

PEDIATRIC FEEDING PROBLEMS: CONCEPT ANALYSIS AND FAMILY MANAGEMENT

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ABSTRACT

Hayley Henrikson Estrem: Pediatric Feeding Problems: Concept Analysis and Family Management
(Under the direction of Suzanne M. Thoyre)

Background: 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. As pressures to eat increase, children's aversive behaviors can worsen, extending the time of under nutrition, and limiting developmental potential. Family mealtime may become a battle with entrenched inappropriate mealtime behaviors. To add to the challenge this presents to healthcare and families, there is no interdisciplinary consensus on terms to describe feeding problems. Lack of common language is a barrier to effective interdisciplinary, family-centered care.

Purpose: This dissertation is comprised of three studies. Chapter 2 presents an evolutionary concept analysis of pediatric feeding problems. Chapter 3 describes family conceptualization of feeding problems. Chapter 4 is a descriptive study of family management of child feeding difficulty.

Methods: In Chapter 2 an evolutionary concept analysis was conducted with 100 post-2000 published reports representing several different disciplines of authorship and additional pre-2000 exemplar manuscripts provide historical perspective. Chapter 3 is a concept analysis of pediatric feeding problems from parental perspectives using interview data from nine families of children with feeding difficulty. Based on qualitative interview data and information about child and family, Chapter 4 presents the results of parents' reports of

their efforts to manage their child's feeding problems. A within-and-across family-case analysis was conducted.

Results: Chapter 2 illustrates divergent conceptualizations within and between disciplines. Emphasis is given to areas of consensus. Chapter 3 highlights shared and discrepant ways of writing and speaking about the problem from interviewed parents and references Chapter 2 for comparison to literature on provider perspectives. Chapter 4 describes family management of feeding problems and parental perceptions of the child, using within and across family thematic analysis.

Conclusion: A new conceptualization for feeding problems as a phenotype condition manifesting along a spectrum of severity is presented. This conceptualization lends itself to interdisciplinary collaboration and pragmatic research by defining the problem as one of function. A family nurse role is suggested for working with families of children with feeding problems.

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LIST OF ABBREVIATIONS

| | |
|--------|--|
| ASD | Autism spectrum disorder |
| APA | American Psychiatric Association |
| DD | Developmental delay or disability |
| DS | Down syndrome |
| CP | Cerebral palsy |
| CF | Cystic fibrosis |
| DNP | Doctor of Nursing Practice |
| DSM-V | Diagnostic and Statistical Manual of the Mental Disorders: 5 th Edition |
| EE | Eosinophilic Esophagitis |
| EI | Early intervention |
| FaMM | Family Management Measure |
| FMSF | Family Management Style Framework |
| FTT | Failure to thrive |
| GI | Gastrointestinal |
| GERD | Gastro esophageal reflux disease |
| G-tube | Gastric tube |
| IEP | Individualized education program |
| IFSP | Individual family service plan |
| IGUR | Intrauterine growth restriction |
| LEA | Local education agency |
| NICU | Neonatal intensive care unit |
| NOFT | Nonorganic failure to thrive |
| OFT | Organic failure to thrive |
| VLBW | Very low birth weight |

CHAPTER 1: INTRODUCTION

Background and Significance

When a child will not or cannot consume adequate nutrition orally, a feeding problem is diagnosed (Williams, Riegel, & Kerwin, 2009). Feeding problems are reported to occur in 25% of typical children and up to 80% of those with developmental delays or disabilities (Manikam & Perman, 2000). For 3-10% of children, feeding problems will be severe and persistent (Kerwin, 1999). When feeding problems result in faltering growth, the need for a surgical feeding tube may be evaluated during a trial of increased feeding efforts at home (Batchelor, 2008). Ensuring proper nutrition for a child is a basic part of the parenting role (Silverman, 2010), and in families where parents are challenged to meet this basic nutrition need, there is potential for significant distress (Greer, Gulotta, Masler, & Laud, 2008). The time between identification of a significant feeding problem and tube placement or resolution of the feeding problem, is a great challenge to family management of feeding and can have negative consequences for both child and family.

Multiple comorbidities often exist in children with feeding problems making this a heterogeneous group (Sharp, Jaquess, Morton, & Herzinger, 2010). Because this is a group with multiple comorbidities (Sharp et al., 2010) including most often the general diagnosis of developmental delay or disability, it is critically important that their nutritional status support optimal neurodevelopment. A latent class analysis shows that while patterns of comorbidities exist in children with feeding problems, the co-morbidities do nothing to indicate the severity of the feeding problem and relate only a non-specific risk (Berlin, Lobato, Pinkos, Cerezo, & LeLeiko, 2011). Children with different conditions such as autism

or Down syndrome can present with the same functional feeding problem and children with any one condition do not necessarily present with the similar feeding problems. Families, however, are thought to share common responses to management of feeding a child with feeding problems regardless of particular background conditions. The heterogeneous nature of this problem leaves both the families experiencing having a child with feeding problems and the pediatric providers who need to identify and treat this in a state of conceptual tension.

Conceptual Problem

Reviews of the literature on pediatric feeding problems and disorders repeatedly reference the lack of a shared conceptualization of feeding problems (Bryant-Waugh, 2013; Davis, Bruce, Cocjin, Mousa, & Hyman, 2010; Lukens & Silverman, 2014; Sharp et al., 2010). This makes the significance of pediatric feeding problems difficult to establish for those clinically unfamiliar with the problem. Also, among the disciplines that are involved with this phenomenon, there are divergent ideas of etiology, assessment, diagnosis, and treatment. Herein lies a significant problem for the population of infants and children experiencing feeding difficulty, because “When the attributes (definitions) that comprise the concept are not clear, the ability to communicate and categorize phenomena is severely limited.” (Rodgers & Knafl, 2000, p. 80). This makes for a conceptual problem that leaves all involved in a vulnerable and poorly recognized situation. Clinically speaking, infants and young children with significant feeding issues may go undetected or waste valuable developmental time in inappropriate or under-dosed treatment. Lack of common language is a barrier to effective communication between clinicians, researchers, and caregivers, and inhibits collaboration.

A conceptual analysis was undertaken to attempt to find common ground for interdisciplinary work on the subject. Both an evolutionary and a hybrid-type concept

analysis of pediatric feeding problems will advance the science and art of interdisciplinary treatment forward. These are not meant to be endpoints on the development of the concept, but rather steps towards developing a common language that is practical and understood by all who come into contact with children with feeding problems. This will be presented in Chapters 2 and 3.

Family Management of Feeding

Parents of children with feeding problems have reported a lack of guidance beyond being told to take their child home and get the child to eat (Thoyre & VanRiper, 2010). In six focus groups of parents with a child with Down syndrome (DS), parents reported having to make their own path for teaching their child to eat, after they learned that the standard approaches for getting children to eat did not work for their families (Thoyre & VanRiper, 2010). Batchelor (2008) noted that mothers of children who eventually enrolled in a feeding program reported being “desperate” for help. The mothers felt like failures as parents, and they said this feeling of failure was reinforced by family, friends, and some professionals, who did not understand how it was possible that their child refused to eat. For most of the parents, “Successful feeding of their child was intimately bound with their sense of themselves as competent and caring” (Batchelor, 2008, p. 385). This linkage of successful feeding to being a competent parent was also reported by Sleigh (2005) in interviews with parents of children with cerebral palsy.

Often for the child at risk for feeding tube placement, the quality of the mealtime experience is already comprised. For example, children with delayed development of eating skills can experience choking or gagging when offered foods that are more complex than they can handle; those with gastroesophageal reflux can experience pain with eating; those with chronic constipation typically have decreased appetite and limited interest in eating; and those encouraged to eat amounts or types of foods that are beyond their capacity can

learn to be averse to eating (Field, Garland, & Williams, 2003; Kerwin, 2003). While infants and young children are developing as eaters, they learn and adapt to experiences with food. If feeding has been painful or unsafe, if they associate food in their mouth with fear and discomfort, then they will be left with behavioral feeding problems even after the medical issues have been treated and safer eating modes established. Learned behaviors that once served them well in meeting their goals of pain avoidance, will become entrenched maladaptations (Burklow, McGrath, & Kaul, 2002; Patel, 2013).

When children learn that eating is undesirable, parents are in uncharted territory that requires non-intuitive management of their child's nutrition. When parents boost calories in food forms the child accepts more easily (preferred foods), the development of feeding skills and the range of foods the child receives may be restricted. Management strategies can result in loss of child autonomy, development of more intense avoidance behaviors incompatible with intake, and strengthening of negative mealtime associations (Batchelor, 2008). Hours spent in "battleground" or difficult mealtimes impact the functioning of the whole family, yet parents of children with significant feeding problems have not yet been asked what would help or hinder their attempts at making feeding their child a more easily manageable, and therefore sustainable, family activity (Spalding & McKeever, 1998; Weisner, 2002).

As stated above, parents presented with the possibility of feeding tube placement may feel that they have failed at parenting on a very basic level. Specific clinical guidelines for helping a parent feed a child with feeding problems are limited. While some children will receive specialized feeding therapy, the majority of feedings will continue to occur at home, or within the family setting. A common prescription is to encourage parents to be more "aggressive" in feeding their undernourished child while the need for the feeding tube is established (Axelrod, Kazmerski, & Iyer, 2006). Because families are often resistant to tube placement (Cook, Hooper, Nasser, & Larsen, 2005; Spalding & McKeever, 1998), and

therefore try hard to avoid it, parents will often change or intensify their style of feeding management during this time. Using a limited skill set, and with no clear roadmap of how to successfully feed a child with feeding problems (Thoyre & VanRiper, 2010), the literature reports that parents spend excessive time in “mealtime” trying to achieve adequate intake (Spalding & McKeever, 1998), and may adopt methodical or mechanical feeding styles that disregard cues from the child (Levy et al., 2009). Parents must take on the responsibility of feeding this child using the guidelines their child’s physician provides and incorporate these into family life.

Parental caregivers often have perceived enteral feeding tubes as unnatural or wrong (Pedersen, Parsons, & Dewey, 2004; Sleigh, 2005; Spalding & McKeever, 1998; Thorne, Radford, & McCormick, 1997). They reported holding out on tube placement, or trying to “get by without [the tube]” (Sleigh). Parents reported spending hours just trying to get their child to eat, or trying to avoid feeding tube acceptance (Spalding & McKeever, 1998). Children with developmental delays or other medical conditions already require some type of intervention or non-intuitive family care. The expectation that families will aggressively apply normal societal feeding practices to these children and be successful is perhaps unrealistic and unfair (Craig & Scambler, 2006; Mahant, Jovcevska, & Cohen, 2011).

Because feeding tube placement is most commonly meant to serve as a temporary means to deliver necessary nutrition with a long term goal to return to oral eating, the neglect of the family’s management of feeding risks worsening of the child’s feeding problem and setting a more difficult path to future oral eating. Recent literature supports this viewpoint and identifies the need to explore family management strategies, child feeding behaviors, and parent goals for the child’s eating before tube placement (Berlin, Davies, Lobato, & Silverman, 2009; Mason, Harris, & Blissett, 2005). Developing future interventions for families of children with feeding problems will require knowledge of family perspectives,

strategies and goals. Feeding studies to date have neglected to encompass the family embedded nature of feeding by limiting scientific inquiry to only the child or parent (Berlin et al., 2009), and rarely examining shared or discrepant views of feeding management between both parents.

Healthcare providers could partner with families at this delicate time, a time when children are being monitored closely for the consequences of feeding problems. This information would set the stage for informed prevention of the maladaptive mealtime behaviors clinicians commonly see demonstrated by both children and their parents (Sharp et al., 2010; Williams, Field, & Seiverling, 2010).

Family Management Style Framework. The study presented in Chapter 4 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, and it originated with conceptual work on family normalization of childhood chronic illness (Deatrick, Knafl, & Murphy-Moore, 1999; Knafl & Deatrick, 2006) and research to identify patterns of family management (Knafl, Breitmayer, Gallo, & Zoeller, 1996). According to the FMSF, individuals in the family contribute to developing a family management style or pattern that can influence both individual and family outcomes. The 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 et al., 2012) using integrative literature reviews.

The FMSF can be used as a lens to explore the gaps in existing knowledge about how families manage feeding problems. These gaps can be filled by asking questions about parent view of child as an eater such as: when the feeding problem started, what is their child capable of eating now, what is their child willing to eat now? If a feeding tube has been presented as a possibility, what were their initial feelings about this? How do they feel now? There is a need to know how the parent sees their own role and capabilities when managing

feeding in the context of family life: what strategies are used to feed their child day-to-day, how do they make goals for their child's eating? What elements have to be balanced or weighed against other elements in the context of family life? Do they have resources to accomplish those goals? What has been helpful, what has been detrimental? Is the feeding problem in the foreground or background on daily family life? Knowledge of parent perspectives on the future is helpful when planning intervention: what are their goals for their child's feeding, when do they anticipate their child self-feeding, if ever? What do parents think needs to happen to accomplish those goals? What is the impact of feeding the child on the rest of the family? Also important to know is the degree to which partnered parents share views on feeding management and contextual influences. The information gleaned from use of the FMSF as a lens on family feeding management will assist us in learning areas for intervention or supplementing existing intervention with family-centered care. Table 1 outlines how the FMSF components align with aspects of family management of feeding when a child had feeding difficulty.

Aims

This dissertation conducted three studies: two primary studies and a combined secondary analysis of data from the primary studies. Together, these explore and describe the issues of conceptualization and family management of pediatric feeding problems. The aims for Chapters 2 through 4 are listed below.

Chapter 2:

1. Trace the evolution of the concept of pediatric feeding problems from professional perspectives using historical exemplar manuscripts.
2. Present themes of conceptual elements (attributes, surrogate terms, related concepts, antecedents, consequences of feeding problems, and family conceptualization) within and across disciplines

3. Highlight conceptual discrepancies and areas of consensus within and across disciplines.

Chapter 3:

1. Present themes of conceptual elements (attributes, surrogate terms, related concepts, antecedents, and consequences of feeding problems) from parent perspectives
2. Highlight conceptual discrepancies and surrogate terms that characterize parents' perspectives.

Chapter 4:

1. Describe parent perspectives of their child's eating and of managing the feeding problem.
2. Identify factors parents perceive as facilitating or impeding their ability to manage the feeding problem.
3. Examine themes of management across families.

Full description of family feeding management and perceptions of the child diagnosed with feeding problems will provide a foundation for developing and testing family-centered partnerships with early intervention to preserve child interest in eating at a time when treatment would still be proactive and foster sustainable feeding practices at home.

Prepared Manuscripts

This is a three-manuscript dissertation. Chapter 1 is an introduction of the problem of pediatric feeding problems for both the concept itself, and for family management when their child has a feeding problem. Chapters 2, 3, and 4 are the three manuscripts prepared from the three studies that comprise the dissertation project. Chapter 5 is a discussion of the implications of the three studies, and directions for future research studies to continue this program of research.

Chapter 2, titled “Feeding problems in infancy and early childhood: Evolutionary concept analysis,” examines the concept of pediatric feeding problems over time and then compares the current conceptualization in the literature within and across the disciplines that treat children with feeding.

Chapter 3 is titled “Parent perspective on pediatric feeding problems” and presents a secondary analysis of parent interviews to describe how parents conceptualized their child’s feeding problem.

Chapter 4 is a descriptive study of how families manage care for their child with a feeding problem. Data from parent interviews were analyzed with the Family Management Style Framework as a guide (Knafl et al., 2012).

Table 1

FMSF Applied to Pediatric Feeding Problems

| FMSF Component | Topic of Interest |
|---|--|
| Definition of the Situation Management Approach Perceived Consequences | Parents' perceptions and interpretations of the child's feeding problems and of the child's health and feeding capabilities; Strategies used by parents to feed their child, goals they have for their child's feeding, routines and priorities for feeding; Parents' views of their abilities to balance their child's feeding and other responsibilities; Expectations of the future for the child and family when considering the child's feeding difficulty |
| Contextual Influences | Parents' perceptions of factors contributing to the ease or difficulty of feeding the child |
| Contextual Influences Definition of the Situation Management Approach Perceived Consequences | Configuration of perspectives across FMSF components; Patterns of family management |

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CHAPTER 2: FEEDING PROBLEMS IN INFANCY AND EARLY CHILDHOOD: EVOLUTIONARY CONCEPT ANALYSIS

Introduction

It is generally agreed upon that feeding problems occur when an infant or young child is physically unable to eat, or will not eat enough, despite the availability of adequate nutrition (Kedesdy & Budd, 1998). Also, inherent in the meaning of feeding problem is the implied relationship, of at the very least, a dyad of caregiver and child, for feeding to occur (Tarbell & Allaire, 2002). Feeding problems in early childhood are common, affecting approximately 25% of typically developing children and up to 80% of children with developmental disabilities (Manikam & Perman, 2000, p. 217). For about 3-10% of children, feeding problems will become clinically significant (Kerwin, 1999). Discussions of feeding problems in the literature vary in severity from phases of pickiness to complete food refusal. There is no interdisciplinary consensus on terms or conceptualization to describe the phenomenon of pediatric feeding problems. As a result, primary care providers have difficulty differentiating problematic eating from typical child development and adopt a “wait and see approach” (Patel, 2013, p. 180), which often delays identification and treatment of children with feeding problems (Bahr & Johanson, 2013). The average age of entry into specialized care for a pediatric feeding problem is 2 years, while parents often report noting a problem early in the child’s life (Rommel, De Meyer, Feenstra, & Veereman-Wauters, 2003). Early signs of feeding problems tend to pass under the radar because this issue is poorly recognized and tracked in its early stages. Reviews of the literature on pediatric feeding problems and disorders repeatedly reference the lack of a shared conceptualization of feeding problems (Bryant-Waugh, 2013; Davis, Bruce, Cocjin, Mousa, & Hyman, 2010;

Lukens & Silverman, 2014; Sharp, Jaquess, Morton, & Herzinger, 2010). The healthcare system cannot be faulted for this directly, as the concept of pediatric feeding problems has historically been fodder for disciplinary turf wars (Linscheid, 2006), and often was conflated with symptoms of abuse (Batchelor, 2008; Bray, 1989). This lack of a shared conceptualization makes the significance of pediatric feeding problems difficult to establish for those clinically unfamiliar with the problem. It is difficult to track etiology, prevalence, and incidence of a phenomena when available definitions and diagnoses lack practical utility. In a time when personalized care is realized more and more as an essential precursor to quality care, it is necessary to revisit this conceptual chaos around pediatric feeding problems, and find attributes, which could comprise an interdisciplinary conceptual model.

Since the 1990s, the variety of terms used to describe and diagnose feeding problems has grown, and the number of children and families impacted by this problem has also increased. One possible reason for the increase is that infants and children with the co-occurring conditions that contribute to risk for development of feeding problems are living longer. As medical technology has advanced, greater numbers of infants are surviving extreme prematurity and previously lethal cardiac anomalies (Field, Garland, & Williams, 2003; Rommel et al., 2003; Stephens & Vohr, 2009), and many of these children face chronic illnesses (Lefton-Greif & Arvedson, 2008). Another possible reason for increased numbers of children with feeding problems is that similar to what has occurred with autism spectrum disorders (Millon, Krueger, & Simonsen, 2011): with an increase in diagnostic plurality/range comes an increased awareness and referral for treatment (Bryant-Waugh, 2013).

As children with these chronic conditions are living longer, families are expected to care for them in the home environment. With this comes the parental responsibility to provide adequate nutrition for their child, but for many, feeding is extremely challenging (Craig, Scambler, & Spitz, 2003; Sullivan et al., 2004). Contributing to this challenge is the

fact that it can take years before families have their child's feeding problems acknowledged and then find appropriate, personalized care (Rommel et al., 2003).

Among the disciplines that are involved with this phenomenon, there are divergent ideas of etiology, assessment, diagnosis, and treatment. Herein lies a significant problem for the population of infants and children experiencing feeding difficulty, because "when the attributes (definitions) that compromise the concept are not clear, the ability to communicate and categorize phenomena is severely limited." (Rodgers & Knafl, 2000, p. 80). This makes for a conceptual problem that leaves all involved in a vulnerable and poorly recognized situation. Infants and young children with significant feeding issues may go undetected or waste valuable developmental time in inappropriate or under-dosed treatment. Lack of common language is a barrier to effective communication between clinicians, researchers, and caregivers, and inhibits collaboration (Bryant-Waugh, 2013).

The purpose of this study is to (1) examine the historical conceptualization of feeding problems (2) explore and clarify the current conceptualization of feeding problems within and across disciplines and highlight areas of consensus amenable to creation of an interdisciplinary conceptualization. In discussion, given the contextual history of the concept and its current applications in the literature, a clarification of current consensus will be presented, along with a proposed interdisciplinary model for further development.

Methods

Sample

Literature for the sample was selected as follows. A search was conducted of Google Scholar, CINAHL, PubMed, and Web of Science databases, with MeSH terms and key words including: failure to thrive, feeding disorder/difficulty/problems, infantile anorexia, oral aversion, mealtime behavior, and dysphagia. Inclusion criteria were: subject of feeding problems, index children 0-10 years of age, English language, and available in full text with

abstract. The disciplines represented by the searched literature were determined by authorship of the retained sample. Indexed literature from these disciplines represent the providers who interact with infants and young children with feeding problems in primary care, allied health, early Intervention, and specialty services.

The literature search was inductive and emergent, and conducted in October 2014. References and citations of exemplar manuscripts were also searched. Across the search engines and reference searches, over 2000 abstracts were reviewed. The reviewed abstracts were narrowed for inclusion by Estrem by scanning them and eliminating those that did not have a feeding problem focus. When abstracts did not provide enough information, the full article was reviewed.

There were 266 articles that met inclusion criteria after redundancies were eliminated. These documents were placed into Atlas.ti for sorting into disciplines of authorship, including Psychology, Medicine, Nursing, Nutrition, Occupational Therapy, Speech Language Pathology or Other. Categorization of the articles into disciplines was completed by the author and a research assistant, and was based on the following guidelines:

- If > 50% of authors were of a discipline including first author, then it was classified as that discipline.
- When there was no majority of authorship, the article was categorized as “multidisciplinary”.
- When the authorship was unclear from information in the manuscript and after researching authors by name, the manuscript was declared “unclear”.
- The “Other” category was created for disciplines with low representation.

Because this analysis aimed to describe conceptualization within and across disciplines, items with unclear authorship (n=3) were excluded from the final sample. Nutrition had low representation and was included in the “Other” category along with articles from social work.

A paradigm shift was evident early in the literature search with an expansion of terms to describe and diagnose feeding problems that occurred in the late 1990s, thus a decision was made to consider the 42 publications prior to the year 2000 as historical references on evolution of the concept. The remaining current articles, or post-2000 sample (n=224), were then further narrowed to a sample of 100 articles using the following steps. First, redundancies of viewpoints were eliminated. Manuscripts by the same first author were reduced to the one manuscript that was deemed most saturated in content on feeding problems. The final step in reaching the post-2000 sample size of 100 was guided by proportions of articles authored by disciplines (Table 2.1). For example, the 72 post-2000 articles on feeding problems in psychology comprised 32% of the total post-2000 sample of articles. Therefore 32% of the final sample of 100 articles (n=32) was selected to be from psychology. Of note, Speech-language pathology and Occupational Sciences did not “just” arrive in the literature, but, based on publications dates, were newer to research relative to other disciplines.

Evolutionary Concept Analysis

Roger’s Evolutionary concept analysis (2000) was used to evaluate the roots of the concept of pediatric feeding problem along with influencing factors that have shaped the attributes over time. The historical analysis was completed on the pre-2000 sample, selecting those exemplary items that were most often cited in subsequent works. The post-2000, current sample was systematically analyzed for conceptual attributes that collectively clarify a concept. The 100 manuscripts of the current sample were coded for the following conceptual elements outlined by Rodgers:

- Surrogate terms - exact words or phrases used for feeding problems
- Related terms - phenomena that have some but not all features of feeding problems

- Attributes - qualities of the problem
- Antecedent - events or qualities that preceded the feeding problem
- Consequences - outcomes attributable to pediatric feeding problems.

A start set of codes for each element was based on an initial working definition. A team of four coders coded the manuscripts. Another team member also coded the first five manuscripts coded by each team member. Any discrepancies in coding were discussed and consensus was reached. Attributes and antecedents were the largest categories by frequency of codes. Data analysis was facilitated by use of Atlas.ti (Berlin, Germany), a software program that supports the coding and analysis of qualitative data.

Results

Historical Conceptualization of Feeding Problems

In this section, an overview of the concept over the last century will be described, drawing from the pre-2000 sample of manuscripts. Failure to thrive was the first term introduced to describe children with feeding problems. Failure to thrive was first used by von Pfaundler of Munich in the early 20th century to describe institutionalized foundling, or orphaned, children with poor growth (Wolke, 1996). These children were government wards and received poor care giving in environments that often lacked hygiene. Dr. Rene Spitz published a report in 1945 that introduced “maternal deprivation” as the cause for failure to thrive in institutionalized infants. Unfortunately, mortality rates for infants in institutions (foundling homes, orphanages) were abysmal. Children could sometimes be saved by discharge to a foster home. Spitz studied the infants of a foundling institution and compared them to infants born into a penal institution for “delinquent” girls (Spitz, 1945). Spitz interpreted that the children of prisoners were at greater risk due to their heredity (compared to orphan children without mother contact) however they did well in spite of this because they had nurse-guided attention from their imprisoned mothers. Spitz claimed the foundling

institution infants failed to grow and thrive (develop) because they had no maternal interaction. In truth, from Spitz's own descriptions of the institutional environment for orphaned children, their situation could be interpreted as a dismal state of isolation from nearly all human interaction and/or stimulation (not just an absence of mothers, but extremely limited contact and stimulation of any kind).

Later when infants and young children failed to thrive in the home or community setting, the idea of maternal deprivation carried over (Whitten, Pettit, & Fischhoff, 1969). When it could not be proven that these children were deprived of mother interaction, the deficiency assumption became one of disordered or distorted mothering (Fischhoff, Whitten, & Pettit, 1971). Whitten and Pettit (1969) conducted a study to determine if the cause of maternal deprivation syndrome (essentially growth failure) was from psychologically borne absorption or metabolic issues, or if it was from low food intake. They found that failure to thrive/maternal deprivation syndrome was due primarily to under-eating: either from not being offered enough food or from the child not accepting food. They were also one of the first to note that low birth weight was also associated with later growth failure. However, Whitten et al. still named the phenomena maternal deprivation, stating "maternally deprived infants are underweight because of under-eating which is secondary to not being offered adequate food or not accepting it" (Whitten et al., 1969, p. 1675)

In a review of the concept of maternal deprivation, Yarrow (1961) recommended that "maternal deprivation" be used as a concept to describe the experience of loss of a mother or most significant person instead of a description of children failing to grow. However, a decade later Fischhoff et al. (1971) endorsed the conceptualization of maternal deprivation when an intervention of adequate mothering (which included food) improved a child's growth. Fischhoff et al. 's conceptualization is one of the most conflated between nutrition and mothering; to the extreme that mother seemingly equaled food. This study also reported that of the 12 infants included, 10 of the mothers had character disorders. Meals

were provided and mothers were observed feeding their children. When the children gained weight, Fischhoff and colleagues attributed this to adequate mothering.

In the late 1970s, Rutter published a review on maternal deprivation, early child-caregiver relationships, and development of psychopathy, making multiple assertions in an effort to steer the science towards examination of what made some children resilient to difficult environments and loss early in life (Rutter, 1979). He showed that attachment did not have to be with a mother for growth and development to occur, and anti-social disorders later in life were not necessarily linked to lack of a mother. According to Rutter, “maternal deprivation” was a term used to describe a “most heterogeneous range of experiences and outcomes due to quite disparate mechanisms” (Rutter, 1979, p. 283). At this time the literature begins to move away from attributing pediatric growth failure automatically to maternal deprivation. However, there are still themes of mother blame or caregiver abuse in the dichotomous conceptualization of failure to thrive that was developed in the 1970s (Bray, 1989). Specifically, failure to thrive was divided into two different types according to assumed causes for the growth failure (Cupoli, Hallock, & Barness, 1980). Organic failure to thrive (OFT) had a clear pathologic cause (such as a disorder of metabolism); while non-organic failure to thrive (NOFT) was attributed to an abnormal parent-child relationship “due to neglect, emotional disturbances, or parental ignorance” (Cupoli et al., 1980).

Chatoor and Egan (1983) introduced the diagnosis of infantile anorexia as a third type of failure to thrive. With infantile anorexia, infants refuse food to assert their own autonomy during the stage of individuation and separation from the mother. Chatoor explained that mothers of these children were often very involved and anxious, but not abusive. The mother-child attachment could be sufficient, yet the cause for the infant's under-eating was related to an emotional disorder stemming from the parent-child relationship.

In 1985, Altemeier's (Altemeier, O'Connor, Sherrod, & Vietze, 1985) team of pediatricians and psychologists studied the antecedents to NOFT in children of low-income mothers. Of 274 births, fifteen children developed NOFT and six OFT. The mothers of children with NOFT more often had some spousal conflict and history of "aberrant nurture in the mother's childhood" (Altemeier et al., 1985, p. 360). Pregnancy complications, short gestation, and minor medical problems existing at discharge from the hospital nursery were correlated with NOFT. Altemeier and colleagues interpreted these complications and medical conditions as interference with the mother-child relationship, and thus the dysfunctional mother-child relationship caused growth failure. This line of thought, with ignoring the medical history as possible organic causes of interruption in intake, was problematic because it contributed to mother blame and failed to advance understanding. Additionally, the selection of a study population of only low-income mothers was questionable; these results should not have been generalized to the wider population.

In the same year (1985), Skuse, a child psychiatrist, published a different view on NOFT, stating it was necessary to consider all the influences on an infant or young child with growth failure, and that it was a multidimensional problem. Skuse noted that "an emphasis on parental culpability in the aetiology of non-organic failure to thrive, in the absence of direct evidence of neglect, is wrong" (Skuse, 1985, p. 173). He found that mealtimes of children with NOFT were often emotionally charged and demonstrated a vicious cycle of maladaptive behaviors by both parent and child. Skuse observed that parents were more likely to try harder to feed a child or infant who was reluctant to eat because of perceived fault in the growth failure of their child. The unfortunate stigma of failure to thrive was noted by Bray, a community health nurse, (Bray, 1989) in that when a child is labeled as such, parents feel defensive and providers are set on a path to rule out neglect or abuse, wasting efforts and possibly missing medical causes.

The 1990s saw an increase in the description of the presenting behaviors of the child as the problem. Terms that entered the literature in the 1990s included: food refusal, feeding disorder, feeding problems, feeding difficulty, and mealtime behavior. These terms are indicative of a change in thinking toward more focus on what the problem looks like and less dichotomizing, less focus on maternal blame and why a child would not grow. Sanders and colleagues (Sanders, Patel, le Grice, & Shepherd, 1993) compared feeding practices of parents and behavior of young children with and without feeding problems at mealtime. Greater food refusal and disruptive mealtime behaviors were observed from the children with feeding problems. Also parents of children with feeding problems were more negative and coercive in their mealtime parent-child interactions. Sanders linked these refusal behaviors and responses of caregivers in a negative mealtime cycle of parent-child interaction. During that same decade Paul Hyman (1994) presented a subversive medical cause for infant food refusal behaviors. He theorized that food refusal was an adaptation to avoid pain caused by esophageal reflux after eating. According to Dr. Hyman, infants could have pain from acidic reflux without evidence of esophagitis or erosion. This was a unique contribution to the conceptualization of antecedents for pediatric feeding problems, that food refusal behavior could be an adaptation to underlying physiology of the infant, an observable manifestation of a symptom.

The historical conceptualization of pediatric feeding disorder was well stated by Shore and Piazza: “diagnostic confusion has prevailed in the literature” (Shore & Piazza, 1997, p. 1). While the historical conceptualization presented (Figure 2.1) is a sample of the trends and changes in this concept over time, clearly there has been great change from problem as mother deprivation for institutionalized children, to outcomes of undernutrition, to a greater understanding of the complexity of the problem.

Present Conceptualization of Feeding Problems

Each of the disciplines working to define and understand the phenomena of pediatric feeding problems has done so in ways that are reflective of their scope of practice and philosophies therein. While there has been considerable effort to describe this phenomenon as a disorder or diagnosis, emphasis has been on description of discrepant conceptualizations rather than on areas of consensus. In this section, current conceptualizations will be presented within and across disciplines with focus on areas of consensus.

Surrogate terms. Alternative, surrogate terms for feeding problems were numerous. Across the 100 manuscripts, there were 283 different surrogate terms used. Often, authors used multiple terms in the same manuscript. Table 2.2 illustrates the three most often used surrogate terms per discipline of authorship. “Feeding problem” was the term used most frequently over all. “Dysphagia” appeared in the top three only for Speech-Language Pathology and this fits with their scope of practice. “Food refusal” represents a clustering of more specific behaviors such as head turning, clamping the mouth shut, hitting the spoon, throwing the bottle, and spitting food out once it is in the mouth. “Failure to thrive” comes in third for Speech and the “Other” category. As a surrogate term, failure to thrive was used as a description of an outcome of feeding problems, often it is when a child begins to lose weight or growth falters that a feeding problem is suspected. The diagnostic classifications available to pediatric providers, although mentioned (Atzaba-Poria et al., 2010; Chatoor & Ganiban, 2003; Greer, Gulotta, Masler, & Laud, 2008; Uher & Rutter, 2012) were not the most commonly used terms within the literature (Table 2.3). In fact, most often these diagnoses were critiqued for their limited practical use given both the range of presentation of feeding problems encountered clinically, and practical application of cumbersome and often overlapping categories of feeding problem diagnoses (Levine et al., 2011; Piazza, Roane, & Kadey, 2009; Sharp et al., 2010; Williams, Riegel, & Kerwin, 2009).

In the DSM-V the APA (2013a & 2013b) has removed the previous version's "Feeding Disorders of Infancy and Early Childhood" and replaced it with a non-age restricted "Avoidant/Restrictive Food Intake Disorder", citing a lack of information on clinical characteristics and therefore an inability propose valid diagnostic criteria.

In sum, existing classification systems are inadequate with respect to the spectrum that includes many children with feeding disorders. These systems do not provide criteria that reflect the heterogeneity of potential feeding problems, do not account for the complex etiology of feeding problems, and they lack sufficient specificity in terms of operationally defining the criteria for the diagnosis. Most important, the extant classification systems are not prescriptive for treatment development. That is, these systems provide clinicians with a limited categorization of feeding disorders and offer no support for developing interventions based on the presenting problem. (Piazza et al., 2009, p. 477)

Related concepts. Related concepts to feeding problems frequently also fit into the categories of surrogate terms, antecedents, and/or consequences (depending on how the author contextualized the phrase). An example of a related concept with attribute overlap would be "tube feeding." Tube feeding itself does not share all attributes with feeding problems, but there exist some shared features. Eating behavior with enteral tube feeding will be altered significantly from what would typically be expected (Sharp, Jaquess, Bogard, & Morton, 2010). Tube feeding could be seen as an antecedent to a feeding problem, when the problem was conceptualized as feeding tube dependency (Tarbell & Allaire, 2002; Trabi, Dunitz-Scheer, Kratky, Beckenbach, & Scheer, 2010). And lastly, tube feeding could be a consequence of food refusal behaviors (Sharp et al., 2010; Williams, Field, & Seiverling, 2010).

Attributes. An extensive range of attributes of feeding problems was collected in this sample (Table 2.4). Main recurring attributes of consensus across the disciplines will be presented first, followed by areas of discrepancy. Across disciplines, several major themes were clear. Problematic or atypical child feeding behaviors will be present, and the child is likely to have some physiologic or developmental limitation on their function as an eater.

Caregivers will usually be noted to have made feeding adaptations, to be affected by the feeding problem, and the feeding relationship they share with the child may have atypical or dysfunctional features. Family function can be impacted, and overall mealtime can become a negative cycle of maladaptation and poor eating. Together, this paints a picture of a complex phenotype condition that presents along a range of severity depending on functional impact.

The overall most frequently appearing attribute across all disciplines, and ranked within the top three attributes for all, was problematic feeding behaviors displayed by the child. For Multidisciplinary and Occupational Science categories, these behavioral features, such as food refusal or selectivity, were described as key attributes of the problem in 100% of the sample. Within Psychology, problematic feeding behaviors were the most often occurring attribute and were coded within 94% of the articles. Selective or restrictive oral intakes by type, texture, or presentation, and oral hypersensitivity or aversion, were included in this category as well. Growth faltering (including failure to thrive and weight loss) was a top attribute for disciplines of Medicine, Nursing, Speech-Language Pathology, Other, Occupational Science, and Psychology, and occurred in greater than 50% of the Multidisciplinary articles. Dyadic interaction issues, or dysfunction of the caregiver-child relationship was a common attribute across all discipline categories, although it was most often appearing in the Occupational Sciences sample (83%). The most commonly noted attribute of the atypical child physiologic function impacting eating were oral-motor problems and dysphagia. This was one of the most often occurring attributes within Speech, Occupational Sciences, and Nursing, although it had a strong representation within other disciplines as well. Additional sub-themes contributing to the limitations of physiologic function of the child are attributes found to be prevalent within and across disciplines included nutritional concerns (including dietary supplementation), developmental feeding issues, gastrointestinal issues (GI), neurodevelopmental disorders or developmental

delay/disabilities, complex medical conditions or genetic syndromes, and enteral tube feeding.

Some noteworthy differences among the disciplines will now be highlighted. The theme of “range of presentation” applied when a manuscript explained a variety of presentations for pediatric feeding problems. For example, Sharp and colleagues (2010) conducted a review of treatment outcomes for feeding problem interventions. The heterogeneity of presentation was noted with feeding problems varying from selectivity by texture, type, or presentation, to disruptive mealtime behaviors, to tube feeding dependency. This theme of range of presentation was common across the majority of Occupational Science, Speech Language Pathology, and Psychology manuscripts; however, range was not common in Medicine, Multidisciplinary, or Nursing.

Attributes of caregiver coping and adaptation (includes personal impact of child’s feeding problem on parent and changes in parent behavior) related to a child’s feeding problems were supported by the entire Occupational Science sample, while the proportion was lower for all other disciplines. Eighty-three percent of the Occupational Science articles noted an attribute of caregiver feeding role adaptations during feeding. This was followed by Nursing and Speech, and Other disciplines where the attribute was noted in less than 50% of the sample. From Nursing, the mother’s “working model of feeding” is an explicit example of this attribute of feeding problems.

A working model is an internal or mental model of experience that operates in relation to events to regulate goal-directed thought and action. An example of a goal of an internal working model of parenting is giving safe and nurturing care to the very young, VLBW baby...A mother's motivations, feelings, thoughts, and feeding behaviors are functions of her internal working model. A working model is constructed and reconstructed through experience, including relationships with and the guidance of others, and response to changing need. The working model operates actively during a feeding and is likely to be in a mother’s conscious awareness whenever a challenge to feeding goals is confronted. (Pridham, Saxe, & Limbo, 2004, p. 162).

Objective views of the mother’s behavior during feeding show that she may be

perceived as anxious, controlling, inflexible, or depressed when her child has a feeding problem. Maternal mental health issues were an attribute found in 100% of the Occupational Science sample, 50% of Medicine, and 43% of Psychology. Themes of maternal or feeder insensitivity existed in a minority of the Psychology (22%) and Nursing (21%) articles. All disciplines had feeder mealtime rules, roles, or structure as an attribute of the problem; this was highest in Occupational Science (83%) and Nursing (64%), followed by Speech Language Pathology (56%). Atypical family function or impact on family function was noted most often within the Other, Occupational Science, Psychology and Speech Language Pathology samples, although it was present across all disciplinary groups to some degree.

A negative mealtime cycle as an attribute of pediatric feeding problems was found across disciplines, but most often in Psychology. This negative cycle was between the feeder and the child (Greer, 2008) and sometimes proposed within the family context. The cycle was more than just behaviors of the child or the feeder, this included the transactional development of maladaptation and food aversions with motivations for each individuals actions within the system (Figure 2.2).

Antecedents. Antecedents to feeding problems in the literature were often difficult, if not impossible, to separate from overall attributes as the two categories have much overlap. When a child is born with a condition and develops a feeding problem, this other condition often becomes a clue to the feeding problem and vice versa. Numerous conditions often co-occur with feeding problems, as seen in Table 2.5. Children with failure to thrive and inappropriate mealtime behaviors may be pre-diagnostic for an heretofore undiagnosed condition, such as Autism spectrum disorder (Keen, 2008).

Remaining antecedents to feeding problems for infants and young children can be conceptualized as being internal and external to the child. Main themes of internal antecedents, besides concurrent diagnoses, were congenital malformations of structures

related to eating, abnormal functioning or disease of structures related to eating (Arvedson, 2008; Rommel et al., 2003), abnormal sensory processes (Zangen et al., 2003), physiologic cognitive/behavioral (Schwarz, Corredor, Fisher-Medina, Cohen, & Rabinowitz, 2001), experiential, and specific past invasive procedures (Bernard-Bonnin, 2006; Jadcherla, Vijayapal, & Leuthner, 2009).

Main themes of antecedents discussed in the sample that were external to the child were parenting experience, thoughts, and beliefs (Davies et al., 2006; Motion, Northstone, & Emond, 2001), parental psychosocial health (Fishbein, Benton, & Struthers, 2014; Motion et al., 2001), mother-child interaction (Williams et al., 2009), feeding strategies (Levy et al., 2009; Lewinsohn et al., 2005), and family and environmental factors (Arvedson, 2008; Meyer et al., 2014). Also delayed access to care was mentioned as contributing to the feeding problem in a few manuscripts, although this was a low occurring antecedent mostly from studies that used family input (Kessler, 2008; Sleight, 2005; Thomlinson, 2002).

Consequences. Consequences of pediatric feeding problems are some of the most clearly agreed upon conceptual elements across disciplines. Malnutrition, undernutrition, and growth failure were common consequences (Ammaniti, Lucarelli, Cimino, D'Olimpio, & Chatoor, 2010; Burklow, McGrath, & Kaul, 2002; Pridham et al., 2004). Also delayed development of feeding skills (delayed feeding skill acquisition), and impaired global development (Arvedson, 2008; Bachmeyer et al., 2009; Bahr & Johanson, 2013). For the infant or child, health can be impacted by aspiration, increased risk for infection, malnutrition, or the feeding problem may even result in death (Berlin, Davies, Lobato, & Silverman, 2009; Brotherton & Abbott, 2012; Liou, 2013; Locklin, 2005).

Children with feeding problems may have to endure prolonged mealtimes, therapies, invasive testing and procedures (Zangen et al., 2003). Mealtime can be very unpleasant for them, frightening, and even painful (Davis et al., 2010; Kerzner, 2009). Distress in the mother-child relationship and mealtimes becoming increasingly negative (negative mealtime

cycle as shown in Figure 2.2) were common consequences that can also be conceptualized as antecedents (thus the cycle) (Bachmeyer et al., 2009; Kessler, 2008; Patel, 2013; Rommel et al., 2003).

Maternal impact and stress were present throughout disciplines as consequences of feeding problems, as were family impact and family stress. “Families heard their children labeled as failures and were told they were the cause of the problem” (Thomlinson, 2002, p. 541).

Parents may be presented with an option of feeding tube placement, or risk for death of their child (Brotherton & Abbott, 2012). With feeding tube placement comes its own host of issues with extensive impact on the child and family. For the child this includes limited or hindered mealtime social opportunities, lack of association between intake of food and satiety, and invasive surgical procedures (Byars et al., 2003; Sleight, 2005). For families and parents, impact of tube feeding includes economic impact (supply costs, work time lost by parents), perceived social stigma, loss of caregiver sleep, caregiver stress, and limited qualified caregivers for respite (Brotherton & Abbott, 2012; Craig & Scambler, 2006; Davis, Bruce, Cocjin, Mousa, & Hyman, 2010).

Some consequences were mostly limited to a particular discipline. Prolonged hospitalization, or neonatal intensive care unit time, was a factor cited within the Nursing sample (White-Traut & Norr, 2009). Within Speech and Psychology, lingering feeding problems, or inappropriate mealtime behaviors, were noted to persist and require intensive treatments after the medical antecedents for the feeding problem have been resolved (Silverman, 2010; Tarbell & Allaire, 2002)

Proposed Interdisciplinary Model for Further Development

Given the contextual history of the concept and its current applications in the literature, a clarification of current consensus will be presented in this section, along with a

proposed interdisciplinary model for further development. There is consensus that pediatric feeding problems are complex and present in heterogeneous ways. Each discipline tends to focus on certain aspects of the problem. This evolutionary concept analysis has illustrated the landscape of all of those perspectives together to look at the problem in a comprehensive way. Disagreements with the concepts related to feeding problems are likely related to the heterogeneous nature of the problem and complexity of the causes and the foci of the discipline itself. For example, Nursing literature on this subject most often considers a younger population of neonates and young infants. Unlike a toddler with the volition to refuse food, feeding behavior of the neonate is not interpreted as inappropriate. Instead, behaviors indicating distress or feeding avoidance indicate appropriate physiologic and or neurological response to the challenge of participating in feeding at that time; feeding behaviors are thereby considered functional adaptations that require interpretation as such.

When the average age of children presenting to specialty feeding clinics is greater than 2 years and they have complex medical histories with significant feeding disorders (Berlin, Lobato, Pinkos, Cerezo, & LeLeiko, 2011; Rommel et al., 2003), this problem is developing along with the child - seemingly under-the-radar of health care and early intervention. Only when it is obvious (sometimes painfully so for child and family) do they arrive at treatment (Field et al., 2003; Thomlinson, 2002). Interdisciplinary healthcare and early intervention providers can do much better for children and their families if they possess a valid, shared conceptualization of pediatric feeding problems and tools for assessment.

Autism spectrum disorder (ASD): A similar evolutionary path

It is worth noting here some similarities in conceptualization of pediatric feeding problems with the evolution of Autism spectrum disorder. “Infantile Autism” was described with a possible cause of cold, detached parents when first portrayed in a collection of 11 case studies by Kanner (1943). While Dr. Kanner speculated that children were likely born

with the described “autistic disturbances of affective contact” (Kanner, 1943, p. 217), it was his anecdotal remarks about the frigid, highly intelligent, and career driven parents who were lacking warmth that were used by Bruno Bettelheim (Bettelheim, 1967) to endorse cold, affectionless mothers as the cause for Autism. Now Autism is classified as a complex spectrum disorder with multiple known and unknown antecedents (Millon et al., 2011). A strained mother-child relationship can be a part of the presentation because these children may be less inclined to seek typical social interaction and may have delayed development of communication. Mother blame in the refrigerator mother conceptualization of Autism (a condition of complex etiology and heterogeneous presentation) was similar to the strong connotations of mother blame with maternal deprivation (Spitz, 1945) and non-organic failure to thrive (Cupoli et al., 1980). Also as with ASD (Newschaffer et al., 2007), today it is known that the etiology for pediatric feeding problems is largely unknown, but is likely to stem from a complex interaction of biological and environmental influences (Berlin et al., 2009; Berlin et al., 2011).

Autism has been reclassified as a spectrum disorder within the latest version of the DSM; this encompasses a range from classic autism as described by Kanner (Kanner, 1943, 1971), to the higher functioning individuals with Asperger’s (APA, 2013a; Millon et al., 2011). All under the umbrella of autism spectrum disorder (ASD) have two key traits common to ASDs, 1) social impairments of some degree, and 2) restricted interests. A similar classification approach could be beneficial to the conceptualization of pediatric feeding problems.

Consensus Attributes and Further Development of Concept

We have ample description of this problem from the vantage of individual clinics and providers via case study reports and experiential accounts. There is some agreement across all of these presentations of the problem as to what are essential attributes of

pediatric feeding problems. From this analysis of 100 manuscripts, main traits of pediatric feeding problems that were common across disciplinary conceptualizations were *problematic feeding behaviors* and *restrictive intake*. With these two main traits underlying all presentations of feeding problems agreed upon, other features such as developmental delay, growth faltering, and tube feeding would be possible features along the spectrum that impact feeding function. Valid measurement of these constructs along the spectrum would allow for personalized assessment and intervention.

This analysis guides what is needed for a comprehensive assessment of a child with feeding problems. Valid and reliable instruments are needed to assess some of the key attributes of feeding problems across its spectrum of presentation and then tailor intervention to the strengths and difficulties of each child and their family. These include:

1. Infant/Child feeding behaviors
2. Feeding skills/abilities
3. Development (gross, fine, oral motor)
4. Child growth
5. Diet & nutrition
6. Family function and management of feeding problem
7. Impact that the feeding problem has on the family
8. Feeding environment/strategies being used

The comprehensive trait list for assessment presented above was derived from the attributes across the disciplines represented in this concept analysis. Behavior was the number one attribute within Psychology and an all around highly supported attribute of the problem across disciplines. Restrictive or selective food type, texture, and presentation was another category with high consensus as an aspect of pediatric feeding problems, this theme of attributes was most highly supported in the Multidisciplinary, Occupational Science and Psychology samples. Parent and family factors as an attribute of the problem were

most often noted within Occupational Science, Nursing, and Speech, although they had presence within the other disciplines. Now, the science ought to move beyond to practical studies of function, behavioral assessment, and into personalized intervention effectiveness. The varying classifications and descriptions of what “is” a pediatric feeding problem, are likely a result of the complexity of the problem itself. The conceptual plurality of pediatric feeding problems could be ameliorated with a schema to be engaged with across disciplines.

Tube dependency is a conceptual attribute warranting further study. In this sample of 100 manuscripts, enteral tube feeding was sometimes a surrogate term for feeding problem, sometimes a cause of a feeding problem, and sometimes a result of a feeding problem. Research is needed to describe the transition point in which enteral feeding tube placement changes from the consequence of a feeding problem, and becomes tube dependency, an antecedent for one of the most difficult to overcome feeding problems.

Conclusion

Because pediatric feeding problems are complex and often require multi or interdisciplinary treatment, the development of multiple, divergent, and specific typological classifications of pediatric feeding problems (before creation of valid attribute measurement) have been a detriment to children, their families, and professionals alike. This analysis has revealed consensus attributes of pediatric feeding problems to be problematic feeding behaviors and restrictive or selective intake. These two features could serve as a working spectrum model for pediatric feeding problems. If an infant or child does not display problematic feeding behaviors and restrictive/selective intake, then they do not have a feeding problem. Valid measures of problematic feeding behavior are needed, along with validated measures of other feeding problem attributes that may or may not be present along the spectrum of severity. This spectrum model could allow for personalized

interventions, rather than approaches based on proprietary feeding treatments or interventions that categorize children into predetermined problem types. Parents of children with feeding problems are important to engage in assessment and treatment for the child, not because they were the cause of the problem, but because they are the proximal agents for change in the child's natural environment.

Longitudinal description of the comprehensive assessment attributes may reveal the path to one of the more difficult to treat types of feeding problems, and areas for intervention. "Behavioral" approaches that are used for older children with tube dependency are based on operant conditioning and are meant to correct problems that have already developed and taken root (Silverman et al., 2013). Somewhere, sometime along and infant's developmental path the feeding difficulty begins, they have learned that feeding is difficult or undesirable.

Pragmatic research is research conducted in real world settings, driven by the patients and providers, and seeking outcomes which are meaningful for all involved (Glasgow, 2013). Pragmatic research is needed of the feeding problem phenotype. Divergent efforts at defining multiple types of this disorder based off clinical convenience samples have prevented valid diagnostic classification (APA, 2013b). Comprehensive assessment of the child who presents with feeding difficulty and their family will allow for better identification of children who are struggling to eat and assessment of the effectiveness of feeding interventions. This has the potential to improve outcomes for this population.

Table 2.1

Sampled Literature by Discipline

| Discipline | Initial Sample | | Historical (Pre-2000) Sample | | Full Current (Post-2000) Sample | | Final Reduced Sample for Current Analysis |
|----------------------------------|----------------|-----|------------------------------|-----|---------------------------------|-------------|---|
| | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % | <i>n</i> |
| Medicine | 36 | 14% | 10 | 24% | 26 | 12% | 12 |
| Multidisciplinary | 60 | 23% | 11 | 26% | 49 | 22% | 22 |
| Nursing | 37 | 14% | 6 | 14% | 31 | 14% | 14 |
| Nutrition | 5 | 2% | 2 | 5% | 3 | 1% | Moved to Other* |
| Occupational | 14 | 5% | 0 | 0% | 14 | 6% | 6 |
| Other | 10 | 4% | 2 | 5% | 8 | 4% | 5* |
| Psychology | 83 | 31% | 11 | 26% | 72 | 32% | 32 |
| Speech Language Pathology | 21 | 6% | 0 | 0% | 21 | 9% | 9 |
| Total | 266 | | 42 | | 224 | 100% | 100 |

Table 2.2

Top Three Surrogate Terms Per Discipline

| Rank | Medicine | Multi-disciplinary | Nursing | Other | Occupational Science | Psychology | Speech Language Pathology |
|----------|------------------|--------------------|--------------------|--------------------|-------------------------------|--------------------|---------------------------|
| 1 | Feeding Problem | Feeding Problem | Feeding Difficulty | Feeding Difficulty | Feeding Problem | Feeding Problem | Feeding Disorder |
| 2 | Food Refusal | Feeding Difficulty | Feeding Problem | Feeding Disorder | Feeding Difficulty | Food Refusal | Dysphagia |
| 3 | Feeding Disorder | Feeding Disorder | Feeding Issues | Failure to Thrive | Problematic Feeding Behaviors | Feeding Difficulty | Failure to Thrive |

Table 2.3

Available Classifications for Pediatric Feeding Problem Conditions

| Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood (DC-0-3R; Zero to Three, 2005, pg. 35-38) | Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5; American Psychiatric Association, 2013, pg. 334-338) |
|---|---|
| <p>Feeding Behavior Disorder Considered when an infant or young child has difficulty establishing regular feeding patterns – that is, when the child does not regulate his feeding in accordance with physiological feelings of hunger or fullness. If these difficulties occur in the absence of hunger and/or interpersonal precipitants such as separation, negativism, or trauma, the clinician should consider a primary feeding disorder</p> <ul style="list-style-type: none"> • Feeding Disorder of State Regulation (3)* • Feeding Disorder of Caregiver–Infant Reciprocity (3)* • Infantile Anorexia (6)* • Sensory Food Aversions (4)* • Feeding Disorder Associated with Concurrent Medical Condition (4)* • Feeding Disorder Associated with Insults to the Gastrointestinal Tract (4)* <p>*Each of the above subcategories of feeding behavior disorder have criteria that must be met for that particular diagnosis.</p> | <p>Avoidant/Restrictive Food Intake Disorder An eating or feeding disturbance as manifested by persistent failure to meet nutritional and/or energy needs associated with one or more of the following:</p> <ul style="list-style-type: none"> • Significant weight loss or faltering growth • Significant nutritional deficiency • Dependence on enteral feeding or oral nutritional supplements • Marked interference with psychosocial functioning <p>The eating disturbance is not attributable to a concurrent medical condition or not better explained by another mental disorder. When the eating disturbance occurs in the context of another condition or disorder, the severity of the eating disturbance exceeds that routinely associated with the condition or disorder and warrants additional clinical attention.</p> |

Table 2.4.

Attributes of a Feeding Problem and Percentages of Disciplinary Sample

| Attributes | Medicine | Multi-disciplinary | Nursing | Other | Occupational Science | Psychology | Speech Language Pathology |
|------------------------------------|----------|--------------------|---------|-------|----------------------|------------|---------------------------|
| Range of presentation | 8 | 9 | 7 | 0 | 67 | 56 | 78 |
| Negative mealtime cycle | 33 | 36 | 36 | 20 | 17 | 59 | 44 |
| Caregiver behaviors | 30 | 36 | 64 | 20 | 83 | 44 | 56 |
| Caregiver mental health | 50 | 18 | 0 | 20 | 100 | 43 | 33 |
| Changes by caregiver | 58 | 23 | 36 | 20 | 100 | 45 | 67 |
| Family life, day-to-day | 33 | 9 | 21 | 0 | 50 | 22 | 44 |
| Dysfunctional feeding relationship | 42 | 52 | 43 | 60 | 83 | 59 | 56 |
| Temperament or organization | 33 | 27 | 43 | 40 | 33 | 47 | 22 |
| Child mental/ Psychosocial | 33 | 32 | 21 | 40 | 50 | 62 | 67 |
| Feeding behavior | 75 | 100 | 64 | 40 | 100 | 94 | 89 |

| Attributes | Medicine | Multi-disciplinary | Nursing | Other | Occupational Science | Psychology | Speech Language Pathology |
|-------------------------------------|----------|--------------------|---------|-------|----------------------|------------|---------------------------|
| Selective intake | 25 | 77 | 14 | 40 | 83 | 63 | 67 |
| Oral hypersensitivity, aversion | 50 | 50 | 21 | 20 | 67 | 39 | 56 |
| Nutritional concern | 75 | 32 | 57 | 40 | 83 | 66 | 56 |
| Growth faltering | 67 | 59 | 64 | 80 | 67 | 72 | 78 |
| Tube feeding | 67 | 50 | 36 | 0 | 83 | 53 | 44 |
| Structural anomalies | 33 | 9 | 14 | 20 | 17 | 28 | 44 |
| Neurodevelopment disorder DD | 58 | 55 | 36 | 20 | 50 | 78 | 89 |
| GI conditions | 92 | 64 | 43 | 60 | 67 | 53 | 56 |
| Complex medical | 50 | 32 | 57 | 0 | 83 | 50 | 78 |
| Oral-motor skill deficit, dysphagia | 67 | 77 | 64 | 40 | 83 | 56 | 89 |
| Food Allergy, intolerance, EE | 17 | 23 | 0 | 20 | 33 | 22 | 44 |
| Delayed development of feeding | 50 | 64 | 36 | 0 | 67 | 47 | 78 |

Note: yellow represents the most often occurring attribute for that discipline, and orange the second most often. DD = developmental delay or disability, GI = gastrointestinal, EE = eosinophilic esophagitis.

Table 2.5

Top Diagnoses Related to Feeding Problems per Discipline

| Medicine | Multi-disciplinary | Nursing | Occupational Science | Other | Psychology | Speech Language Pathology |
|---------------------------------|----------------------------|--|--|------------------------------|--|----------------------------------|
| Cerebral Palsy 67% | Developmental Delay 68% | Prematurity 57% | Developmental Delay 67% | Metabolic Disorders 40% | Developmental Delay 47% | Developmental Delay 89% |
| Prematurity 58% | Prematurity 36% | Congenital Heart Disease 36% | Autism Spectrum Disorder/ Pervasive Developmental Disorder 50% | *All others n=1 or 20% | Autism Spectrum Disorder/ Pervasive Developmental Disorder 25% | Prematurity 56% |
| Congenital Heart Disease 50% | Allergies 32% | Respiratory Disease 29% | Cerebral Palsy 50% | | Respiratory Disease 25% | Respiratory Disease 56% |
| Developmental Delay 42% | Cerebral Palsy 37% | Cystic Fibrosis 29% | Prematurity 50% | | Allergies 19% | |
| Metabolic Disorders 42% | Chronic Illness 27% | Small for Gestational Age/Low Birth Weight/ IUGR 29% | | | Chronic Illness 19% | |

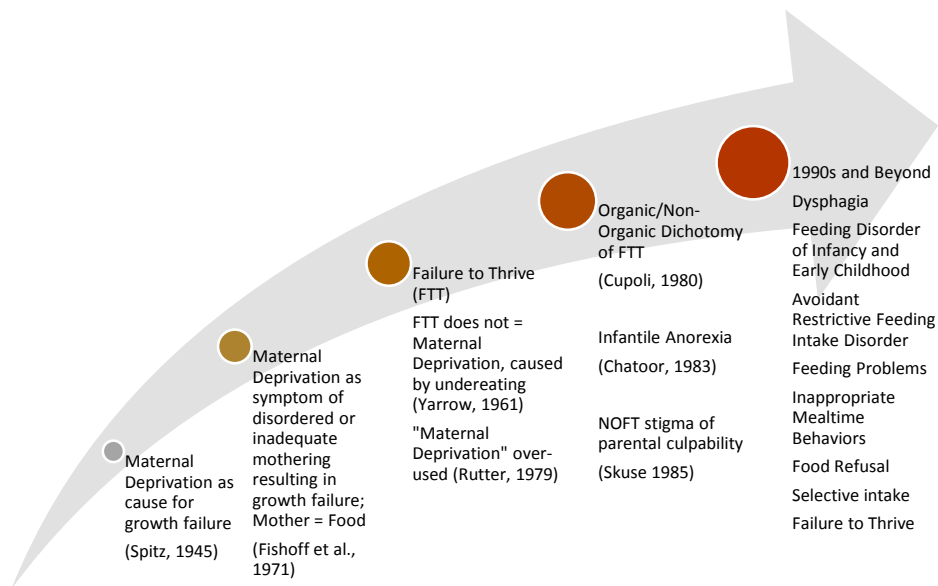


Figure 2.1. Evolution of Feeding Problem Surrogate Terms

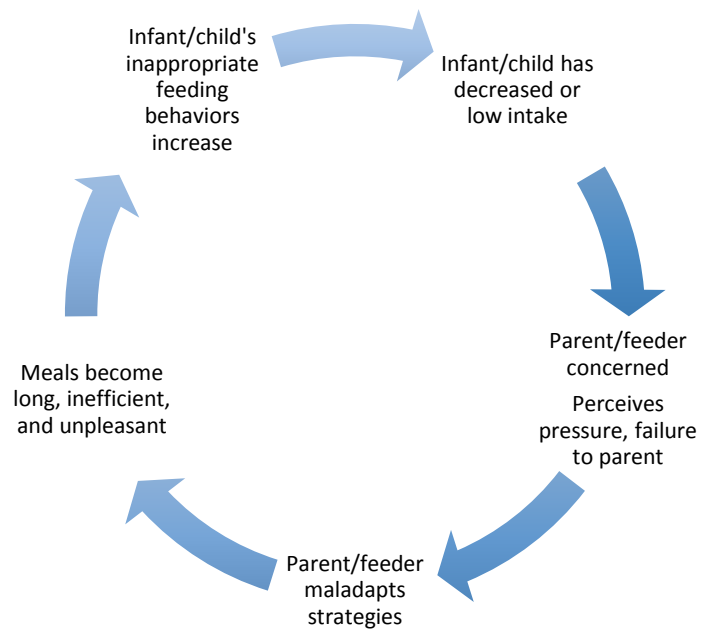


Figure 2.2. Negative Mealtime Cycle

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CHAPTER 3: CONCEPT OF PEDIATRIC FEEDING PROBLEMS FROM PARENT PERSPECTIVE

Overview

Purpose: Feeding problems in early childhood are common, affecting approximately 25% of typically developing children and up to 80% of children with developmental disabilities. There is no interdisciplinary consensus on the definition of a feeding problem and there is lack of input from families in the conceptualization. Lack of common language is a barrier to effective communication between clinicians, researchers, and caregivers, and inhibits collaboration. This study examined the conceptualization of pediatric feeding problems by family caregivers (parents).

Study Design and Methods: This study is the empirical phase of a hybrid concept analysis. Data from interviews with twelve parents of children with feeding problems were coded for related concepts, attributes, antecedents, and consequences of feeding problems, and then analyzed for themes within conceptual categories.

Results: Conceptual elements across interviews are presented with an emphasis on shared perspectives. Parents related pediatric feeding problems to be a process or journey on which they found themselves for an unknown duration. Common themes of attributes were problematic feeding behaviors of the child, restrictive or selective intake, and child weight or growth concerns.

Clinical Implications: Parents conceptualize feeding problems as a condition with symptoms experienced by the child and family that need to be incorporated into family life. In contrast, prior literature coming from provider points-of-view presents this problem to be

of the child. Nurses can improve care of families with children who have feeding problems by coordinating interdisciplinary, family-centered care.

Introduction

Feeding problems in early childhood are common, with 25% of typically-developing children and up to 80% of children with developmental disabilities having problematic feeding (Manikam & Perman, 2000). Feeding problems can occur from birth through age 18, although the highest incidence is reported between 6 months and 4 years of age (Aldridge, Dovey, Martin, & Meyer, 2010). The distinction between the terms *feeding problem* and *eating disorder* is that body appearance is not a motivating factor in the child with a feeding problem. Also, the term *feeding* is differentiated from *eating* because infants and young children are still within a developmental age where a caregiver provides them with food; therefore, they are feeding or being fed (APA, 2013a & 2013b; Kedesdy & Budd, 1998).

Childhood feeding problems present with heterogeneous behaviors and symptoms (Berlin, Lobato, Pinkos, Cerezo, & LeLeiko, 2011). Despite various efforts to classify the problem, there is no agreed upon, interdisciplinary gold standard for assessment, classification, and intervention. Historical changes in the conceptualization of feeding problems can be tracked in classic manuscripts from a psychoanalytic approach (Spitz, 1945), to disordered parenting (Fischhoff, Whitten, & Pettit, 1971), to relational (Davies et al., 2006), behavioral, (Piazza et al., 2003) and typological approaches (Dovey, Isherwood, Aldridge, & Martin, 2010).

Impact of feeding problems

Feeding problems impact more infants, young children, and their families today than in previous decades (Arvedson & Brodsky, 2002; Thoyre, 2007). As advancements have been made in medical and nursing care, infants with previously fatal congenital anomalies

and infants born at younger gestational ages are surviving in greater numbers and living longer lives. These children frequently require long-term care and more often this care is expected to be provided in the home by the child's family (Binnendyk & Lucyshyn, 2009).

Enjoyment of food is a social and family activity that is inextricably linked with quality of life day-to-day (Craig & Scambler, 2006; Redle, 2007; Sleigh, 2005). As children with feeding problems often have co-existing developmental delays or comorbidities, there is a strong priority to deliver nutrition that will optimize neurodevelopmental potential. This amplifies feeding as a significant contributor to the quality of life of both the child and family.

Without effective intervention that families are able to carry out in the home setting, some children will remain on tube feeding or continue to live on a limited number of foods throughout childhood (Gottrand & Sullivan, 2010; Marshall, Hill, Ziviani, & Dodrill, 2014). Because parents are the most proximal agents for change in the environment where feeding happens multiple times every day, classification of feeding problems based on both professional and family perspectives may improve understanding of intervention components that are necessary for maintenance of the fidelity of intervention over time in the home.

Background of the conceptualization of feeding problems

There is conceptual discrepancy among the disciplines that care for children with feeding problems, as demonstrated in Chapter 2 of this dissertation. Even within some disciplines, there is disagreement on what causes feeding problems (e.g., feeding disorders as an emotional problem vs. a relational problem vs. a functional behavior problem), and therefore there is disagreement as to how they should be treated (Chatoor, 2002; Davies et al., 2006; Kerwin, 2003). The attributes of pediatric feeding problems vary greatly across disciplines as the range of issues with feeding spans selective eating to food refusal. Feeding problems have been defined from viewpoints of the provider (APA, 2013a), but not from the viewpoint of the parents who manage feeding day-to-day. Also, despite varied

attempts at classification by clinicians, there is not a valid classification or diagnostic tool for pediatric feeding problems (APA, 2013b).

Data from perspectives of parents of children with feeding problems have not been utilized in the attempts to classify feeding problems. Classifications currently in use by providers (such as non-organic failure to thrive, or NOFT) have been perceived as stigmatizing by family members (Batchelor, 2008; Craig & Scambler, 2006). In addition to managing the challenges of having a child who refuses to eat or has restrictive eating, parents may also feel isolated and blamed for the problem (Thomlinson, 2002). In order for providers to deliver effective family-centered care and for researchers to plan and conduct relevant translational studies, it is necessary to discover the conceptualization of the problem from families experiencing it first hand. The purpose of this analysis was to examine parents' perspectives of pediatric feeding problems in order to generate a more comprehensive definition of the problem.

Study Design and Methods

This is a secondary analysis of interview data from 12 adult parents of children (ages 6 months to 5 years) with a significant feeding problem (i.e., a diagnosis of failure to thrive or feeding difficulty). The purpose of the primary study was to describe family management of feeding. For this study, a concept analysis framework (Rodgers & Knafl, 2000) was used to code interview data for the following conceptual components: related concepts (i.e., words sharing some, but not all, attributes of feeding problem); antecedents (i.e., events or co-occurring/pre-existing conditions associated with feeding problems); attributes (i.e., features of the feeding problem), and consequences (i.e., results of the feeding problem).

The first author completed coding of the parents' interviews. A second coder reviewed three randomly selected coded transcripts with differences resolved through discussion and consensus. Qualitative content analysis (Miles & Huberman, 1994) of the

coded data was used to identify themes within each conceptual component. Analysis was supported by the use of Atlas.ti, a software program used to code qualitative data and retrieve selected coded segments.

Results

The original data set represented 12 parents from nine families of children with feeding problems who had been completely reliant on oral feeding for nutrition. Two of these children previously had feeding tubes that were removed prior to the time of the interview. The children's ages at the time of the interview ranged from 14 months to 4.5 years (mean 2.3 years). Annual household incomes ranged from \$20-29,000 to greater than \$100,000. Children were White ($n=5$), Black/White ($n=1$), Hispanic/Latino/White ($n=2$), and Native American/White ($n=1$). All names in quotations below are pseudonyms.

Related concepts

Related concepts were ideas parents conveyed as sharing some, but not all, of the same features with feeding problems. For parents, any co-occurring conditions their child had were viewed as highly related to the feeding problem itself, and those conditions shared some attributes with feeding problems. The related concepts discussed by parents were: poor sleep ($n=5$), colic ($n=2$), developmental delay ($n=9$), low muscular tone ($n=4$), hemiplegia ($n=1$), Fragile X Syndrome ($n=1$), William's Syndrome ($n=1$), Autism Spectrum Disorder (ASD; $n=3$), food allergies ($n=3$), constipation ($n=3$), and gastroesophageal reflux ($n=3$). Parents of two of the children in the study described feeding problems that occurred at the transition to solids from bottle or breast-feeding as an early indication of an ASD.

Antecedents

Antecedents are events or conditions that parents viewed as occurring with or preceding the feeding problem. The antecedents to feeding problems that parents most identified included the list of related concepts or co-occurring conditions above, but also

included preceding diagnoses, events, or changes in condition, such as breastfeeding difficulties ($n=5$), pre-eclampsia ($n=2$), preterm birth ($n=2$; 33, 34 weeks), ankyloglossia ($n=3$), greater than 10% weight loss ($n=2$), intrauterine growth restriction (IUGR) ($n=1$), aspiration and choking ($n=3$), delayed eruption of teeth ($n=2$), stroke in-utero ($n=1$), or newborn period hospital stay not related to preterm birth (1 cytomegalovirus infection, and one other). Parents did not always describe these phenomena as causing the feeding problem, but did feel they were relevant to discussion of the child's feeding problem history. All but one of the children experienced greater than three related factors and antecedents.

Attributes of the feeding problem

Attributes of the feeding problem are features or characteristics of the problem. The main themes of attributes of feeding problems were *problematic feeding behaviors* displayed by the child and *selective or restrictive eating*. These attributes were followed in prevalence by child growth issues/weight issues. An overarching theme throughout the interviews was that parents characterized their child's feeding problems as a *journey* that unfolds over time. These themes are described below.

Problematic feeding behaviors. Parents of all nine children reported their children displayed problematic feeding behaviors that were a barrier to adequate food intake, such as refusal (i.e. lip closure, turning head, crying, tantrums, hitting spoon), slow feeding, or volume limiting.

Selectivity or restriction by texture, type, or presentation. Parents of all nine children reported their child's food intake was restrictive or selective in some way, due to either food texture avoidance, a known or suspected food allergy, limitations of the amount of intake, and/or distinct preferences for how food is presented. Parents reported varying degrees of restrictive or selective eating as being a characteristic of the feeding problem for their child. One mother described giving her son a different type of applesauce, "He's VERY

picky as to the container it comes in. I very rarely give him applesauce from the store. It's usually always I make it. And that container threw him all off. He didn't wanna eat it."

Failure to thrive and growth issues. Parents of seven children reported being told by a health care provider that their child had failure to thrive (FTT) or a growth problem. While only three of the children had FTT at the time of the interview, and parents of two of the nine never reported having FTT, the label had a significant meaning to the parent even after growth problems had seemingly resolved. Parents worked hard to promote adequate food intake and growth. Parents of the seven children with growth issues reported that being told their child had a growth problem shaped their subsequent feeding strategies. One mother of a 17 month old with resolved FTT described how she was still always in "calorie crisis" and rarely would offer her child water to drink because every time he took something in, it needed to have caloric value. Another mother had her child's growth chart on the refrigerator to show that he had gained weight and was in a more optimal range on the chart. It was a source of great pride, and also a reminder to stay vigilant. Resolved status from FTT meant their child was maintaining a growth curve, however, it did not imply that the problematic feeding behaviors or restrictive/selective eating were resolved. Often parents reported it was the result of working very hard to accomplish feeding with supplements, and specially prepared and presented meals.

Feeding problem as a journey. Parents' descriptions of their child's feeding problems often started with a description of their child from birth and how their child's feeding changed to the present time. According to parents, problematic feeding behaviors or selective/restrictive intake were attributes they had noted long before they had the attention of specialty feeding care.

A huge part of our frustration [...], why we didn't get to [feeding team] until she was almost three? We feel like we wasted...2 and ½ years for her, where she could have felt better. And made progress. [Tearful] Instead of learned pain and learned bad habits. Um, and we realize how related it is now. And we were kind of naive to that going along.

For parents of seven of the children, the feeding problem was perceived as being present from birth with breast or bottle-feeding.

...trying to get him to latch. You know, we tried like ten different holds...different positioning of the nipples. And they were like "Well maybe your nipples, there's something wrong with your nipples," I mean in the hours that it took us, practicing, trying to get him to feed, ...he latched, probably twice.

Parents of the other two children reported that difficulty came at transition to solids at about six months. As one of the parents related, "And [feeding solids] just always seemed to be like a struggle...if it wasn't milk, it was fight..."

Regardless of when parents described the onset of the problem, it was described as an ongoing journey of life with feeding problems. There was often an early ambiguity as to the existence of a feeding problem, with parents being reassured without referral for specialty feeding evaluation or support.

It was early that we knew feeding was going to be hard for her. ... there was a lot of spitting up, there seemed to be a lot more vomiting. She was an awful sleeper. I think it got passed off for a few months as colic, other people around us started to think no, this is more serious, you should try to...find another resource. We were referred to a pediatric GI here... and that's where we got... Julie was seven months at this point, the official diagnosis of GERD, and started putting her on some medicine.

One mother of a 30-month-old child related how problems with feeding started when it was time to introduce solid foods at six months and he was diagnosed with an oral aversion. "There was lots of red flags there...and so then we went on our journey from there. So, that's when we got in with early intervention." With early intervention services provided through military insurance, this mother reported being very pleased with the changes she had seen over time in her child's overall development, and gave much credit to these services for the progress her child made. However, feeding was still a significant problem, and her child's refusal behaviors and selective diet made feeding difficult, to the point that they had plans to attend a 6-week intensive interdisciplinary feeding program.

Not only did parents describe feeding problems as a journey, but also that it was one

that changed over time, as their child developed and as the parents adapted and sought help.

I mean I think it's...it's a long term process. You have to be patient. You know every new day comes with its own opportunities. ... It's kind of like the stock market, you know it, if you follow it too closely, every day, you're going to be on a huge roller coaster. ... you have to take a long-term approach to it.

As noted above, changes in the problem were often described as being on a “roller coaster,” this description was used by three parents of three different children.

Parents described the ups and downs of their child's feeding problems; this contributed to their thinking of the problem as a journey.

Consequences

The consequences of the feeding problem were effects that resulted from the child's feeding problem. Main themes of consequences of the feeding problem were: *adaptations made by parents, parent impact, family impact, and feeding tubes.*

Adaptations made by parents. Parents reported multiple strategies they used to address their child's feeding problems. These included putting their child to sleep in an upright position, changing foods or formulas often, pumping breast milk when the baby could not latch and suck effectively, altering the mother's diet to minimize colic or food allergies, taking medication to produce more breast milk, and using a supplemental nursing system. Parents also reported avoiding eating away from home with family or friends in order to keep the routine and environment somewhat more controlled at home. For parents of five of the children, if they did go out to a restaurant with their child, they described extensive advance planning to ensure the child would eat in the new setting. Parents of seven children reported they usually had their best chance at being successful with feeding a meal when at home. One father of a 30-month-old child said:

We are more centered around that structured routine to another degree than you would be normally...it's all purees and stuff. So it's not like you can just put her on a high chair in a restaurant and just cut up her meal and let her go

to town... you need the quiet environment, I mean to the point where if we have guests over, they go to another room or they go outside while we feed.

Some of these adaptations parents made included making purees for pre-school age children and having them eat in high chairs with securing straps instead of chairs or booster seats. "He does not stay in a high-chair like at the restaurants. ... I hate going places. We need to strap our kids in." Seven of the nine children required seating support beyond what would be typically expected.

Parent impact. Parents reported experiencing limited ability to work or be outside the home and away from their child. In five of the seven dual parent families, the mother was not employed, and their time was fully occupied with care and feeding for their child. Parents in one family where both mom and dad worked had to expend a great deal of effort and expense to engage a talented nanny who, after training, could feed their child. Both mother and father of one child reported spending months seeking the proper legal language and then advocating for the school district to hire someone who could be trained to consistently feed their child in the pre-kindergarten setting. One mother reported that they had learned their child would not eat adequately outside the home and routinely fed the child a "second lunch" after their child came home from child-care.

Some parents reported sadness and frustration because of the limitations to their own life brought about by their child's eating difficulty. One said "Frankly... it's hard being tied to your child when you are the only one that can feed them." Mothers reported nearly constant impact of their child's feeding problem day-to-day, as they were the primary feeders and sometimes ($n=4$) the only person who could successfully feed their child. Even for mothers who worked outside the home, their child's feeding problem weighed heavily on their mind ($n=4$).

Family impact. Parents reported that their child's feeding problems limited time for other family activities. One father shared that even after an intensive feeding program and

feeding tube removal, “We are still tethered to Julie, four times a day”. Outings, holidays, and travel were difficult above and beyond the usual challenges of traveling with young children. One mother said, “Our family life is pretty much dictated by her feeding times... So, our schedules are largely based around eating.” Another mother described the all-consuming nature of managing her child’s feeding problem by saying: “Yeah, especially when doing your best is like, takes everything you’ve got, and leaves nothing for yourself, or anybody else.” Another mom experienced distress with extended family always wanting to go out to eat at restaurants, where her child would not be willing to eat.

And in their head, they think that they are doing something good for us because we are always home. It’s like, no, we choose to be home...Caleb is very dependent upon me, so like even though they are, there are bodies to help, it ends up just being me.

Feeding tubes. Surgically placed feeding tubes were a consequence of feeding problems as conceptualized by the parents of five children. Parents expressed differing views of the feeding tube. Some had positive views, some negative. One mother of a 14-month-old boy recalled: “Neurology was actually the first, they said ‘I don’t want to be the bad guy,’ but they were the first to suggest the G-tube [gastric feeding tube].” Here, the tube was first suggested to this mother as an option from someone outwardly assuming the role of the “bad guy.” This mother in particular was not opposed to getting a tube placed for her child, because her child had a history of aspiration and a particular episode where emergency services had to be called. Another family’s child had a gastric tube placed and it was the last thing they wanted to have to do for their child: “[Getting a tube] was worst-case scenario, and Julie wasn’t worst-case scenario yet.”

Parents of two children who had had G-tubes placed and then removed spoke about how having the gastric tube placed was a relief because it was a sure route for delivery for their children’s nutrition after it had been so difficult otherwise. The feeding tube helped with nutrition, growth, and energy. These two sets of parents were grateful for the tube and

worked on their child's oral feeding and medical management while it was in place, as a safety net. They never described the feeding tube as being part of the feeding problem; instead the tube was part of a solution.

Clinical Nursing Implications

This analysis contributes to the conceptualization of pediatric feeding problems by describing the parents' perspective. Common attributes from parental perspectives were *problematic feeding behaviors* and *restrictive or selective intake*. These findings fit with results of Chapter 2, the evolutionary concept analysis from disciplinary perspectives. These attributes are the common ground that all disciplines and also parents of children with feeding problems have in this shared conceptualization of the problem. *Growth concerns* or *FTT* were also common feeding problem attributes from the parent interviews and literature.

Unique to the parent perspective of feeding problems is their description of pediatric feeding problems as a *journey*. The chronicity, or journey of the family experience was evident when families described the problem, in contrast to the provider's descriptions of episodic intersections with children with feeding problems. The journey consists of turning points, setbacks, and milestones for these children and their families. The components of the journey collectively frame the conceptualization of the problem for the child and family. Families must work to incorporate care for a child with a feeding problem into life at home, and many have had to do so since before they even arrived at home with their infant. Providers lack the day-to-day perspective of the child; however, nurses are uniquely positioned to partner with families along this journey. A family-centered nurse could partner with them and assist in navigation of an optimal feeding care journey for child and family.

The evolutionary concept analysis within Chapter 2 identified a largely uninvestigated time between the neonatal period and the age when children with feeding problems are typically seen in specialty clinics (i.e. approximately 25 months of age; Rommel, De Meyer,

Feenstra, & Veereman-Wauters, 2003). This study identified this gap in attention to feeding problems from providers as well, and this time itself was full of tension and frustration by parents seeking help for their child. Feeding problems are a journey due to the chronicity of the problem overlaid with infant/child development. There is attention in the literature to feeding problems early on, when babies are in neonatal care centers; however, feeding problems are not described in studies again until the toddler or young child has a significant feeding problem (Chapter 2). Clinicians and researchers are left to wonder what happened, how did this develop, and what could be done differently? Nurses can help to fill this gap by asking more questions, engaging with families when concerns are raised, and making the effort to assess feeding problems and the full scope of their impact in the neonatal and pediatric populations they serve. Staff nurses, nurse practitioners, and doctors of nurse practice (DNPs) could head collaborative research projects to examine the prevalence of this issue within their institutions, to ask what parents need and what they think their children need.

Another new finding from this analysis was the contrast in the way parents and the professionals in the literature conceptualize tube feeding. Within the literature, tube dependency is sometimes noted as being a feeding problem type in and of itself. However, parents spoke of tube feeding as the necessary result of a significant feeding problem and more of an alternate nutritional delivery mode; something helping to support their child's growth, rather than a feeding problem of its own kind. Nurses can explore the meaning of a feeding tube for families to support them in the transition to having a child with a tube. For parents, the feeding tube is so much more than tube site care and how to feed through the tube. Nurses could connect parents to online organizations, which support and provide resources for those receiving nutrition through atypical means.

Toward spectrum conceptualization of pediatric feeding problems

Conceptualization of pediatric feeding problems from the perspectives of professional disciplines as well as that of field experts in close proximity to the child (i.e., parents) is the path toward family-centered and personalized interdisciplinary research and practice. This concept analysis builds on the prior chapter's conceptualization of feeding problem spectrum. Professional disciplinary perspectives in the literature as well as parents (with this study) concur, problematic feeding behaviors and restrictive or selective intake are the consensus attributes of feeding problems, and could serve as the two critical attributes of pediatric feeding problems. Meeting these two criteria would place a child on the feeding problem spectrum, and all other features would further clarify the specific nature of the problem and indicate the type of treatment required. Although FTT and weight concerns were common attributes of feeding problems from a parental perspective, it is not essential for a feeding problem to exist. Not all children with feeding problems will have FTT, but all children with feeding problems will have problematic feeding behaviors and restrictive or selective food intake. Within the spectrum, family impact and management also play a part, as this is a feeding problem and at the very least a caregiver-child dyad is needed to make feeding happen.

The chronicity of the problem, the feeding care journey as described by parents, and the impact navigation of that journey has on the child, parent, and family must come into consideration when evaluating and treating a child for feeding issues. During assessment for feeding problems, the family should be part of the team. They will be the individuals who can partner with providers to design a plan that will be sustainable within day-to-day family life. As examples, the approach will be different if a child has been in pain and avoiding eating for days versus years. If a parent is feeling unable to manage a complicated feeding protocol at home, they are going to need some personalized assistance and ongoing support. When a parent becomes anxious or sad about feeding, providers need to

acknowledge that this is sad when a child won't eat. It is nerve wracking when a child refuses to eat, and does not grow. Instead of sending a message that parents have failed in their most basic occupation of feeding and growing their child, a conceptualization of feeding problems with experienced parent input, free of stigmatizing language, may encourage families to seek help when feeding is other than expected. If providers could have greater understanding of the problem from the parent point of view, they may be able to more sensitively assess the feeding situation for child and family. For example, some parents in this study reported that they were the only person who could feed their child. They had to spoon feed or bottle feed special foods, in a specific way, or with special seating, or their child simply would not eat for anyone else. It is an exceptional expectation that a parent would be solely responsible for feeding their child every successful meal multiple times a day, for years beyond what is typically expected for feeding children. A parent in this situation will need attention and respite to avoid burn out. If the conceptualization of the problem is not expanded to include its chronic nature or impact on the parents and family, such issues will go unnoticed by those healthcare professionals who set goals, suggest strategies, provide therapy recommendations, and document progress.

In conclusion, this analysis sheds light on the conceptualization of feeding problems from the parent perspective, and how that differs from the disciplinary perspectives in the literature. A key difference revealed was that parents conceptualize the feeding problem as a journey. Family is part of the whole picture. A child and their family have a feeding problem; they experience this journey together. It is more inclusive to consider this issue in the context of the child's natural environment with the people who are most familiar and invested. A shared conceptualization that families can relate to (without perceived stigma) and that providers could use to classify pediatric feeding problems would improve potential for early feeding assessment, referral, and for feeding intervention efficacy to last long term.

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CHAPTER 4: FAMILY MANAGEMENT OF FEEDING WHEN A CHILD HAS FEEDING DIFFICULTY

Overview

Pediatric feeding problems occur in 25% of the general pediatric population and up to 80% of those who have developmental delays. For about 3% to 10% of children, feeding problems will be severe and persistent. When feeding problems place the child at nutritional risk, families are typically encouraged to increase their child's intake. In more extreme cases, this is to avoid the need to have a feeding tube placed. As pressures to eat increase, children's aversive behaviors can worsen, extending the time of under nutrition, resulting in an increased risk for illness or infection, and limiting developmental potential. Family mealtime can become a battle, which further reinforces problematic feeding behaviors from the child and intensifies well intentioned but unguided parental mealtime efforts. Feeding experts acknowledge that family has an essential influence on feeding, however, studies to date neglect to address the family context of feeding difficulty. Recent literature points to a need to explore family management strategies for their child's feeding, child feeding behaviors, and parent goals for the child's eating. The purpose of this study was to describe, in the context of everyday life, family management of feeding when a child has a significant feeding problem. For this study, parents of children who had feeding problems and were reliant on oral intake for nutrition were interviewed using the Family Management Style Framework as a guide. Twelve parents, representing nine families of children with feeding problems participated. This description of family management of the child diagnosed with a feeding problem provides a foundation for developing and testing

Interventions to preserve child interest in eating and to optimize family approaches to feeding during this vulnerable time for children and families.

Background and Significance

Pediatric feeding problems occur when an infant or young child cannot, or will not, eat enough (Kedesdy & Budd, 1998; Kerwin, 1999). Multiple comorbidities often exist in children with feeding problems making this a heterogeneous group (Sharp, Jaquess, Morton, & Herzinger, 2010). A latent class analysis showed that while patterns of comorbidities exist in children with feeding problems, these patterns did not indicate the severity of the feeding problem (Berlin, Lobato, Pinkos, Cerezo, & LeLeiko, 2011). For example, children with different comorbid conditions, such as autism spectrum disorder or Down syndrome, may present with the same functional feeding problem of food refusal.

Feeding problems early in life are linked to developmental impairments, malnutrition, and poor growth. In a population based study, Motion et al. (2001) found that children who had persistent feeding difficulties for the first 15 months of life also had significantly more developmental delays in motor, language, and behavior at 18 and 30 months than population controls. Because children with feeding problems often have multiple comorbidities (Sharp et al., 2010), it is critically important that their nutritional status support optimal neurodevelopment. As restricted diet is a major attribute of pediatric feeding problems (see Chapter 2), optimal nutrition is a major challenge for this group of children. Indeed, children with feeding problems and disability have been shown to consume a diet largely of cow's milk in varying forms (Sullivan et al., 2002). While textures found in puddings and drinkable dairy products can be easier to consume and deliver sufficient calories, this food source is deficient in iron, and iron deficiency early in life is detrimental to neurodevelopmental progress and healing (Sullivan et al.).

Children learn how to eat, or how not to eat, within a family setting (Toomey, 2002). Studies of feeding problems have concluded that feeding problems such as gagging, retching, and food refusal are often a result of learned aversions (or adaptive behavioral reactions) to painful eating experiences (Field et al., 2003; Zangen et al., 2003). For example, Field et al. found that gastroesophageal reflux, a painful condition that children link to eating, was associated with food refusal (Field et al., 2003). Children with feeding problems also often present with food allergies and constipation; both of which are conditions that can make a child very uncomfortable with eating (Berlin et al., 2011; Meyer et al., 2014).

Critical first behaviors during infancy indicate hunger and fullness to their caregiver and guide the caregiver's approach to feeding (Arvedson & Brodsky, 2002). However, research has shown that some children (e.g., those with autism and failure to thrive) may not even 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 et al., 2005; Sharp et al., 2010; Williams, Field, & Seiverling, 2010). In the literature, reviews tell us that treatment for feeding problems is too 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 (Humphry & Wakeford, 2008; Thoyre, Pados, Park, Estrem, & VanRiper, 2010; Weisner, 2002). There is a reciprocal relationship between feeding problems and both child and family outcomes (Berlin et al., 2009). Development of feeding behaviors and skills are dependent both on functioning of the child's body and its ability to manage various types and quantities of food, and 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 the vast majority of child feeding occurs in the family setting, it is essential we understand how families approach feeding when their child has significant feeding problems.

In families where parents feel pressure to achieve certain nutritional requirements for their child, family function can suffer at mealtime. Blissett and Harris (2002) have proposed that parental mismanagement of feeding starts with good intentions: the parents are anxious to have their child eat enough. For example, parents of children born preterm have been found to focus more on their child's intake than on normal-for-age eating patterns (Cerro, Zeunert, Simmer, & Daniels, 2002). In Cerro et al.'s study, parents had greater concerns about growth and health, and were more likely to deliberately control served portions and use more coercive feeding.

In a family where a child has significant feeding problems, there is tremendous pressure to deliver nutrition; the focus is on feeding outcome or quantity of intake, rather than the quality and sustainability of the feeding process (Franklin & Rodger, 2003). Documented medical guidelines for use with children with feeding problems state that aggressive oral interventions must first be attempted when a child is at risk for feeding tube placement (Axelrod et al., 2006). Parents must take on the responsibility of feeding this child using the guidelines their child's physician provides and incorporate these into family life.

When a child has feeding difficulty but is not acutely at risk for tube placement, parents have reported a lack of guidance beyond being told to take their child home and get the child to eat (Thoyre & VanRiper, 2010). In six focus groups of parents with a child with Down syndrome, parents reported having to create their own strategies for teaching their child to eat, after they learned that the standard approaches for getting children to eat did not work for their children (Thoyre & VanRiper, 2010). Batchelor (2008) noted that mothers of children who eventually enrolled in a feeding program reported being "desperate" for help.

The mothers felt like failures as parents, and they said this feeling of failure was reinforced by family, friends, and some professionals, who did not understand how it was possible that the child refused to eat. For most of the parents, “Successful feeding of their child was intimately bound with their sense of themselves as competent and caring” (Batchelor, 2008, p. 385). This linkage of successful feeding to being a competent parent was also reported by Sleigh (2005) in interviews with parents of children with cerebral palsy. Parental caregivers often report seeing enteral tubes as unnatural or wrong (Pedersen, Parsons, & Dewey, 2004; Sleigh, 2005; Spalding & McKeever, 1998; Thorne, Radford, & McCormick, 1997). They reported holding out on tube placement, or trying to “get by without [the tube]” (Sleigh). Parents reported spending hours just trying to get their child to eat, or trying to avoid feeding tube placement (Spalding & McKeever, 1998).

Children with developmental delays or other medical conditions already require some type of intervention or non-intuitive family care. The expectation that parents will aggressively apply normal societal feeding practices to these children and be successful is perhaps unrealistic and unfair (Craig & Scambler, 2006; Mahant, Jovcevska, & Cohen, 2011). Professionals need to learn how to partner with parents at this delicate time, a time when all involved in family mealtime learn how difficult it is to nourish a child with significant feeding problems. This information would set the stage for informed prevention of the maladaptive mealtime behaviors clinicians commonly see demonstrated by both children and their parents (Sharp et al., 2010; Williams et al., 2010).

The time during which a decision is made about tube placement can last months, and it has consequences for the child and family (Rouse, Herrington, Assey, Baker, & Golden, 2002). If a tube is placed, and the child is able to eventually come off the tube, tube weaning to oral intake can require intensive treatment for weeks or months (Sharp et al., 2010). Very little description is available on the subsequent post-tube, oral feeding management in daily life. This sparse literature following up on children after the feeding

tube weaning (Davis, Bruce, Cocjin, Mousa, & Hyman, 2010) has focused on volume of intake and growth (Silverman et al., 2013; Williams, Riegel, Gibbons, & Field, 2007) or feeding acceptance (Sharp et al., 2010) but lacks description of how families manage successfully at home over the long term. Children with significant feeding problems are often fed separately from the rest of the family, simply because they require a large amount of feeding attention, and parents report feeling guilty about the excessive amounts of attention required for the child (Brotherton, Abbott, & Aggett, 2007). Pressuring children to eat teaches children to associate eating with negative experiences, and they are not able to establish food preferences (Mason et al., 2005). Malnutrition for the child can be prolonged, because the child and parent become averse to battleground mealtimes. One product of mealtime aversion is amplification of child escape behaviors whereby the child learns the parent will stop feeding and the meal is over when they display certain behaviors, such as vomiting, batting or blocking the spoon, or turning the head away (Piazza, Roane, & Kadey, 2009).

For parents without adequate interdisciplinary guidance, the short term, high-pressure goals of calorie delivery in feeding may not be congruent with supporting the child to be a successful eater in the future. When children are learning to eat and are at nutritional risk, and their parents have been encouraged to step up efforts to deliver calories despite diminished behavioral cues, there is a great challenge to family management. Discovery of areas where professionals can best intervene with families during this critical time is essential to prevent adoption of strategies that perpetuate the feeding problem, affecting both family processes and child outcomes. This study aims to discover those areas most needing intervention through description of parental management of feeding, investigating parent perspectives of their child's eating and feeding problem, and identifying factors were perceived as being facilitators and barriers to feeding management.

The neglect of the family's management of feeding when a child has a significant feeding problem risks worsening of the child's feeding problem and setting a more difficult path to future oral eating. Recent literature supports this viewpoint and identifies the need to explore family management strategies, child feeding behaviors, and parent goals for the child's eating (Berlin, Davies, Lobato, & Silverman, 2009; Mason, Harris, & Blissett, 2005). Developing future interventions for families of children with feeding problems will require knowledge of family perspectives, strategies and goals. However, feeding studies to date have neglected to encompass the family embedded nature of feeding by limiting scientific inquiry to only the child or parent (Berlin et al., 2009).

This study aimed to 1) describe parent perspectives of their child's eating and of managing the feeding problem when their child's feeding problem is significant, 2) identify contextual factors parents perceived as facilitating or impeding their ability to manage the feeding situation, and identify themes of feeding problem management across parents 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-centered interventions to preserve child interest in eating and foster sustainable feeding practices at home.

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, and 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). According to the FMSF, individuals in the family contribute to developing a family management style or pattern that can influence both individual and family outcomes. The

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 et al., 2012) using integrative literature reviews. The FMSF was the conceptual basis for a measure of family management, the Family Management Measure (FaMM; Knafl & Deatrick, 2006; Knafl et al., 2011) that was structured by six scales. The current study used the six scales from the FaMM plus added the construct of contextual influences from the FMSF to conceptualize family management.

Methods

Design

Purposive sampling (Patton, 2002) was used to recruit parents of children in care for feeding problems. Parents completed a semi-structured interview and a demographic form. The family was considered 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). The interview guide, based on the FMSF and FaMM scales, was piloted with three families to refine the interview guide and behavior specific probes.

Setting and Sample

The primary study recruitment setting was a southeastern 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. Parents of children receiving professional care for feeding problems when the child was between the ages of six months and five years, were recruited if they were English speaking and 18 or older. "Feeding problems" in this study represents a span of presentations from children who were high risk for feeding tube placement, children who had lived with a feeding tube for a time and were transitioned back to oral feeding, and children who had feeding delay but were not failing to

thrive at that time. 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 (child had inappropriate mealtime behaviors and selective or restrictive intake). Screening included child age and the developmental appropriateness of what and how they were eating. While the range of presentations for children with feeding problems can be wide (Berlin et al., 2011), this study did not include children who demonstrated high selectivity (or pickiness) but were able to eat developmentally appropriate foods. The study excluded parents of children who had been deemed unsafe to eat orally through screening with parents and appropriate recruitment referrals; for these children the decision already had been made and oral feeding management was not an option. The six month lower boundary of the age range of the child was selected since this 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; Morris & Klein, 2000). This developmental age is also when feeding problems often become clinically apparent (Aldridge, Dovey, Martin, & Meyer, 2010; Williams et al., 2010). The upper boundary of 5 years captures the majority of gastric tube placements (AHRQ, 2010) and the upper age for identification of the majority of clinically significant feeding problems while allowing inclusion of those still in their fourth year (Aldridge et al., 2010).

Recruitment had a goal of providing a thick description of feeding views and approaches; this was reached with nine families of nine mothers and three fathers (Miles & Huberman, 1994; Patton, 2002). While recruitment sought to include both mother and father figures, the higher rate of participation from mothers was expected (Knafl et al., 1996; 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 both recruited for maximum variation sampling on family structure (Patton, 2002). In families where there were two persons in parental roles, both were invited to participate.

Most previous studies related to childhood feeding problems have involved only the mother (Garro, 2004); including both parents when possible aimed to provide fuller description of family processes and management efforts.

Measures

Data were collected from semi-structured interviews with individual parents. One parent from each family additionally completed a demographic family information form. This form included information about the parent's ethnicity, education, gender, and age; family income; and the child's age, gender, and major health and developmental history. The form also included questions about the child's history of feeding therapies or evaluations. See Appendix A for the family information form and Appendix B for the interview guide.

The interview guide was based on six Family Management Measure scales (FaMM; 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). The FaMM was developed by Knafl and colleagues to measure aspects of family management of a child's chronic condition (Knafl et al., 2011). Additionally, questions about contextual issues parents perceive as relevant to feeding management were included, as contextual issues are part of the FMSF that is not included in the FaMM. The semi-structured, open ended interview guide used detail oriented and elaboration probes (Patton, 2002). Parents were encouraged to elaborate on their feeding experiences with their child and introduce topics not in the guide if they were of importance to the parent.

Procedures

IRB 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. Telephone interviews have been shown to yield data of equal, if not better, quality than in-person interviews (Novick, 2008) and it has been our experience that parents of children with chronic conditions generally are more available for telephone interviews. Also, fathers are more likely to participate openly in family research via telephone (Kirsch & Brandt, 2002).

Analysis

All interviews were recorded and transcribed verbatim. Each transcript was checked for accuracy against the taped interview by the researcher or a research assistant. Following transcription, all interviews were coded using Atlas.ti 7 qualitative data analysis software (Berlin, Germany) by the first and second coder using a start list of codes reflecting the FaMM scales and contextual influences, and then supplemented with codes derived from the interview data. To capture the contextual influences most often mentioned by parents in the study, contextual Influences were coded with the most often mentioned being social network, resources, healthcare providers, and early intervention. The start list of codes and definitions are in Table 4.1.

The first two interviews coded by each coder were then reviewed by a second coder. Any discrepancies in coding were resolved with discussion and consensus was reached. The data analysis software program 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). In order 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 et al., 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 prior to the study. It is important to point out that while these two children had their feeding tubes removed, they were still receiving professional treatment for feeding problems. Tube removal means they are able to maintain nutrition and hydration orally, but it does not mean the child eats as their typically developing peers eat. Technically, they are then feeding to stay off the tube.

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 GI function (reflux, constipation, poor motility, delayed gastric emptying), dysphagia, colic, food allergy, and other conditions (autism spectrum disorder, hemiplegia, Fragile X, William's 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 medical conditions that would help to explain their trouble with feeding. Parents of six children first noticed a feeding problem in the newborn period, while the other three children had first issues at the transition to solids from breast 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 with their child. Two were scheduled to receive gastric feeding tubes within the next month.

Annual household incomes ranged from 20-29,000 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). At the time of the interview, one family had an older sibling to the index child, and another family had a younger sibling.

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. The first theme within this category of findings was that parents defined their child's eating by how it was different, either in comparison to standards or in comparison to same age peers. Next, the child's mealtimes and identity as an eater was defined by the unpredictability of mealtime success. Last, within definition of the child's daily life and identity, was that the child's feeding problems were seen as being inseparable from other conditions or diagnoses the child had. All nine of the children included in this study were in specialty treatment for 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 child's eating 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 only eat if seated in a high chair and spoon-fed pureed food in a specific way, stated, “Feeding her right now...like feeding a six month old or a seven 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.”

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 high chair 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 all age appropriate foods that required some chewing, and that was a recent accomplishment. His mother recounted how her son used to refuse most foods that her friends children were eating.

When describing their child as a feeder, parents would often use comparisons to other children through casual observations of children of friends, day care and siblings. These contrasts in eating with same age peers made a child’s feeding problems more apparent. The following quote is from a mom of a 2 ½-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 difference in eating from her friends’ children.

It started out very frustrating, I thought, [sigh] all my other friends you know, have babies who are eating everything, ..., but then I was like you know that’s him, I’m not going to let what they’re eating bother me. Every child is born with something; I don’t care what it is. You know, it’s just something. And no one’s perfect, and we’ve very accepting of that.

Another mother’s 14-month-old child had been recently diagnosed with failure to thrive. She remarked on seeing the difference between her daughter’s abilities in comparison with the other children at day care.

...from what I’ve seen at daycare, ...they all have teeth [laughs], they’re all

walking, she's not walking yet...she's getting closer, which is great. ...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.

The last example for comparison comes from a mother of a 14-month-old who was going to have a tube placed soon. His mother compared his desire to eat with what she had seen from other children, and her older child at the same age.

I feel like most kids his age are like snacking a lot and eating a lot more often. They want a lot to drink, like I know [the older sister] was like that. Like, she was always eating, always drinking ...and then I'm like...something's missing, there's just like all these hours between when he takes food or drink and he's just like "I don't want it."

Defined by [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. When a family is willing to live out of state and work on feeding every weekday, 4-5 meals a day, for six to eight weeks, it is a reflection of how serious they interpreted the feeding problems to be. This mother described her child as, "He is so roller coaster" 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.

He's very firm in his routine, like he is a routine kid. Um, I've tried deviating from this, the regular program...and it just does not work. It does not at all, I mean he just will flat out refuse if you try to give him something at a different time of day.

This same child was very unpredictable in how much he would eat at those set times, often not eating all that he needed calorically. The second child with plans in place for tube placement was very unpredictable with accepting a food one day and not the next.

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.

Only one child, a three year old, had feeding delay as a single condition. When asked to describe her daughter’s day in comparison to same age peers, this mother replied “I would say her day is completely similar, except when it is time to eat, they are feeding themselves and Layla needs to be fed, or is refusing to eat.”

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, parents 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 felt the knowledge they had developed of how their child responded to foods and feeding schedules was a strength that helped them to manage.

I really just kinda hav’ta listen to him. Some days he’s just not hungry. Ya know, he’s... very good at, saying I’m... NOT gonna do what you want to do... that lil’ mouth is like a steel trap. It shuts and it says “no more.” ... I’ve come to know what’s, what he does an’ ...I know what limit I can push him to... And so I will, just to get the food in ‘em.

Knowing which seating and supports work for their child to eat at mealtime was important to seven families, and they felt this was a strength they had developed. Eight parents felt they knew which foods their child liked, and this would often be a food that did not need to be chewed, and/or was easily meltable 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. For the mother's quote above, we see that her child used to eat peas, but he has lost that food.

Parents knowing 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 significant other brought to feeding management.

One mother felt she was very able to be consistent and give breaks (take the 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 felt able to not only take the advice of feeding therapists or other providers, but felt confident in their ability to modify those recommendations to do what worked best for their child and family. One mother felt 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 felt that tracking it would show to 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 when feeding the child. Also, one mom in particular praised her husband's skills at keeping beautiful detailed charts and graphs for tracking their daughter's intake and growth.

Finding the easy way, and identifying the "harder stuff". Families reported working towards 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 a routine that worked well for the family was disrupted in some way. One family had a highly skilled nanny who fed their

child multiple meals every day. They felt day care personnel would not have the skills or time to complete their child's feedings successfully (their daughter had been at a day care 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, its...it is stressful because it's new and, that's the hard part... pushing yourself as an individual to do the advancement at home instead of [at the therapist's office or in front of feeding program personnel] where they sort of push you anyway. It's having the discipline *here* to advance Julie. Because really, unless we do it with her [advance her feeding through the hard work], she is not going to make that progress. ... Cause 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. As stated earlier in this chapter, tube removal does not mean the child eats as their typically developing peers. 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 weren't 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, upwards 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 they 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 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 six 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 3-5 meals a day, four or five days a week. These efforts are extraordinary.

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 spent on her daughters care.

Since she got the diagnosis of failure to thrive 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 Miles 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 of 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 impacted 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, you know, whenever we're feeding... in order to get the best results with her eating, she needs to be in her home environment where it's just not as much there to distract her.

Five of nine families could not eat out at restaurants with their child. The four other families were able to go out, but said they must be planful if they tried and go into the situation with adjusted expectations. These adjusted expectations included bringing alternative foods for the child or not expecting the child to eat at all, but instead just to sit at the table. Others

would go only to a restaurant if it had menu items and seating options that the child had handled well before.

I mean, it's not like, I would imagine that with a typical kid, if you decide "I'm not cooking tonight, we're just gonna go pick up something." It would be pretty easy to do that, but with Miles, you have to know that you have to decide that whatever it is you want to pick up to eat, if it's something he will eat. And if not, what you are going to get for him, or how are you going to make—if we go out to dinner, I really have to be careful what restaurants I choose, or make sure I bring his food with me.

This same playful 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 while at the gathering.

Most of the children were also very limited in who could feed them. The mother of a young girl whose feeding status was post-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 off the tube.

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; a time while they struggled with no 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. Because Evan was waking up, [Child's Father] had to go to work, you know, and he couldn't be getting up like that...we had no conversation, and what conversation we did have was a fight. ... But now within the last few months as the feeding problems and the sleeping problems have been addressed, it's gotten so much better.

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

While the 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. Changes were evident both in their interactions within the family and their intersections with contextual influences of social networks, resources, healthcare providers, and early intervention. Here a mother explains some of the highs and lows of managing care for her child with a feeding problem.

Um, over time, like back to 10 months up until now, 2 years 2 months, um, just it's been emotional, ...it's very frustrating, it's very um, but it's also very rewarding. Because we see him progress and it's like, I had tears in my eyes the first time he took a bite, ... I think it was grilled cheese or something. ...and it seems so silly, but not to parents who have children with feeding difficulties. It's a miracle. So, it's been like a roller coaster of ups and downs.

Parents noticed that their struggles with managing the feeding situation were not typical compared to 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 jus', I feel kind of defeated. A lot. Because... I feel like there should be something more that I can do and...' I think jus' that feeling of defeat would have to be the biggest thing... 'Cause I can't be the only one. I'm sure. 'Cause it just, I mean feeding your child seems to be such a basic thing that...you would think...it would be easy. But sometimes it just isn't...

Three of the mothers specifically stated the interview had been the first opportunity for them to discuss their child's feeding problems in detail with anyone. Also, the requirements of management for feeding and other closely related conditions made adaptations necessary to create a new way to be a family.

Yeah. I never thought that I would be a stay-at-home mom, ever. You know, I got a [graduate degree] for a reason, you know? Um, but I, 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, I want to be serious about it...I want to pay attention.' ...I just—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.

This father described how he felt a wider view was needed to appreciate overall progress:

I mean I think it's... ... it is a ... it's long term process. You have to be patient. You know every new day comes with its own opportunities. ... It's kind of like the stock market, you know it, if you follow it too closely, every day, you're going to be on a huge roller-coaster... you have to take a long term approach to it. ... I think it's brought our family closer together because it's a common goal that we have to work on, every three hours, every day.

He described how he felt this challenge of feeding difficulty, while it was not what they ever could have planned for, was something that kept their family very close.

The above family had been managing feeding for nearly five years of their child's life.

Other families were newer to the process and related that the impact was living with a lot of uncertainty, and while they were hopeful for the future, it was often difficult to imagine what family life could be like. A mother of a 14 month old described an ambiguity between keeping a “conscious optimism” and still being worried over her daughter's feeding problems and failure to thrive in the back of her mind. She felt trying to think into the future was too overwhelming to consider. Another father said this of feeding management:

Yeah, it needs to be adaptable because we grew up with Evan trying to say, well he needs all he can eat, any time you can get it down, because he's losing weight. It's not looking good. Because that's what the RN's would tell us at the hospital. “Oh he's, give him a schedule, just feed him the next four hours, he'll eat.” And he didn't eat, because he cried too much and, it's just kind of been hard, kind of like a guessing game.

His partner's goals for their son's feeding in the next year were “just to eat enough...I want to keep it very simple. I just want him to eat enough and not fall off the growth charts.”

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 nine of 10 partnered parents, goals were the same for their child's feeding within the next year and five years. Most just wanted their child to eat more, gain or maintain weight, or to advance in textures, variety, and self-feeding. A couple with the most discrepant views on approach to management was still very mutual about goals, "Yes, the end game's the same... The weight gain in post-position here!"

As the mother quoted below states, while their goals may have been quite different, she thought it was because her husband was in denial about the severity of their son's feeding issues.

He was more in denial, and I was more like, "No, there is something wrong and it needs to be fixed." So, he's, he's ok now, ya know. He's like all right we'll do the tube. Ya know, hopefully it won't be that long...um...we'll just have to see what Caden does. He keeps asking. "How long do you think it's gonna be [to have a feeding tube]? How long do you think he's gonna have that?" "Ask Caden! I don't know."

While 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. One father compared his approach to that of his partner saying, "I'm a little more laid-back, but, she's very persistent." A mother of a 30 month old described how she approached feeding management differently from her husband because she was the one with more hands-on experience with feeding, and she knew more how her son would react to certain foods.

I'm not being mean, like that was one thing my husband had a hard time with. He's a kid, like, he'll eat, like one thing that Nolan will eat is [brand name] cookies...Nolan will eat those, but he can't have them, like they have too many ingredients that he can't have, and [the Father] would be like "you're being mean, he's just a kid," and I'm like "OK, you feed it to him, and you watch how the night goes" ...and it's a night he didn't sleep and in the morning you're gonna tell me "you're right" and sure enough, that's how it went.

For the parents with greater discrepancy in their feeding management strategies, they still appreciated this difference in opinions as being complimentary in working towards their mutual goal of weight gain and health for their daughter.

Contextual Influences

Parents discussed four main themes of contextual factors that help or hinder feeding management efforts. These included social network, resources, healthcare providers, and early intervention services (EI). Within each theme, helpful factors will be discussed first. In some cases, parents identified influences that might have been helpful, however they were not present or available.

Social network. The theme of social network included influences from extended family, friends, church nursery, and some interaction with co-workers. Extended family members who influenced feeding management were usually the child's grandparents, but for one single mother, she said, "I had him for the village" in reference to her son, just because her family was very involved with his care day to day. Her son stayed with an aunt a couple times a week and saw his grandparents, aunts, and uncle often. Because his difficulties with sleep disturbance added a layer of complexity to management of his overall care, and she had to work full time, these efforts by extended family to care for the child were something she valued. However, she also pointed out that when she was home with her son, it was just the two of them. "I'm a single parent, I do work full time. I do have a huge support network, but even with a support network, you're still home alone [Laugh]. You know? ... They don't live here." One other parent mentioned a maternal grandmother as

being very understanding and willing to help with feeding, because she was trained in the child's special mealtime protocol and was one of the five people who knew how to feed this little girl. However, this grandmother lived a ways out of town, and could only be physically present to help with feeding occasionally.

Parents in three of the families mentioned grandparents as being least helpful in terms of giving advice that seemed insensitive, saying there was not a problem with feeding, withholding reflux medication when they cared for the child, or insisting that the family go out to eat all together at a restaurant even when the grandchild would definitely not eat there.

Six parents indicated a missing social support resource that they believed would have been helpful. Most of them wanted to be around others who were in a similar situation, so they would be with people who understood their struggles and would not question, for an example, why they had to have an iPad (for reward or distraction) and a high chair (for support) to spoon-feed their three year old.

Everybody has a different thing that frustrates them the most about the whole feeding issue. It's really good to vent every now and then and just have someone recognize that what you're up against is really hard. Just say "gosh, yeah, that sucks." Not necessarily anyone trying to fix it, or give advice. ... for instance a friend who has a child who feeds normally and has never had developmental issues or never been to therapy or admitted to hospital many times... they just don't understand.

The parents in the above family were friends with a family who recently had an infant with a feeding problem, and they were happy to be able to know how to support them. Some parents expressed having a child with a feeding problem as stigmatizing. As above, several parents mentioned a feeling that others did not understand and it was too exhausting to try to explain. One mother said that she intentionally avoided sharing with other people about her son's feeding problems and associated condition, because "what you show of your kid is what people will see and that's all they're gonna see. ...so I don't really tell a lot of people, and I don't really ask for a lot of help." This mother was unique among the sample in wanting to keep the people aware of his condition to a minimum.

Resources. Resources that influenced management of feeding were health insurance, and childcare providers. Two families had Medicaid for their child that helped with coverage of therapies and supplies. Others had to struggle to have expensive special formulas or feeding therapies covered by private insurance. Even when a special medical grade formula was covered by private insurance, the copay could be cost-prohibitive.

A resource that influenced feeding was presence or lack of specialized childcare. Two of the children who attended child care outside the home care were able to eat meals there successfully without having a specially trained feeder. Another child did have a specially trained feeder at pre-Kindergarten. Of the other six children, two were not expected to eat at childcare and were fed once they were home again. “I don’t feel like they keep track of it as close as I do. But, I have to let go because I can’t, I really can’t be there every single second. You know, you need help.”

Others avoided childcare outside the home all together (n=4), specifically because they expected feeding wouldn’t be successful when the child had a different feeder. Typical childcare ratios were also mentioned as a barrier to using childcare outside the home, because the time and attention required to feed their child would not be feasible.

Healthcare providers. This theme appeared frequently. Seven of the nine children were in the care of a specialty children’s hospital clinic. They often had interaction with multiple primary care and specialist physicians, nurses, nurse practitioners, and speech therapists. Main sub themes for healthcare providers were *feeding needs a team approach*, and *mixed messages*.

Feeding needs a team approach. Seven of the nine children were under the care of an interdisciplinary feeding team, and all seven felt supported by that team and that it was helping them to manage and improve their child’s eating. “Honestly, I feel that any time there is a feeding disorder, it needs a team...cause there’s more issues.” This mother was referring to the food allergies, reflux, and sensory processing problems that her son had.

She remarked that the improvement for her son's eating started after they were referred to an interdisciplinary feeding team. However, she felt she had to push to get this referral to the team, as was the case for parents in six of the seven families seeing the team. Another family had taken their child to two different centers, but only one had an interdisciplinary feeding team. The mother said:

...what I really like about being in the [Feeding Team] program is that it is this holistic look at the issue, because [Other Providers]...they don't have feeding therapists that work...hand in hand with GI, that work hand in hand with the nutritionist. ...they have a nutritionist that works with the GI team, but the feeding therapy component wasn't there, and ...it's been so impressive to watch the [Feeding Team] work with each other, bounce ideas off each other, come up with a plan together like everyone getting in the same room at the same time.

Mixed messages. Families received mixed messages from providers, especially when a child was receiving both early intervention (EI) therapy for feeding at home with outpatient feeding therapy. Two families had to rectify different feeding approaches that were taught to them by outpatient feeding therapist and an EI provider. In other instances, conflicting messages came from different members of the healthcare team.

I go to the [outpatient] feeding therapist, and I meet with the nutritionist, and they're saying "Get calories in him." But then they're saying "Nutrients." And so then I get focused on, I think one session I brought some strawberries. And he just won't eat 'em, and the therapist was like "He's not eating those, can we give him something else?" And I was like "But y'all keep telling me that I need to give him healthy stuff!" And it's like, how do I balance the two? And how do I know when to give up on the healthy stuff?

Early intervention. Children ages zero to five with certain levels developmental delay in the United States are covered under the Individuals with Disabilities Education Act (IDEA), and are entitled to EI services. EI is administered by two parts of the IDEA: Part C and Part B. Part C, the infant-toddler program is for zero to three year olds and services are provided to the infant or toddler in a natural environment via an Individualized Family Service Plan (IFSP). Part B is for three and older and is customized for the child's educational needs via an Individualized Education Program (IEP).

EI as gateway to feeding help. Two families directly linked referral to EI services (from IDEA part C and B for children ages zero to five) as the time that they received effective help in managing their child's feeding problems. One mother described the resource of the local infant-toddler program agency for early intervention services (provides EI service coordination, evaluation, therapies, assistive technology, and more for qualifying children) as being the resource that changed their feeding management for the better.

I think that a really pivotal point... for us... was... getting involved with the [infant toddler program] and getting involved with, feeding therapy.... It really gave some structure to how we were approaching it or how we were approaching it, which is good. I feel like I have more of a support system, a team now, of people that are helping me help Ava.

Another parent detailed the initial struggle with the local EI provider to achieve the feeding supports to which their daughter was entitled when she turned three and transitioned to IDEA part B (under school system).

When she turned three and we transitioned to the whole IEP thing..."they aren't going to provide anybody for her feeding delay because that's a medical problem." And at the time I thought, that just sounds wrong to me. ... What I should have been told is, they have to be able to help her eat, *the way* she knows.

This family was able to show their daughter was entitled to having someone at the school to help her eat in the way that she was most successful. The Local Education Agency provided a dedicated feeder who was trained by the mother. Until that point, her mother had to go into school and feed her daughter meals.

Discussion

Overall, the parents in this study described how they developed feeding management strategies for their children as consumers of feeding care in a field where there is little care to choose from. Feeding care was largely piecemeal, 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. Their location, social network, financial resources, and insurance coverage influenced management ability, effort, and impact. Also, for the two single parent families, having to work to support the child who may not fare as well with being fed in a day care was a strain.

As healthcare 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 they participated because they wanted to improve care for children with feeding problems and their families. They were distressed by the lack of awareness of the problem and did not want other families to experience the same struggles. Families most often found their spouse or partner to be helpful, then interdisciplinary feeding teams, then healthcare providers that supported families to manage care and would allow customization of care prescriptions. Last, they seemed often satisfied with the relationship they had with therapy providers that came to the home for feeding, but nearly all families felt those individuals lacked the ability to advance feeding for their child (either due to a limited skill set or lack of access to an interdisciplinary team).

A needed healthcare service would be more interdisciplinary feeding teams spread in a more easily accessible distribution. Also, instead of having to relocate to intensive feeding programs out of state for children who are unable to make the desired progress with feeding in the home setting, it would clearly be better if they could have a more local option. Interdisciplinary feeding teams are rare overall, and those that offer intensive treatment are even more rare.

In other areas there is clearly room for improvement; such as when families indicate missing resources with care coordination and social connections. And as we have seen with one family in particular with the school system, sometimes there are adequate resources or supports available for feeding, but they can be difficult to access, or even unknown to those responsible for providing the services.

This may be the first application of the Family Management Style Framework to the study of a childhood phenotype condition (Knafl et al., 2012). Phenotype conditions are based on presentation of function; in this case functional feeding presentation. Feeding problems are observed as infants and young children are fed. For most of the parents in this study, the feeding problems their children had were evident first to the parent, and then a great deal of time was spent seeking medical confirmation that the feeding situation was other than normal. Pediatric feeding problems are a functional disorder that represents a heterogeneous group of children with many different concurrent conditions. Feeding problems may have a known or unknown genetic contribution, could be due to health history, congenital malformations, and so on, but depending on whether the causes can be ameliorated, the feeding problem may be resolved someday.

Children with feeding problems have changing presentations and nutritional needs as they grow and develop. Unlike other childhood chronic conditions, there is no set management regimen to be applied across their lifetime, nor is there a gold standard treatment. Parents managing feeding problems in this study expended large amounts of mental and physical energy and efforts in management of a poorly defined problem, and often felt unable to manage. Parents described a struggle to find their own way to an unclear destination, while on a journey of indeterminate duration.

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 feeding care coordination, a lack of guidance on feeding when there is a significant feeding problem, and communication within immediate family and then with extended 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 picture of care management for a child with (for all but one child) multiple conditions. Parents in this study described how they were on an uncharted path to find what was wrong that their child would

not eat as typically expected. Parents described having communication struggles within family between partners, and also with extended family. A previously untapped provider to help with these management challenges would be a family nurse coordinator. The family nurse could coordinate between early intervention and medical providers, could partner with families, and assist them in setting goals meaningful to the family to help them have the life they would enjoy most. A family nurse could also facilitate conversations to improve communication regarding the feeding problem and management, and then work through any management discrepancy.

In this study, children with feeding problems were identified as an eater by *what* and *how* they ate, and how that was different from what they expected and saw in other children. Parents saw this as making their family different, and most felt homebound by the specific adaptations required to make feeding successful. The stigma associated with having a child who does not eat as their typically developing peers can contribute to this home bound situation, but also reinforces the current lack of awareness by laypersons and primary care providers alike.

Table 4.1.

Start List of Code Categories from FaMM and FMSF

| FaMM Scale¹ | Definition of Scale |
|--|--|
| Child's Daily Life/Child Identity | The extent to which parents view their child's everyday life as normal despite the feeding problems. |
| Feeding Management Ability | Parental perceptions of their ability to manage their child's feeding problems. |
| Feeding Management Effort | The time and work parents perceive themselves devoting to management of their child's feeding problems. |
| Family Life Difficulty | The extent to which parents view their child's feeding problems as making life difficult. |
| View of Condition Impact | Parental perception of the seriousness of the child's feeding problems and its future implications for the child and family. |
| Parent Mutuality | For partnered parents; the extent to which parents have shared or discrepant views of the feeding situation and approach to management. |
| Contextual Influences from FMSF² | Definition |
| Social Network | Extended family (beyond household), friends, church, specialized organizations or groups, virtual and in-person |
| Resources | Insurance, Medicaid, \$, assistance with feeding help People who can be called on for more than social networking, they are called on to help manage feeding (e.g., nannies, babysitters) |
| Healthcare Providers | Healthcare personnel (Nurses, Doctors, Speech Therapists or any therapists in Hospital) |
| Early Intervention | Individual Family Service Plans, Individual Education Plans, Intervention or accommodation in natural setting or in school for feeding |

¹(Knafl et al., 2011); ²(Knafl et al., 2012)

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CHAPTER 5: DISCUSSION

The studies of this dissertation are the building blocks for a foundation of a program of research, which will begin to address the need for family-centered research for children with feeding problems. This beginning work synthesized literature across disciplines to analyze the concept of pediatric feeding problems, and proposed a working conceptualization of the problem as occurring along a spectrum. A current barrier to research, assessment, diagnosis, and treatment of feeding problems in children, is the lack of a shared conceptualization of the issue across the disciplines. I examined shared and discrepant views on feeding problems across disciplines in Chapter 2 (including, but not limited to: medicine, nursing, speech-language pathology, occupational therapy, and psychology). The two foundational attributes 1) problematic feeding (mealtime) behavior and 2) restrictive or selective intake, were also found in data from parent perspectives in Chapter 3. A spectrum conceptualization of pediatric feeding problems was suggested along with a systematically constructed list of assessment constructs. Psychometrically sound measures for these constructs would complete a feeding profile for a child and family and allow for personalized intervention.

Following the evolutionary concept analysis, further understanding of the concept from the perspective of the family was a next step in concept development. In Chapter 3, a parent perspective on the concept of pediatric feeding problems added understanding of how parents defined their child's feeding problems, the related preceding events or child conditions, and consequences. While parents shared common foundational attributes with the professional disciplines represented in the literature sample (see Chapter 2; problematic eating behaviors and restrictive or selective intake), parents' perspectives revealed that they

saw the feeding problem as beginning much earlier than when their child received specialized feeding help. Also parents conceptualized pediatric feeding problems much more as a process or a journey. The child's feeding problem was an issue that impacted the whole family. Knowing parent perspectives of pediatric feeding problems will contribute to the development of pragmatic research design and intervention (Glasgow, 2013). This type of study would include parent input in the design and would address outcomes of the problem that are important to families.

Lastly in Chapter 4, the family management of pediatric feeding problem study was a presentation of 12 interviews from nine families of children with feeding problems. Guided by the Family Management Style Framework (Knafl, Deatrick, & Havill, 2012) the findings from this study were numerous. Most pertinent implications to come from the analysis are as follows:

- Parents identified their child by what they ate and how they ate (i.e. a child who was three years old would be identified as eating like an infant if they ate pureed foods and needed to be fed by a caregiver).
- Parents perceived family management effort as high and family management ability as low when mealtime success was less predictable.
- Family life difficulty came primarily when feeding management strategies kept families at home in order for meal times to be successful for the child.
- View of feeding management impact on the family was quite high at the time of the interviews for eight of the nine families. However, most parents were hopeful it would impact the family less in the future as the child's eating improved.
- Parents who were married or had a partner (seven of the nine families) were highly mutual on long term goals for their child's feeding and eating. There was limited

discrepancy on some of the day-to-day strategies to best achieve those long-term goals.

- Parents identified contextual influences on family management of child feeding problems to be social network, healthcare providers, Early Intervention (EI), and resources. Feeding teams were noted as being most helpful for feeding management success.
- Parents reported feeding management barriers to be communication difficulty among care providers for care coordination for feeding, related medical, and developmental conditions between healthcare, schools, and home.

Future Directions for Research

Unclear or siloed conceptualizations of pediatric feeding problems have stymied research efforts to track the significance, prevalence, and etiology of childhood feeding problems. It is widely agreed upon that interdisciplinary teams for feeding care are ideal; however there is not a shared or valid diagnostic language of classification of feeding problems that is used across disciplines clinically or in research. Further concept development of pediatric feeding problems as a spectrum condition is needed, along with concurrent development of measures to assess the key attributes for constructs of the problem.

Studies are needed to describe the gap in research between the neonatal period and the average age of arrival at specialty feeding care reported in the literature (approximately two years of age) (Rommel, De Meyer, Feenstra, & Veereman-Wauters, 2003). This will illustrate the need for prospective, longitudinal studies on this topic with infants at higher risk for development of feeding problems. Another needed area for research is to identify the parent and family experience of pediatric feeding problems as a phenotypic condition occurring along a spectrum of functional severity. This conceptualization will be critical to

design pragmatic intervention research. Parents are the most proximal agents for change in the home environment and will manage feeding in day-to-day life. While other health conditions introduce an entirely new set of challenging management skills (i.e. asthma, diabetes), these needed skills are known and have well established gold standards. On the other hand, pediatric feeding problems require extremely personalized and non-intuitive feeding management, all while families are typically without appropriate health care support. I am working to identify what has been helpful (or not) and how families find their way to a sustainable feeding management practice.

Validated parent-report instruments for assessment of attributes of an infant or young child's feeding problem are essential for the establishment of sound description of this condition and to measure meaningful outcomes. The concepts relevant to this work will be similar to those that were critical attributes of pediatric feeding problems from Chapter 2, followed by the other attributes that may or may not be present. The science would benefit from having these measures validated with the stakeholders involved. With these measures, longitudinal studies could be conducted to describe this problem and discover which interventions could be most effective for an individual child and family. Trajectory science may be a good fit to develop family-centered interventions for infants and young children with significant feeding problems. Identification of the severity and which interventions work to help make successful feeding fit well within every day family life will help in a meaningful way to families.

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APPENDIX A: FAMILY INFORMATION FORM

Today's Date ___/___/___

What is your child's age? _____

What is your child's gender? ___ Male ___ Female

What is your child's current mode of feeding? (*choose all that apply*)

- | | |
|--|--|
| <input type="checkbox"/> Breastfeeding | |
| <input type="checkbox"/> Expressed breast milk via cup or bottle | <input type="checkbox"/> Soft, chopped foods |
| <input type="checkbox"/> Infant formula | <input type="checkbox"/> Table foods that require chewing or biting |
| <input type="checkbox"/> Milk or dairy alternative, such as soymilk or almond milk | <input type="checkbox"/> Eats more than one type of fruit |
| <input type="checkbox"/> Cereals: rice, oat, barley | <input type="checkbox"/> Eats more than one type of vegetable |
| <input type="checkbox"/> Meltables: puffs, cereal, crackers | <input type="checkbox"/> Eats more than one type of protein (meats, yogurt, nuts, soy) |
| <input type="checkbox"/> Store-bought foods that are pureed | |
| <input type="checkbox"/> Homemade foods that are pureed or mashed | |

Choose all of your child's protein sources:

- ☐ Plant (beans, nuts, soy)
☐ Animal (chicken, beef, pork)
☐ Dairy (eggs, cheese, yogurt)

Is your child vegetarian? ___ Yes ___ No

Do you think your child has a feeding problem? ___ Yes ___ No ___ Not Sure

If yes, when do you think it started _____

Does your child currently:

- snore when he/she sleeps? ___ Sometimes ___ No ___ Not Sure
have large tonsils or adenoids? ___ Yes ___ No ___ Not Sure
breathe through his/her mouth? ___ Sometimes ___ No ___ Not Sure.
have bad or sour breath? ___ Sometimes ___ No

Did your child have a food allergy test?

- ☐ No
☐ Elimination testing
☐ Blood test

____ Skin prick

Does your child have diagnosed food allergies? ____ Yes ____ No

If yes, choose all that apply:

____ Egg

____ Tree nut

____ Shellfish

____ Milk

____ Peanut

____ Fish

____ Soy

____ Wheat

O Other – Please specify ____

Do you think your child has food allergy or food intolerance? ____ Yes ____ No ____ Not Sure

If yes, choose all that apply:

____ Lactose

____ Tree nut

____ Fish

____ Egg

____ Peanut

____ Other – Please specify _____

____ Milk

____ Wheat

____ Soy

____ Shellfish

Do any of your child's family members (siblings, parents, and grandparents) have food allergies?

____ Yes ____ No

If yes, choose all that apply:

____ Egg

____ Peanut

____ Other – Please specify _____

____ Milk

____ Wheat

____ Soy

____ Shellfish

____ Tree nut

____ Fish

Has your child seen any of the following professionals because of feeding issues? (choose all that apply).

Within the last 6 months:

____ No, has not seen anyone for feeding issues in last 6 months

____ Physical therapist

____ Feeding specialist

____ Dietician/Nutritionist

____ Speech therapist

____ Psychologist

____ Pediatrician / Nurse Practitioner

____ Other- Please specify: _____

____ Occupational therapist

Prior to the last 6 months:

☐ No, has not seen anyone for feeding issues prior to the last 6 months

| | |
|--|---|
| <input type="checkbox"/> Feeding specialist | <input type="checkbox"/> Physical therapist |
| <input type="checkbox"/> Speech therapist | <input type="checkbox"/> Dietician/Nutritionist |
| <input type="checkbox"/> Pediatrician / Nurse Practitioner | <input type="checkbox"/> Psychologist |
| <input type="checkbox"/> Occupational therapist | <input type="checkbox"/> Other- Please specify: _____ |

Do you think or have you been told that your child has reflux? ☐ Yes ☐ No

Is your child currently taking any medicines for gastroesophageal reflux or GERD? ☐ Yes ☐ No

Has your child had any feeding tests? (such as a swallow study, upper GI, pH probe) ☐ Yes ☐ No

Is your child given foods to help with digestion (such as soy formula, carnation good start, nutramigen, alimentum)? ☐ Yes ☐ No
If yes, which one(s)? _____

Is your child given foods to help him/her grow (such as high calorie supplements, Pediasure, Duocal)? ☐ Yes ☐ No

If yes, which one(s)? _____

Does your child currently have a feeding tube? ☐ Yes ☐ No

If yes, what type of tube? ☐ G-Tube ☐ NG Tube

How much of your child's diet is given through a tube each day? (*choose one*)

☐ none ☐ less than 25% ☐ 25-50% ☐ 50-75% ☐ 75-100%

How would you describe your child's weight at the moment?

☐ Very underweight, ☐ somewhat underweight, ☐ normal, ☐ somewhat overweight, ☐ very overweight

At your last visit with your child's health care provider, how did they describe your child's weight?

☐ Very underweight, ☐ somewhat underweight, ☐ normal, ☐ somewhat overweight, ☐ very overweight

Developmental History (please enter approximate age your child first did these things, or if not doing these yet, leave blank)

☐ Prop up on elbows while on stomach

☐ Say words

☐ Sit up

___ Combine words

___ Mouth toys

___ Crawl

___ Walk

___ Cruise (walk holding furniture or objects for support)

___ Imitate sounds/words/gestures

Birth and Early Feeding History

Babies are considered to be born full term if they are born between 37 and 42 weeks gestation. Was your child born before 37 weeks? ___ Yes ___ No

If yes, how many weeks before your due date was your child born? _____

What was your child's birth weight? _____ pounds, kilogram, or gram (make drop down boxes for the unit)

How was your baby fed after they came home? (choose all that apply)

___ Breastfeeding, if yes, how long?

___ Bottle, expressed breast milk, if yes, how many months?

___ Bottle, formula or others, if yes how many months?

___ Tube, if yes how many months?

Did your baby start eating solid foods in their first year? ___ Yes ___ No

If yes, approximately at what age?

Which of the following describe your child's eating during infancy (0-12 months)? (choose all that apply)

___ No concern

___ Spit up/ vomited regularly

___ Difficult bottle feeding

___ Multiple formula changes

___ Difficult breastfeeding

Questions About You and Your Family

What is your relationship to your child?

___ Mother or Mother Figure

___ Father or Father Figure

___ Other (specify): _____

What is the highest education you completed?

___ Grade School / Middle School

___ College

___ High School

___ Graduate School

___ Technical School /Community College

How many adults live in your household? _____

How many children live in your household? _____ Ages: _____

Please describe the family type where your child spends most of their time

☐ Two parent family

☐ Single parent family

☐ Other family type (specify): _____

What is your household's approximate yearly income (before taxes)?

☐ Less than
\$20,000

☐ \$40,000 to
\$49,999

☐ \$70,000 to
\$79,999

☐ \$20,000 to
\$29,999

☐ \$50,000 to
\$59,999

☐ \$80,000 to
\$89,999

☐ \$30,000 to
\$39,999

☐ \$60,000 to
\$69,999

☐ \$90,000 to
\$99,999

☐ Over \$100,000

Where do you live? _____ Country _____ State, if US _____ County, if NC

Which of the following describe your race/ethnicity? (*choose all that apply*)

☐ American Indian or Alaskan Native

☐ Native Hawaiian or other Pacific
Islander

☐ Asian

☐ White

☐ Black or African American

☐ Other (if desired, specify): _____

☐ Hispanic or Latino

Which of the following describe your child's race/ethnicity? (*choose all that apply*)

☐ American Indian or Alaskan Native

☐ Asian

☐ Black or African American

☐ Hispanic or Latino

☐ Native Hawaiian or other Pacific Islander

☐ White

☐ Other (if desired, specify): _____

APPENDIX B: FAMILY MANAGEMENT INTERVIEW GUIDE

Interview Guide

To avoid sensitizing the parent to the topic of tube feeding, all questions specifically pertaining to this will be reserved for once parent responses lead to the topic of tube feeding. Otherwise, if the parent does not lead the interview to the topic of possible tube feeding, the interviewer will ask tube related questions at the end of the interview.

Opening

I would like to thank you for taking the time to talk to me about how you feed your child. The questions I will ask are to learn how your family manages feeding, and feeding is something that is known to be pretty difficult at times. Because parents sometimes feel there are a lot of expectations about feeding children, we have seen that for some people it can be deeply frustrating when feeding is not what was expected. The questions I'm about to ask are not meant to upset you in any way, but if at any time you would like to stop, please don't hesitate to let me know. Or, if you think of something else you would like me to know that I haven't asked that is important for how your family manages feeding your child, please feel free to tell me. This is a research study. I am required to tell you that if any evidence of abuse or neglect is shared with me I am mandated to report this by the state. Also though, please know that I am a nurse who can discern the difference between a child who doesn't eat well and one who is abused or neglected. I myself have a child who was diagnosed as failure to thrive and know that nearly all parents of children with feeding difficulty are extremely caring and concerned for their children.

****If I will also be, or have already interviewed your partner, please know that both of your responses will be kept confidential. I will not share what you say with them, or what they say with you.***

When did you first notice [your child] had a feeding problem?

Child's Daily Life -The extent to which parents view their child's everyday life as normal despite the feeding disorder.

Tell me about your child's day.

How would you describe your child's day in comparison to other children his [or her] age?

Tell me about your child's mealtimes.

What do you see your child do at mealtime that tells you there might be a problem with their eating?

Compared to other children your child's age, how would you describe your child's mealtimes?

How do these mealtimes fit within your family's life?

How would tube placement change your child's daily life?

How would it change your life?

Condition Management Ability - Parental perceptions of their ability to manage their child's feeding disorder.

Tell me about some of the aspects of feeding [child's name] you think you manage well.

What are some things you feel less able to manage?

What gets in the way of managing your child's feeding?

What helps or guides you to manage your child's feeding?

Condition Management Effort - The time and work parents perceive themselves devoting to management of their child's feeding disorder.

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?

What would the job description be?

What would they need to know or learn?

How long would it take to train someone for this job?

How much of your day is spent actually feeding your child?

How much time every day would you say you think about your child's feeding?

How do you think tube placement might change the time spent managing your child's feeding?

Family Life Difficulty - The extent to which parents view their child's feeding disorder as making life difficult.

How does feeding your child fit into family life?

If you were to make support group topics for families of children with feeding problems, what do you think would be most important to discuss?

Could you tell me about what is difficult about feeding your child?

Besides "fixing" your child's eating, what might make [the difficult thing] easier for you and your family?

View of Condition Impact - Parental perception of the seriousness of the child's feeding disorder 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?

How do you see this impacting your family in the future?

What hopes/goals do you have for your child's eating in...the next year? In five years?

How do you see your child's eating in...the next year? In five years?

If your child gets a feeding tube, how would you describe your goals from that point?

How do you feel about feeding tubes in general?

How do you feel about your child possibly having a feeding tube?

Contextual Influences – Social networks, care providers and systems, and resources identified by the family.

What things or people outside of your immediate family influence how you manage feeding your child (this could be anything in the community, providers, your friends, extended family, therapy, healthcare, etc.)?

Sometimes families are unsatisfied with the help they receive, or they might find excellent help in unexpected places. Can you tell me more about your experiences with the [above mentioned resource(s)]? What has been most helpful for you in managing feeding? What has been least helpful? Have you felt there was anything from outside your family that interfered with feeding your child? Is there a resource that you feel is lacking/doesn't exist, but should?

Parent Mutuality –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?

How much would you say you and your partner have in common with how you want to manage feeding?

How would you describe your partner's approach to managing your child's feeding?

How similar is this to your own approach?

You said earlier you have [X previously mentioned goals] for your child's eating in the future. How much would you say your partner shares these goals?

Closure - Debriefing

What else, if anything, would you like to tell me about [child's name]'s eating?

Is there anything you think would be important to ask other families that I have left out?

Is there anything else you want me (a researcher) to know about your family life and feeding your child?

As a parent of a child with feeding disorder, I know this can be difficult to talk about at times and this focused research interview might leave you with a leftover uncomfortable feeling. I would like to tell you that while it can feel very isolating to have a child who won't or can't eat, there are other families out there in similar situations. [make affirming statement related to something parent has done or observed]. I appreciate your time in sharing with me your

family's story. If you have any questions about your involvement in this study please do not hesitate to contact me.

*This working guide is an anticipated set of questions and can be changed from family to family as necessary. Further, interview data will inform questions for future interviews. Major decisions (i.e., changes in order of concepts addressed) will be made in consultation with the study advisor.