful. Intensive programs do this for three to five meals a day, 4 or 5 days a week. The two single-parent families would not be able to access such a program without negotiating time off from work.

Care coordination—Coordination of care, appointments, referrals, and other such activities required substantial parental effort. The mother of the oldest child in the study reflected on the time she had spent over the years coordinating care:

The hard part, frankly, was that we were the coordinators.... We were the synthesizers of the information, and I still think that's the hard part of being a special needs parent.... You have to understand what the specialists do, and how they overlap, or how they don't ... and then fill in the blanks.

Another mother was newer to the responsibilities of care coordination and related many of the efforts and mental energy she spent on her daughter's care as a single parent.

Since she got the diagnosis of FTT I'm always thinking about some aspect of her.... This week I had doctors' appointments, feeding therapy, physical therapy, and a genetics consult ... last week it was being on the phone for hours trying to figure out if [special formula] was going to be covered by the medical insurance.

Eight of the nine children had mothers who said they thought about managing feeding for their child all the time. The mother of a 23-month-old child said, "All day long I think about, what is he going to eat today? How much has he eaten today? Is it enough?"

Family Life Difficulty

Family life difficulties in the setting of pediatric feeding problems are the extent to which parents viewed the child's feeding problems as making family life a challenge. Family life difficulties in this sample were based in the limitations of feeding success when outside the home environment, followed by family life being made difficult by concurrent feeding and sleep problems.

Feeding was not flexible—Eight of the nine families could not feed as successfully outside the home. This made day-to-day family activities outside the home a challenge families would either adapt to or avoid all together. Limited portability of feeding affected family life by making parents unable to travel, either with or without the child. Outings and errands were planned around mealtimes because feeding outside the home environment was not an option.

I feel like maybe other moms will go out for longer periods of time, you know with their kids? But because of the way Ava eats, I really try to be home, whenever we're feeding.... In order to get the best results with her eating, she needs to be in her home environment.

Five of nine families could not eat out at restaurants with their child. Four other families were able to go out but said they must be planful if they tried and approach the situation with adjusted expectations. These adjusted expectations included bringing alternative foods for the child or not expecting the child to eat at all. Others would go only to a restaurant with menu items and seating options their child had handled well before. This same planful approach applied for eating at family gatherings for holidays or for birthday parties. Menus were carefully selected, or children were not expected to eat what everyone else ate, if they ate at all.

Most of the children were also very limited in who could feed them. The mother of a young girl who had previously had a feeding tube said, "We are still tethered to our child four times a day." This was because there were only a handful of people who were trained to feed their daughter, and meals had to be successful to maintain nutrition by mouth.

Not sleeping, not eating—For a few, poor sleep made nighttime difficult on top of challenging daytimes with slow feeding or dealing with food refusal. One third of the children's parents reported enduring a time where there was never a respite: they struggled with limited rest at night and problematic feeding during the day.

His feeding problems have just been awful. You know, the whole taking an hour to get him to drink just an ounce. And on top of that, the screaming.... Especially when doing your best is like, takes everything you've got, and leaves nothing for yourself, or anybody else.

These three children with concurrent sleep and feeding problems were also receiving treatment (medication) for reflux, and two had colic. Some of the same symptoms that were making feeding unpleasant for the child may have been disrupting their sleep.

Feeding Management Impact

Although specifics of management are varied for each family and parent, having a child with feeding problems changed the way they lived their day-to-day lives; they related that it had changed them as a parent and as a family. All parents related that their child's feeding problems brought unexpected and undesirable changes. Five parents also mentioned a "silver lining" of the feeding challenges their child had as bringing them closer together.

Parents noticed that their struggles with managing the feeding situation were not typical compared with other families with infants and young children. They often felt isolated and anxious: "... because I am just SO weighed down with the anxiety an' the, I just, I feel kind of defeated." Three of the mothers specifically stated that the interview had been the first opportunity for them to discuss their child's feeding problems in detail with anyone. Also, the requirements of feeding management and other closely related conditions made adaptations necessary to create a new way to be a family.

I never thought that I would be a stay-at-home mom, ever. I got a [graduate degree] for a reason, you know? Um, whatever work that I do, whether it's paid or not paid, at home or otherwise, I think it's just important to take pride in what you do. And this right now, I don't get paid, but this is my job. And I want to be serious about it ... I want to pay attention.... He is the most important thing. And his doing well is everything to me.

Projecting what the impact would be in the future for their family was sometimes difficult. One father described how he believed that a wider view was needed to appreciate overall progress: "... It's a long-term process. You have to be patient.... Every new day comes with its own opportunities." He described how their challenge of managing feeding care for their child (for nearly 5 years), while unexpected, kept their family very close. Other families were newer to the process and related living with great uncertainty. Although they were hopeful for the future, it was often difficult to imagine what family life could be like.

Parent Mutuality

Ten of the 12 parents in this study were either married or partnered. These 10 parents were also interviewed about parent mutuality, or the degree to which they had shared or discrepant views of the feeding situation. For 9 of 10 partnered parents, short- and long-term goals were the same for their child's feeding. Most just wanted their child to eat more, gain or maintain weight, or advance in textures, variety, and self-feeding. The couple with the most discrepant views on approach to management was still very mutual about goals: "Yes, the end game's the same ... weight gain is in post-position here!"

Although goals were often the same for feeding, parents reported having different approaches and philosophies for management of mealtime and the feeding situation than their partner. For the couple with greater discrepancy in their feeding management strategies, they still appreciated this difference in opinions as being complimentary in working toward their mutual goal of weight gain and health for their daughter.

DISCUSSION

For most of the parents in this study, the feeding problems their children had were evident first to them. Then, parents spent a great deal of time seeking medical confirmation that the feeding situation was atypical. Overall, the parents in this study described how they developed feeding management strategies for their children as consumers of feeding care in a field with scarce options. Feeding care was largely piecemeal and reactive rather than proactive, and there was a lack of coordination for most families. Parents defined their child as an eater by how and what the child was eating and how this was different from their typically developing peers. Parents saw this as making their family different, and most felt homebound by the specific adaptations required to make feeding successful. The stigma of having a child who does not eat as their typically developing peers do can contribute to this homebound situation but also reinforces the current lack of awareness by laypersons and primary care providers alike. Also, for the two single-parent families, being sole provider for the child unable to eat at daycare was a strain.

As providers for young children and their families, we can extend and promote care that families have found helpful. Besides having the opportunity to tell their stories in these interviews, parents stated that they participated because they wanted to improve care for children with feeding problems and their families. Distressed by a lack of awareness of the problem, they did not want other families to experience the same struggles.

This study illustrates needs identified by the families of children in care for feeding problems. Opportunities for improvement shown in this study were related to guidance on feeding when there is a significant feeding problem and to communication within the family. Parents of children with feeding problems sensed a lack of care coordination, and this added to the time and effort they had to expend to manage feeding care within the larger reality of care management for a child with multiple conditions. A family coordinator could link between early intervention and medical providers, partner with families, and help them set goals that are meaningful to the family to optimize day-to-day feeding.

Parents described how they were on an uncharted path to find a cause and remedy for their child's feeding disorder, and they felt alone.

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References

- Aldridge VK, Dovey TM, Martin CI, Meyer C. Identifying clinically relevant feeding problems and disorders. *Journal of Child Health Care*. 2010; 14:261–270. [PubMed: 20534637]
- Arvedson, JC., Brodsky, L. *Pediatric swallowing and feeding: Assessment and management*. 2. Albany, NY: Thompson Delmar Learning; 2002.
- Ayres L, Kavanaugh K, Knafl KA. Within-case and across-case approaches to qualitative data analysis. *Qualitative Health Research*. 2003; 13:871–883. [PubMed: 12891720]
- Berlin KS, Davies WH, Lobato DJ, Silverman AH. A biopsychosocial model of normative and problematic pediatric feeding. *Children's Health Care*. 2009; 38:263–282.
- Clayton HB, Li R, Perrine CG, Scanlon KS. Prevalence and reasons for introducing infants early to solid foods: Variations by milk feeding type. *Pediatrics*. 2013; 131:e1108–e1114. [PubMed: 23530169]
- Estrem HH, Pados BF, Park J, Knafl KA, Thoyre SM. Feeding problems in infancy and early childhood: Evolutionary concept analysis. *Journal of Advanced Nursing*. 2017; 73:56–70. [PubMed: 27601073]
- Humphry R, Wakeford L. Development of everyday activities: A model for occupation-centered therapy. *Infants & Young Children*. 2008; 21:230–240.
- Kedesdy, J., Budd, K. *Childhood feeding disorders: Biobehavioral assessment and intervention*. Baltimore, MD: Paul H. Brookes Publishing Co; 1998.
- Keen DV. Childhood autism, feeding problems and failure to thrive in early infancy: Seven case studies. *European Child and Adolescent Psychiatry*. 2008; 17:209–216. [PubMed: 17876499]
- Kerwin ME. Empirically supported treatments in pediatric psychology: Severe feeding problems. *Journal of Pediatric Psychology*. 1999; 24:193–214. [PubMed: 10379133]
- Knafl K, Breitmayer B, Gallo A, Zoeller L. Family response to childhood chronic illness: Description of management styles. *Journal of Pediatric Nursing*. 1996; 11:315–326. [PubMed: 8908900]
- Knafl K, Deatrick J. Further refinement of the family management style framework. *Journal of Family Nursing*. 2003; 9:232–256.
- Knafl KA, Deatrick JA. Family management style and the challenge of moving from conceptualization to measurement. *Journal of Pediatric Oncology Nursing*. 2006; 23:12–18. [PubMed: 16689399]
- Knafl K, Deatrick JA, Gallo A, Dixon J, Grey M, Knafl G, O'Malley J. Assessment of the psychometric properties of the Family Management Measure. *Journal of Pediatric Psychology*. 2011; 36:494–505. [PubMed: 19451173]
- Knafl KA, Deatrick JA, Havill NL. Continued development of the Family Management Style Framework. *Journal of Family Nursing*. 2012; 18:11–34. [PubMed: 22223495]
- Mason SJ, Harris G, Blissett J. Tube feeding in infancy: Implications for the development of normal eating and drinking skills. *Dysphagia*. 2005; 20:46–61. [PubMed: 15886967]
- Miles, M., Huberman, M. *Qualitative data analysis: An expanded sourcebook*. 2. Thousand Oaks, CA: Sage Publications, Inc; 1994.
- Patton, MQ. *Qualitative research and evaluation methods*. 3. Thousand Oaks, CA: Sage Publications, Inc; 2002.
- Sandelowski M. "Casing" the research case study. *Research in Nursing and Health*. 2011a; 34:153–159. [PubMed: 21381044]
- Sandelowski M. Parallelism in constant comparison analysis. *Research in Nursing and Health*. 2011b; 34:433–434. [PubMed: 22045436]
- Sharp W, Jaquess D, Morton J, Herzinger C. Pediatric feeding disorders: A quantitative synthesis of treatment outcomes. *Clinical Child and Family Psychology Review*. 2010; 13:348–365. [PubMed: 20844951]
- Sullivan-Bolyai S, Bova C, Deatrick JA, Knafl K, Grey M, Leung K, Trudeau A. Barriers and strategies for recruiting study participants in clinical settings. *Western Journal of Nursing Research*. 2007; 29:486–500. [PubMed: 17538128]

- Thoyre SM, Pados BF, Park J, Estrem H, Hodges EA, McComish C, Murdoch K. Development and content validation of the Pediatric Eating Assessment Tool (Pedi-EAT). *American Journal of Speech-language Pathology*. 2014; 23:46–59. [PubMed: 24097795]
- Weisner TS. Ecocultural understanding of children's developmental pathways. *Human Development*. 2002; 45:275–281.
- Williams K, Field D, Seiverling L. Food refusal in children: A review of the literature. *Research in Developmental Disabilities*. 2010; 31:625–633. [PubMed: 20153948]

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TABLE

Start list of code categories from FaMM with example interview questions

FaMM scale	Definition	Example question
Child's Daily Life/Child Identity	The extent to which parents view their child's everyday life as normal despite the feeding problems	How would you describe your child's day in comparison to other children his [or her] age?
Feeding Management Ability	Parental perceptions of their ability to manage their child's feeding	Tell me about some of the aspects of feeding you think you manage well.
Feeding Management Effort	The time and work parents perceive they devote to management of their child's feeding problems	If you could hire someone to take care of managing your child's day-to-day feeding needs, how many hours per week would they work?
Family Life Difficulty	The extent to which parents view their child's feeding problems as making life difficult	How does feeding your child fit into family life?
View of Condition Impact	Parental perception of the seriousness of the child's feeding problems and its future implications for the child and family	How would you describe the impact of feeding your child on day-to-day family life?
Parent Mutuality	For partnered parents; the extent to which parents have shared or discrepant views of the feeding situation and approach to management	How much would you say you and your partner have in common with how you think about your child's feeding problems?

Note. FaMM, Family Management Measure.

Sources: Knafl et al. (2011).