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Family-centered outcomes that matter most to parents: A pediatric feeding disorders qualitative study

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Abstract

Objective: The purpose of this study was to examine the perspectives of caregivers of children with feeding disorders. We sought to understand their child's feeding impairment through the lens of caregivers, including the impact impairments had on daily life and social participation, what outcomes matter most to caregivers, contextual determinants that affect achieving desired outcomes, and how treatment approaches can optimally support families.

Methods: We interviewed caregivers of children, ages 2–5 years, who received care at the Center for Feeding and Nutrition at MassGeneral Hospital for Children in Boston, MA. All children had a feeding disorder diagnosis, defined as an impairment in oral intake. We analyzed interview transcripts using principles of immersion-crystallization.

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Contributor's Statement
Dr. Simione conceptualized and designed the study, acquired the data, analyzed and interpreted the data, and drafted the initial manuscript.

Dr. Fiechtner conceptualized and designed the study, analyzed and interpreted the data, and critically reviewed the manuscript for important intellectual content.

Ms. Dartley acquired the data, analyzed and interpreted the data, and critically reviewed the manuscript for important intellectual content.

Drs. Cooper-Vince, Martin, Hartnick, and Taveras assisted with interpretation of the data and critically reviewed the manuscript for important intellectual content.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Results: We reached thematic saturation after interviewing 30 caregivers (25 female). 66.7% of the children were white, 13.3% Asian, 10.0% Black, and 10.0% were more than one race. 30.0% were Hispanic. We identified the four themes: (1) feeding impairments impact the daily life and social participation of children; (2) improving their child's health and quality of life is most important to caregivers; (3) child, caregiver, and community factors are facilitators of achieving desired outcomes; whereas time, financial, access, and knowledge factors are barriers; and (4) caregivers prefer treatment approaches that incorporate principles of family-centered care.

Conclusions: Given the daily life and social participation impacts of pediatric feeding disorders, treatment approaches should be family-centered, focus on functional and meaningful outcomes to improve the health and quality of life of children and their families, and address modifiable sociocontextual determinants.

Keywords

Pediatric dysphagia; caregiver experiences; feeding problems; children

Introduction

Pediatric feeding disorders are highly prevalent and encompass a broad range of difficulties resulting in oral intake impairments, including, for example, food selectivity, oral motor dysfunction, or limited appetite.¹⁻³ Impairments in oral intake, defined as the “inability to consume sufficient food and liquids to meet nutritional and hydration requirements” may be associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction.⁴ Pediatric feeding disorders can affect nutrition, growth, health, development, and overall well-being.^{5,6} Given the consequential effects of feeding disorders, it is imperative that treatment approaches focus on functional outcomes that improve overall health and quality of life.⁷ By capturing and understanding the experiences and perspectives of families, we can ensure treatment approaches focus on outcomes that are meaningful to families.

The International Classification of Functioning (ICF) developed by the World Health Organization (WHO) provides a framework to describe and organize information about health and functioning.⁸ It conceptualizes how impairments affect a person's functioning and participation while accounting for contextual factors (i.e., environmental and personal factors). By using the ICF to understand the health, functioning, and needs of children of with feeding disorders, it can assist in developing standardized treatment approaches that focus on function and participation, plan future research, and inform social and healthcare policy.⁹⁻¹¹ To date, few studies have focused on how feeding disorders affect activities and participation of daily life.

Interviews with caregivers of children with feeding disorders have revealed that feeding difficulties are perceived to be more impactful than other physically-related issues, and also depicted the challenges of mealtimes and attending social functions that involve food.^{12,13} Treatment efficacy studies have reported outcomes that include impairment based outcomes, as well as functional outcomes.¹⁴⁻¹⁶ However, few research studies have explored the treatment outcomes that are most meaningful to families and the contextual determinants

that impact achieving those outcomes which could be incorporated into targeted treatment approaches.

The purpose of this current study is to examine the perspectives of family caregivers of children, ages 2–5 years, with feeding disorders and understand their feeding impairments through the lens of the family, the impact the feeding impairment has on daily life and social participation; what matters most to caregivers; contextual determinants affecting achieving desired goals; and to characterize how treatment approaches and healthcare professionals can optimally support families. This study is a preliminary exploration of themes.

Methods

Setting and Caregiver Interviewees

The current study was conducted at MassGeneral Hospital for Children's Center for Feeding and Nutrition in Boston, MA. The Center for Feeding and Nutrition is an interdisciplinary clinic that cares for children with feeding disorders. At the time of their child's appointment, a clinical research coordinator asked caregivers if they were interested in participating in the research study. Eligible caregivers had a child between the ages of 2–5 years diagnosed with a feeding disorder by a physician (as documented by ICD-10 coding) who received some proportion of oral feedings and spoke English. All caregivers were the legal custodians of their child. All children had a feeding disorder diagnosis, but their primary cause of the feeding disorder varied across the sample. Children's primary medical diagnosis collected from the medical record included neurologic/ genetic, gastrointestinal, cardiac, airway, and no known diagnosis. These groupings were created based on existing classifications in the literature.^{17–19}

Interview Procedure

Research staff conducted semi-structured interviews between December 2017 and June 2018. Study investigators, including one from pediatric gastroenterology and one from speech- language pathology, developed the interview guide reflecting the study's aims. Two parent advisors then reviewed the guide, and modifications were made accordingly. The guide was developed to mirror the ICF by including questions about feeding impairments, activities, participation, and contextual factors and to focus on modifiable determinants for future intervention development. Caregivers consented to participate and gave permission for the interview to be audio recorded. Interviews were conducted over the phone and lasted between 45–60 minutes. Caregivers received \$30 as compensation for their participation. The Partners Institutional Review Board reviewed and approved all study procedures.

Data Analysis

Interviews were audio recorded, professionally transcribed (Landmark Associates), and then imported into NVivo QRS 10.0 (QRS International Pty Ltd, Doncaster, Victoria, Australia). Two researchers read the first five transcribed interviews and created codes based on the interview guide. The individual analyses were compared, interrater reliability calculated, and discrepancies were discussed until consensus was achieved. To test interrater reliability percent agreement (96.2%) and a kappa coefficient (92.3) was calculated between the two

researchers developing the codes. A third researcher then reviewed the codebook and minor modifications were made. Content analysis was used for the remaining interviews using principles of immersion-crystallization.²⁰ This approach consists of repeatedly reviewing the interview transcriptions and determining after reflection the dominant themes that emerge. Researchers independently read the transcripts and made analytical notes and then came together as a group to identify and discuss coding, content, and emerging themes. If consensus was not achieved during the meetings, a third researcher reviewed discrepancies. Interviews and analysis continued until saturation was reached which was the point that no new concepts were generated. Interview content and themes were reviewed weekly to determine thematic saturation among the three researchers. Direct quotes from the interviews were then selected to represent the themes.

After the data analyses were complete and direct quotes were selected, two parent advisors independently reviewed a document with the emergent themes and representative quotes and then discussed their impressions with the first author to ensure the interpretation of the data accurately represented the caregiver perspective. The parent advisors were in agreement with the themes and the discussion focused on implications of the emergent themes, specifically how services and treatment approaches can address the issues that were identified.

Results

We interviewed 30 caregivers of children with feeding disorders; 83.3% of the interviewees were mothers and the mean (SD) age was 35.9 (4.7) years. The mean age of the children was 43.0 (13.4) months, and 66.7% were white, 13.3% were Asian, 10.0% were Black, and 10.0% were more than one race. 30.0% were Hispanic (see Table 1). We identified the following themes: (1) feeding impairments impact the daily life and social participation of children and caregivers; (2) enhancing child health and child and family quality of life is most important to caregivers; (3) child, caregiver, and community factors were facilitators of achieving desired outcomes; whereas time, financial, access, and knowledge factors were barriers to achieving desired outcomes; and (4) caregivers preferred health professionals and treatment approaches that incorporated principles of family-centered care. The themes and representative quotes are shown in Table 2, and the frequency or number of caregivers who discussed different aspects of each of the themes is provided below.

Impairments in feeding impact daily life and social participation

When asked how feeding was challenging for their child, caregivers described their child's feeding impairments which included food selectivity (38%), limited appetite (34%), oral motor dysfunction (19%), and pharyngeal dysphagia (9%). For food selectivity, caregivers discussed their children only eating certain foods based on, for example, texture, color, or taste. Other caregivers described their child as eating a variety of age-appropriate foods, but only in small volumes. For oral motor dysfunction, children were described as having difficulty using the muscles of their mouth to eat. Finally, other caregivers discussed their children having swallowing difficulty.

We found that the feeding impairments detailed by the caregivers impacted activities of daily life, particularly during meal and snack times. The impacts included meals being longer than

developmentally appropriate (n=14), the child having difficulty sitting at the table for the duration of the meal (n=6), and the child being messier when eating than developmentally expected (n=5). Caregivers reported that their children required special assistance or supports when eating, such as verbal prompting, being fed by an adult, or using specialized utensils (n=11). Caregivers also discussed their child eating better for other people than the primary caregiver, whereas for some families, the child would only eat for the primary caregiver (n=6). In addition to activities of daily life, participation at school and social outings, including play dates, birthday parties, and family functions were also affected by the child's feeding difficulties (n=26).

The impact of feeding disorders also affected caregivers. Because of the consequential effects of feeding disorders, caregivers felt very high-levels of stress and had challenges balancing the needs of their child with other personal, family, and work responsibilities (n=22). Caregivers reported that they often worried about their child's health, nutrition, and weight (n=19), and felt pressure to have their child eat and gain weight due to societal and cultural expectations (n=7).

What matters most to caregivers

Outcomes that improved their child's health and quality of life mattered most to caregivers. Caregivers reported that health-related outcomes including expanding their child's diet (n=19), eating healthy foods and meeting nutritional needs (n=14), and their child maintaining or gaining weight (n=8) was of high importance to them. Quality of life related outcomes were also important to caregivers. These included mealtimes being enjoyable and stress-free (n=20), and the child being able to eat without medical interventions, such as medications, tube feedings, or parental prompting and assistance (n=13).

Facilitators and barriers to achieving outcomes that mattered most

Caregivers identified child, parent, and community factors that helped to facilitate the achievement of meaningful outcomes. Child factors included the child being healthy and free of intercurrent illnesses (n=5), the child having an awareness of their hunger (n=6), and establishing a child-led environment (n=7). Caregivers reported that by providing consistent routines and approaches to feeding and minimizing pressure on the child to eat facilitated improved outcomes (n=9). Caregivers also acknowledged the importance of their own acceptance of their child's (n=10) and the extended family's (n=6) acceptance of the child's feeding difficulties, and providing support was key (n=21). Community factors, such as the availability of health care services (n=15), connections to other caregivers of children with feeding difficulties to create a support network (n=14), and opportunities in daycares, schools, and other community settings for the child to eat with peers (n=5), were described by caregivers as essential to achieving meaningful outcomes.

Caregivers identified time, financial, access, and knowledge barriers that hindered their ability to achieve their desired outcomes. Caregivers discussed the time spent scheduling and traveling to the frequent appointments for their child, and the time spent shopping and preparing specialized foods (n=13). These responsibilities often conflicted with other work and family obligations (n=6). Caregivers discussed the expense of treatment services and

purchasing the variety of specialized foods (n=12). The lack of community-based feeding treatment services impacted caregivers being able to access services for their child (n=11). Lack of knowledge of a “pediatric feeding disorder” was identified as a barrier. This knowledge barrier resulted in not understanding why the child was struggling to eat and family members pushing their own feeding advice (n=7).

Characteristics of healthcare professionals and treatment approaches

Caregivers preferred healthcare professionals and treatment approaches that incorporated principles of family-centered care. Caregivers identified characteristics of healthcare professionals that were most important to them: being knowledgeable and experienced (n=13), personable (n=16), and available (n=7). Healthcare professionals collaborating with caregivers and other professionals were important (n=10). Caregivers also wanted services to be accessible in their community, and covered by insurance (n=12).

Discussion

Our study of family caregivers of children with feeding disorders revealed four emerging themes: (1) feeding impairments impact the daily life and social participation of both children and their caregivers; (2) improvements to health and quality of life are most important to caregivers; (3) facilitators of achieving desired outcomes include child, parent, and community factors, and barriers include time, financial, access, and knowledge factors; and (4) caregivers prefer treatment approaches that incorporate family-centered principles.

Our findings expand on previous studies by providing an in-depth and systematic understanding of the daily life and social participation impacts of pediatric feeding disorders and how to best support families. Previous studies report that the daily life of caregivers of children with feeding disorders revolves around feeding, and families are “living life on the margins” due to their child’s feeding difficulties.^{12,13} Hewetson and colleagues¹² found that caregivers perceived feeding-related issues more challenging to cope with than other physically-related issues. Consistent with our findings, other qualitative and quantitative studies report that caregivers feel high-levels of worry and stress.^{21–23} Lefton-Greif and colleagues²² found that caregivers, despite the presence or absence of a feeding tube, experienced similar amounts of stress and impact on their family. We enrolled children with a wide variety of medical diagnoses and found many commonalities across these children and their caregivers.

Caregivers often discussed the same concerns and challenges despite the heterogeneity in primary medical diagnoses and presence or absence of a feeding tube. For example, these concerns and challenges included participation in social activities, extended family’s knowledge, and financial and time constraints. Our findings are also consistent with the literature regarding children with special healthcare needs. Studies have shown that, similarly, families of children with special health care needs experience daily life impacts, constant worry, and their social participation is affected.^{24,25} Additionally, families faced financial burdens related to their child’s healthcare needs.^{25,26}

Our study used the ICF as a guide to systematically examine levels of health, functioning and sociocontextual factors. This information has far-reaching clinical implications and can be used to improve upon existing treatment approaches, develop new approaches, and to prioritize social, educational, and healthcare policy reform.^{7,9} Overall, our findings reinforce the importance of holistic, interdisciplinary management approaches delivered in ecologically valid settings and that multiple agencies must be involved in the management of these children (i.e., early intervention programs, early childhood programs, schools, medical centers).^{27,28} We identified facilitators and barriers that impacted achieving meaningful outcomes. Some of the determinants we identified can be incorporated into existing approaches, while other of these determinants will require a shift in service delivery, reimbursement, and policy. Caregivers reported the lack of access to services in their community (in regards to proximity and insurance reimbursement), and similar barriers identified by Winston and colleagues¹³, including time and financial expenses involved with scheduling, attending, and traveling to appointments. These barriers could be addressed through the development of community-based services rather than specialized services that are predominately offered in academic medical centers. Also, by ensuring clinicians in community-based programs, such as early intervention or schools, have adequate training we can begin to decrease barriers to treatment.^{29,30} Caregivers also identified the lack of knowledge about feeding disorders as a factor that negatively affected outcomes; whereas having support systems that understood the feeding disorder positively affected outcomes. Treatment approaches that focus on family education and offer familial support through individual therapy or support groups can promote overall family well-being. They can also position primary caregivers to better attend to their child's needs and cope with the high levels of stress experienced when having a child with a feeding disorder.^{12,29}

Treatment approaches should focus on outcomes that are meaningful to caregivers and incorporate principles of family-centered care. Caregivers in this study identified meaningful outcomes that improve their child's overall health and quality of life. The process of developing meaningful goals provides an opportunity to help caregivers operationalize how these goals could be achieved. Healthcare professionals should collaborate with families to set treatment goals that are explicitly tied to concrete health and quality of life improvements and routinely measure meaningful progress towards these goals.³¹⁻³⁴ For example, training a caregiver (i.e., daycare provider, teacher) to follow a feeding protocol to expand the child's feeding skills across people and social settings could help to reduce family stress and social isolation.³⁵ This approach also provides an additional opportunity to help caregivers and extended family members understand that supporting their child in feeding is a process of unknown duration.^{36,37} As discussed by caregivers in this study and other studies, evidence-based feeding treatment approaches need to incorporate principles of family-centered care to ensure family members are active members of the team and their strengths, expertise, and culture are honored.^{23,36} Family-centered care leads to better experiences with services and improvement in child and family health and quality of life outcomes.^{38,39} This might be achieved, for example, by asking families questions about their cultural feeding values and expectations.

As with qualitative studies, our findings are not representative of all caregivers and children with feeding disorders. Rather this study was intended to provide an in-depth understanding.

We only interviewed caregivers who had children with a feeding disorder diagnosis who were receiving medical care, spoke English, and attended a center that predominately served the Greater Boston area. Our findings may have differed if our sample varied on those factors. For example, if we included caregivers who were not yet receiving medical care, we may have identified other determinants and meaningful outcomes as the period prior to diagnosis and initiating care can be stressful and challenging for families.⁴⁰ We did not explore the heterogeneity of this population and therefore are unable to draw conclusions about differences between etiologies or types of feeding dysfunction. Two parent advisors reviewed the interview guide and the emergent themes, but caregivers did not assist with the development of these materials or analysis, which would have provided a different perspective.

In conclusion, pediatric feeding disorders impact the lives of children and their families, and thus creating effective treatment approaches that incorporate what matters most to families can greatly improve the quality of life of children and their caregivers. Caregivers preferred outcomes that improved their child's health and quality of life. Some of the sociocontextual determinants we identified that facilitated or impeded progress towards meaningful outcomes were modifiable and can be incorporated into new or existing treatment approaches, while others will require paradigm shifts and policy changes. Given the tremendous impacts of feeding disorders, it is important that clinicians use evidence-based treatment approaches and incorporate principles of family-centered care to best support caregivers and children.

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What is known

- Pediatric feeding disorders encompass a broad range of difficulties resulting in oral intake impairments.
- To date, most research has been impairment-based and limited information exists on the daily life, social impacts, and what matters most to families.

What is new

- The findings of this study suggest that feeding disorders impact the daily lives of children and their families.
- Evidence-based treatment approaches should incorporate principles of family-centered care, focus on meaningful outcomes to improve health and quality of life, and address modifiable sociocontextual determinants.

Table 1.

Sociodemographic characteristics of interview participants (n=30)

Caregiver and household characteristics	Mean (SD) or n (%)
Age (years)	35.9(4.7)
Relationship to child	
Mother	25(83.3)
Father	5(16.8)
Income	
<\$20,000	5(16.7)
\$20,000 to \$39,999	1(3.3)
\$40,000 to \$59,999	4(13.3)
\$60,000 to \$79,999	4(13.3)
\$80,000 to \$99,999	3(10.0)
>\$100,000	8(26.7)
Unknown	5(16.7)
Education	
<College	10(33.3)
College	20(66.7)
Child characteristics	Mean (SD) or n (%)
Age (months)	43.0(13.4)
Sex	
Male	19(63.3)
Female	11(43.3)
Ethnicity	
Hispanic	9(30.0)
Non-Hispanic	21(70.0)
Race	
White	20(66.7)
Asian	4(13.3)
Black	3(10.0)
More than one race	3(10.0)
Primary medical diagnoses	
Neurologic/ Genetic	13(43.3)
No known diagnoses	9(30.0)
Gastrointestinal	6(20.0)
Other	2(6.7)

Table 2.

Illustrative caregivers' quotes representing the emergent themes

1	<i>Feeding impairments impact the daily life and social participation of children and families</i>
	<p>"It pretty much takes about an hour for him to eat every meal from start to finish. We pretty much don't eat on the go. We have to be stationary wherever he is, because he's hooked up to his pump." "I would say early on, we were denied access to play groups, which was hard. At one point, we were told they were glad we weren't coming to the birthday party because we were a liability."</p>
2	<i>Improving their child's health and quality of life is most important to families</i>
	<p>"I want to make sure they are following their own [growth] curve, and they're heading in the right direction. Their growth chart flat lines a lot, so I want appropriate growing." "Ultimately, as long as he's healthy and getting what he needs. That's the number one goal. We are hoping towards the future that he will be able to eventually eat by mouth and enjoy foods and eating as part of life."</p>
3	<i>Child, caregiver, and community factors were facilitators of achieving goals</i>
	<p>"As she gets older I feel like she's realizing that little tickle in her stomach or when she feels hungry means 'I have to go get my mom. She's probably going to get me a snack. It's time for me to eat.'" She's connecting the hunger with eating, which is good." "It's a super slow process. It's daunting. When you look at it and break it down, you've seen how much they've actually learned. But when you're in the moment, it definitely feels like there is so much more to go." "He also went to the toddler group. There he got the experience of sitting and eating with other kids, and it was an amazing experience for him. That's where he grew the most. I'm hoping with preschool maybe he'll pick up more feeding skills from [his peers]."</p>
4	<i>Time, financial, access, and knowledge factors were barriers to achieving goals</i>
	<p>"I actually had to cut my [work] position, but I'm hoping, once he does get into a full-day program, I can try and get back into it." "That was really expensive when [insurance] stopped paying for it. Our insurance just decided they no longer cover therapy, so that's \$400 a visit. We were seeing them weekly, but we're trying to figure out that. The foods that he eats are not cheap [either]." "I don't think it's very good insurance, so we are also limited on where we can go. That's stressful." "I think every family member at some point has doubted that it was a real thing or that bad. I think at some point each family member has tried. 'Oh, let me do it. I'll get her to eat,' and then they realize that it was not just us, that she really is like that."</p>
5	<i>Caregivers preferred health professionals and treatment approaches that incorporated principles of family-centered care</i>
	<p>"I think it's important to level with parents and to individualize treatment plans, and really hear the parents out. I might not be right all the time, but something what I'm telling you matters. It's good when you find a provider who genuinely listens to you and bases their treatment plan on what you said to them."</p>