



CONCEPT OF
Pediatric
Feeding Problems
FROM THE PARENT PERSPECTIVE

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Abstract

Purpose: Feeding difficulties 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 no input from families in the conceptualization. Lack of common language is a barrier to effective communication between clinicians, researchers, and caregivers, and inhibits collaboration. The purpose of this study was to examine the conceptualization of pediatric feeding problems by family caregivers (parents).

Study Design and Methods: This study reports an empirical phase of a concept analysis. Data from interviews with 12 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 providers' point 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.

Key words: Enteral feeding; Failure to thrive; Feeding and eating disorders of childhood; Feeding behavior.

Feeding difficulties in early childhood are common. Approximately 25% of typically developing children and up to 80% of children with developmental disabilities have problematic feeding (Manikam & Perman, 2000). Feeding problems can occur from birth through age 18; although highest incidence is reported between 6 months and 4 years of age (Aldridge, Dovey, Martin, & Meyer, 2010). Unlike eating disorders, such as anorexia, where body appearance is a motivating factor to not eat, children with feeding problems have no such motivation. Also, the term *feeding* is differentiated from *eating* because young children are within a developmental age where a caregiver provides them with food; therefore, they are feeding or being fed (American Psychiatric Association [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 (APA, 2013b). Historical changes in 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

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 (Berry, Hall,

Cohen, O'Neill, & Feudtner, 2015). With increased survival of these infants and children, several sources report an increasing prevalence of feeding problems (Arvedson & Brodsky, 2002; Thoyre, 2007), although definitive statistics are not available.

Enjoyment of food is a social and family activity that is inextricably linked with quality of life day-to-day (Craig & Scambler, 2006; Sleight, 2005). As children with feeding problems often have coexisting 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 and contribute to parents' willingness and capacity to sustain interventions over time.

Background of the Conceptualization of Feeding Problems

There is conceptual discrepancy among disciplines that care for children with feeding problems (Kerwin, 2003). 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 on how they should be treated (Chatoor,

Classifications of feeding problems used by healthcare providers have been perceived as stigmatizing by family members.

2002; Davies et al., 2006; Kerwin, 2003). Attributes of pediatric feeding problems vary greatly across disciplines as range of issues with feeding spans selective eating to food refusal.

Feeding problems have been defined from viewpoints of the healthcare provider (APA, 2013b; Marshall et al., 2014), but not from the viewpoint of the parents who manage feeding day-to-day. Despite some literature in which healthcare professionals report that parents express anxiety about feeding their child (Batchelor, 2008; Sleigh, 2005), there have been no efforts to gather data directly from parents in defining the problem. Although there have been varied attempts at classification by clinicians, there is not a valid classification or diagnostic tool for pediatric feeding problems (APA, 2013b). Classifications currently in use by providers (such as nonorganic failure to thrive) have been perceived as stigmatizing by parents (Batchelor, 2008; Craig & Scambler, 2006). Thomlinson (2002) found that parents of children who refuse to eat or have restrictive eating often felt isolated and blamed for the problem. In order for providers to deliver effective family-centered care and for researchers to plan and conduct relevant translational studies, it is necessary to learn how parents define the problem from their day-to-day experience. The purpose of this analysis was to examine parents' perspectives of pediatric feeding problems 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) in care for a significant feeding problem (i.e., a diagnosis of failure to thrive or feeding difficulty). The primary study sought to describe how parents managed their child's feeding in day-to-day life through individual parent's interviews guided by the Family Management Style Framework (FMSF) (Knafl & Deatrick, 2003; Knafl, Deatrick, & Havill, 2012). English-speaking parents age 18 years or older were recruited if they identified as having a child with feeding problems and met the above screening criteria. Ten of 12 parents were recruited from an outpatient feeding specialty clinic in the eastern United States and the remaining two via convenience referral. The interview guide was semistructured with questions that addressed all components of the FMSF. A key component of the FMSF, and the focus of this analysis, is the parent's definition of their child's chronic condition, in this case feeding difficulty.

We used a concept analysis framework (Rodgers & Knafl, 2000) 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/preexisting 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 parents' interviews. Early in the process, a second coder reviewed three

coded transcripts with differences resolved through discussion and consensus. Qualitative content analysis (Miles & Huberman, 1994) of coded data was used to identify themes within each conceptual component. Analysis was facilitated by use of Atlas.ti (Scientific Software Development GmbH, Berlin), 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 were completely reliant on oral feeding for nutrition. Two of these children previously had gastric feeding tubes that had been removed prior to the time of the interview. Children's ages at the time of interview ranged from 14 months to 4.5 years (mean 2.3 years). Annual household incomes ranged from \$20–29,000 to >\$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 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, 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 most often discussed by parents were developmental delay ($n = 9$) and poor sleep ($n = 5$). For a list, see Table 1; these related concepts were not mutually exclusive (i.e., a child could have more than one). Parents of two of the children in the study described feeding problems that occurred at the transition to solids from bottle or breastfeeding as an early indication of autism spectrum disorder.

Antecedents

Antecedents are events or conditions that parents viewed as occurring with or preceding the feeding problem. Antecedents to feeding problems that parents most identified included the list of related concepts or co-occurring conditions previously mentioned, but also included preceding diagnoses, events, or changes in condition, such as breastfeeding difficulties ($n = 5$), preeclampsia ($n = 2$), and preterm birth ($n = 2$). Parents did not always describe antecedents as a cause for the feeding problem, but did express as relevant to the child's feeding problem history. All but one of the children experienced more than three related concepts and antecedents (antecedents in Table 2).

Attributes of the Feeding Problem

Attributes of the feeding problem are features or characteristics of the problem. Main themes of attributes of feeding problems were *problematic feeding behaviors* displayed by the child and *selective or restrictive eating*. These were followed in prevalence by child growth



Components of the family's journey with their child's feeding difficulties collectively frame conceptualization of the problem for the child and family.

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 as follows.

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, known or suspected food allergy, volume-limiting, and/or distinct preferences for food presentation. Parents reported varying degrees of restrictive or selective eating as being a characteristic of their child's feeding problem. 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. 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. Although 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 parents 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 6 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 6 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."

Table 1.
Related concepts to feeding difficulty

Related concept	n
Developmental delay	9
Poor sleep	5
Low muscular tone	4
Autism spectrum disorder	3
Food allergies, constipation, gastroesophageal reflux	3 per concept
Colic	2
Fragile X Syndrome, Williams Syndrome, hemiplegia	1 per concept

Note: Total sample size was 9 children.

Table 2.
Antecedents to feeding difficulty

Antecedent	n
Breastfeeding difficulty	5
Aspiration and choking, ankyloglossia	3 per antecedent
Greater than 10% weight loss after birth	2
Preterm birth, preeclampsia	2 per antecedent
Delayed eruption of teeth	2
Newborn hospital stay unrelated to preterm birth	2

Note: Total sample size was 9 children.

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 previously, changes in the problem were often described as being on a "roller coaster," three parents of three different children used this description. Parents described the ups and downs of their child's feeding problems; this contributed to their thinking of the problem as a journey.

Consequences

Consequences of the child's feeding problem were their effects. Main themes of consequences 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, including 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. Parents of five of the children reported if they did go out to a restaurant with their child, extensive advance planning was needed 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 preschool 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 typical for their age.

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 prekindergarten 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



All children with feeding problems in this study had problematic feeding behaviors and restrictive or selective food intake.

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 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 attributes are often found in literature from involved disciplines (Aldridge et al., 2010; Piazza et al., 2003) and may be common ground for a shared conceptualization of the problem. *Growth concerns* or *FTT* were common feeding problem attributes from the parents' interviews.

Unique to the parents' 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 parents described the problem and how they manage it in daily life. This is a vantage that healthcare providers do not have. The journey consists of turning points, setbacks, and milestones for these children and their families. Components of the journey collectively frame the conceptualization of the problem for the child and family. Parents 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. Healthcare 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.

Feeding service clinics report the average age for onset of specialty feeding problem treatment is 25 months of age (Rommel, De Meyer, Feenstra, & Veereman-Wauters, 2003). In this study, parents identified this lag in attention to feeding problems, and this time itself was full of tension and frustration by parents seeking help for their child. Feeding problems are a journey due to chronicity of the problem overlaid with infant/child development. Nurses can help during this time 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 nurse scientists could lead collaborative research projects to examine prevalence of this issue within their institutions, to ask parents what they need and what they think their children need.

A 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 (Sharp, Jaquess, Morton, & Herzinger, 2010). However, parents spoke of tube feeding as the necessary result of a significant feeding problem and more of an alternate nutritional delivery mode; some-

Clinical Implications

Consider the child to have a feeding problem if parents report *problematic feeding behaviors and restrictive or selective intake*.

Partner with families as they adapt to and manage an often arduous and challenging journey of feeding care.

Assess for unmet care needs and help to design a plan that will be sustainable within day-to-day family life.

thing 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 the parents in this study whose children previously used a feeding tube, management of feeding was 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 New 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 person and family-centered interdisciplinary research and practice. This study is a step toward a new conceptualization of pediatric feeding problems. Identification of consensus between professional disciplinary perspectives in the literature and parents' perspectives on feeding problem attributes is needed. Problematic feeding behaviors and restrictive or selective intake are the consensus attributes of feeding problems from this study, and could serve as two critical attributes of pediatric feeding problems.

A child who presents with these two attributes could be considered to be on a spectrum of feeding problems, and all other features could 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, they were not essential for a feeding problem to exist. Not all children with feeding problems will have FTT, but it is possible that all children with feeding problems will have problematic feeding behaviors and restrictive or selective food intake. Within the new conceptualization, family impact and management would play a part, as this is a feeding problem and at the very least, a caregiver-child dyad is needed to make feeding happen.

During assessment for feeding problems, the family should be part of the team.

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 be considered when evaluating and treating a child for feeding issues. Pediatric nurses can support patient and family-centered care of children with feeding problems by partnering with parents and other caregivers by asking for parent input, creating and affirming common care goals, and assuring the parent that their unique insights and experiences with the patient are important (Dokken, Parent, & Ahmann, 2015). Nurse family care coordinators could assess for unmet care needs and help to design a plan that will be sustainable within day-to-day family life. Children with developmental delay and feeding problems fit into the categorization of children with special healthcare needs (CSHCN); and parents of CSHCN report higher unmet needs and higher rates of specialty care use than in the general care population (Boudreau et al., 2014). Boudreau et al. (2014) found that among CSHCN, those with care coordination had lower levels of unmet needs. In this study, parents described feeding problem as being a journey where they sometimes felt unable to manage difficult feeding and they did not know where to go for help. The personalized assistance and ongoing support of a family-centered nurse coordinator could have made a positive difference. With patient and family-centered care, acknowledgment of the need for emotional and social support is important (Dokken et al., 2015). Parents in this study reported feeling they were on a roller coaster of ups and downs with successes and setbacks.

When a child receives the diagnosis of FTT, parents may associate that with a personal parenting failure (Thomlinson, 2002). Although not every child in the current study was diagnosed with FTT, the close association and overlap in attributes with feeding problems point to a need to rework the classification in a family-centered way. 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 parents' 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 family-centered nurse coordinator could work with patient and family to define the situation in a way that is meaningful to them. Parents in this study related aspects of the chronic nature of feeding problems and impacts this had on their child, their selves, and their family. Without asking the family, such issues would go unnoticed by those healthcare professionals who set goals, sug-

gest strategies, provide therapy recommendations, and document progress.

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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References

- Aldridge, V. K., Dovey, T. M., Martin, C. I., & Meyer, C. (2010). Identifying clinically relevant feeding problems and disorders. *Journal of Child Health Care, 14*(3), 261-270. doi:10.1177/1367493510370456
- American Psychiatric Association. (2013a). *Diagnostic and Statistical Manual of Mental Disorders (DSM-5[®])*. Arlington, VA: American Psychiatric Pub.
- American Psychiatric Association. (2013b). *Highlights of changes from DSM-IV-TR to DSM-5* [Press release]. Retrieved from www.dsm5.org/Documents/changes%20from%20dsm-iv-tr%20to%20dsm-5.pdf
- Arvedson, J. C., & Brodsky, L. (2002). *Pediatric swallowing and feeding: Assessment and management* (2nd ed.). Albany, NY: Thompson Delmar Learning.
- Batchelor, J. (2008). 'Failure to thrive' revisited. *Child Abuse Review, 17*(3), 147-159. doi:10.1002/car.1018
- Berlin, K. S., Lobato, D. J., Pinkos, B., Cerezo, C. S., & LeLeiko, N. S. (2011). Patterns of medical and developmental comorbidities among children presenting with feeding problems: A latent class analysis. *Journal of Developmental and Behavioral Pediatrics, 32*(1), 41-47. doi:10.1097/DBP.0b013e318203e06d

- Berry, J. G., Hall, M., Cohen, E., O'Neill, M., & Feudtner, C. (2015). Ways to identify children with medical complexity and the importance of why. *The Journal of Pediatrics*, *167*(2), 229-237. doi:10.1016/j.jpeds.2015.04.068
- Boudreau, A. A., Perrin, J. M., Goodman, E., Kurowski, D., Cooley, W. C., & Kuhlthau, K. (2014). Care coordination and unmet specialty care among children with special health care needs. *Pediatrics*, *133*(6), 1046-1053. doi:10.1542/peds.2013-2174
- Chatoor, I. (2002). Feeding disorders in infants and toddlers: Diagnosis and treatment. *Child and Adolescent Psychiatric Clinics of North America*, *11*(2), 163-183. doi:10.1016/S1056-4993(01)00002-5
- Craig, G. M., & Scambler, G. (2006). Negotiating mothering against the odds: Gastrostomy tube feeding, stigma, governmentality and disabled children. *Social Science & Medicine*, *62*(5), 1115-1125. doi:10.1016/j.socscimed.2005.07.007
- Davies, W. H., Satter, E., Berlin, K. S., Sato, A. F., Silverman, A. H., Fischer, E. A., ..., Rudolph, C. D. (2006). Reconceptualizing feeding and feeding disorders in interpersonal context: The case for a relational disorder. *Journal of Family Psychology*, *20*(3), 409-417. doi:10.1037/0893-3200.20.3.409
- Dokken, D., Parent, K., & Ahmann, E. (2015). Family presence and participation: Pediatrics leading the way ... and still evolving. *Pediatric Nursing*, *41*(4), 204-206.
- Dovey, T. M., Isherwood, E., Aldridge, V. K., & Martin, C. I. (2010). Typology of feeding disorders based on a single assessment system. *ICAN: Infant, Child, & Adolescent Nutrition*, *2*(1), 52-61. doi:10.1177/1941406409360038
- Fischhoff, J., Whitten, C. F., & Pettit, M. G. (1971). A psychiatric study of mothers of infants with growth failure secondary to maternal deprivation. *The Journal of Pediatrics*, *79*(2), 209-215. doi:10.1016/S0022-3476(71)80103-8
- Gottrand, F., & Sullivan, P. B. (2010). Gastrostomy tube feeding: When to start, what to feed and how to stop. *European Journal of Clinical Nutrition*, *64*(Suppl. 1), S17-S21. doi:10.1038/ejcn.2010.43
- Kedesdy, J., & Budd, K. (1998). *Childhood feeding disorders: Biobehavioral assessment and intervention*. Baltimore, MD: Paul H. Brookes Publishing Co.
- Kerwin, M. (2003). Pediatric feeding problems: A behavior analytic approach to assessment and treatment. *The Behavior Analyst Today*, *4*(2), 162-176. doi:10.1037/h0100114
- Knaf, K., & Deatrick, J. (2003). Further refinement of the family management style framework. *Journal of Family Nursing*, *9*(3), 232-256.
- Knaf, K. A., Deatrick, J. A., & Havill, N. L. (2012). Continued development of the family management style framework. *Journal of Family Nursing*, *18*(1), 11-34. doi:10.1177/1074840711427294
- Manikam, R., & Perman, J. A. (2000). Pediatric feeding disorders. *Journal of Clinical Gastroenterology*, *30*(1), 34-46. doi:10.1097/00004836-200001000-00007
- Marshall, J., Hill, R. J., Ziviani, J., & Dodrill, P. (2014). Features of feeding difficulty in children with Autism Spectrum Disorder. *International Journal of Speech-Language Pathology*, *16*(2), 151-158. doi:10.3109/17549507.2013.808700
- Miles, M., & Huberman, M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Piazza, C. C., Fisher, W. W., Brown, K. A., Shore, B. A., Patel, M. R., Katz, R. M., ..., Blakely-Smith, A. (2003). Functional analysis of inappropriate mealtime behaviors. *Journal of Applied Behavior Analysis*, *36*(2), 187-204. doi:10.1901/jaba.2003.36-187
- Rodgers, B. L., & Knaf, K. A. (2000). *Concept development in nursing: Foundations, techniques, and applications*. Philadelphia, PA: Saunders.
- Rommel, N., De Meyer, A. M., Feenstra, L., & Veereman-Wauters, G. (2003). The complexity of feeding problems in 700 infants and young children presenting to a tertiary care institution. *Journal of Pediatric Gastroenterology and Nutrition*, *37*(1), 75-84. doi:10.1097/00005176-200307000-00014
- Sharp, W. G., Jaquess, D. L., Morton, J. F., & Herzinger, C. V. (2010). Pediatric feeding disorders: A quantitative synthesis of treatment outcomes. *Clinical Child and Family Psychology Review*, *13*(4), 348-365. doi:10.1007/s10567-010-0079-7
- Sleigh, G. (2005). Mothers' voice: A qualitative study on feeding children with cerebral palsy. *Child: Care, Health & Development*, *31*(4), 373-383. doi:10.1111/j.1365-2214.2005.00521.x
- Spitz, R. A. (1945). Hospitalism; an inquiry into the genesis of psychiatric conditions in early childhood. *The Psychoanalytic Study of the Child*, *1*, 53-74.
- Thomlinson, E. H. (2002). The lived experience of families of children who are failing to thrive. *Journal of Advanced Nursing*, *39*(6), 537-545. doi:10.1046/j.1365-2648.2002.02322.x
- Thoyre, S. M. (2007). Feeding outcomes of extremely premature infants after neonatal care. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, *36*(4), 366-375. doi:10.1111/J.1552-6909.2007.00158.x