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ORIGINAL ARTICLE

Examining Health Conditions, Impairments, and Quality of Life for Pediatric Feeding Disorders

Meg Simione[1,2] · Stephanie Harshman[3,4,5] · Christine E. Cooper-Vince[6] · Kelly Daigle[3] · Jessica Sorbo[7] · Karen Kuhlthau[1,2] · Lauren Fiechtner[1,2,5,8]

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Abstract

By understanding health conditions, impairments, and impact on quality of life for pediatric feeding disorders, assessment and treatment approaches can target multiple levels of health-related domains that improve child health and well-being. The purpose of this study was to characterize medical diagnoses and feeding impairments for children with feeding disorders; examine child quality of life and caregiver impact; and compare quality of life differences between children with feeding disorders and children with other conditions. A cross-sectional study was conducted in the Greater Boston Area, between October 2017 and June 2018. Fifty children with a feeding disorder diagnosis, ages 2–5 years, were enrolled. Demographic and clinical data were abstracted from the electronic health record to characterize medical diagnoses and impairments. Parents completed the Pediatric Quality of Life Generic Core Scales 4.0 (PedsQL) and the Feeding/Swallowing Impact Survey (FS-IS) to understand child quality of life and caregiver impact. We calculated descriptive statistics across the medical diagnosis and impairment groups, and for the surveys. Children presented with heterogeneous medical diagnoses and feeding impairments. We found a mean (SD) total score of 72.82(19.21) on the PedsQL and 2.33(0.89) on the FS-IS demonstrating that children with feeding disorders presented with poor quality of life and their caregivers were negatively impacted by their feeding difficulties. By understanding medical diagnoses, impairments, and quality of life, assessment and treatment methods can be tailored to children's specific needs, as well as address the overall wellbeing of children and their families.

Keywords Pediatric feeding disorders · Quality of life · Caregiver impact · Functional limitations

Introduction

Pediatric feeding disorders (PFD) are highly prevalent [1] and impact the health and functioning of children [2, 3]. As proposed in the PFD Conceptual Framework, feeding disorders are associated with medical, nutritional, feeding skills, and psychosocial dysfunction [4]. The framework was developed based on the International Classification of Functioning, Disability, and Health (ICF) which organizes information about functioning and disability and how impairments affect a person's functioning and participation while accounting for socio-contextual factors [5].

✉ Meg Simione
msimione@mgh.harvard.edu

1 Division of General Academic Pediatrics, Department of Pediatrics, Massachusetts General Hospital for Children, 125 Nashua Street, Suite 860, Boston, MA, USA

2 Department of Pediatrics, Harvard Medical School, Boston, MA, USA

3 Neuroendocrine Unit, Massachusetts General Hospital, 55 Fruit Street, Boston, MA, USA

4 Eating Disorders Clinical and Research Program, Massachusetts General Hospital, 55 Fruit Street, Boston, MA, USA

5 Division of Gastroenterology and Nutrition, Massachusetts General Hospital for Children, 175 Cambridge St, Boston, MA, USA

6 Department of Psychiatry, University of Geneva, Rue Verte 2, 1205 Geneva, Switzerland

7 Department of Speech, Language, and Swallowing Disorders, Massachusetts General Hospital, 275 Cambridge St, Boston, MA, USA

8 Greater Boston Food Bank, Boston, MA, USA

Although studies have described medical diagnoses and impairments for children with feeding disorders [6–8], most have not used a conceptual framework to guide their work. These studies have revealed that there is group heterogeneity in regards to medical diagnoses and feeding presentations. Additionally, limited empirical data support the PFD Conceptual Framework and associated environmental and personal factors, such as child quality of life and caregiver impact [9–12]. By using a framework to understand health conditions, feeding impairments, and impact on quality of life, we can ensure assessment and treatment approaches target multiple levels of health-related domains that improve child health and well-being.

The purpose of this study was threefold. Guided by the PFD Conceptual Framework and the ICF, we (1) characterized medical diagnoses and feeding impairments for children with feeding disorders; (2) examined child quality of life and caregiver impact for children with feeding disorders; and (3) compared quality of life differences between children with feeding disorders and children with other acute and chronic health conditions. We hypothesized that children would be heterogenous in their presentations and have a poor quality of life.

Methods

Setting and Participants

This cross-sectional study with an additional comparison to data in the published literature was conducted at MassGeneral Hospital for Children in the Center for Feeding and Nutrition, an interdisciplinary clinic that serves infants and children with feeding disorders. The Center is located in Boston, MA and provides services to children in the Greater Boston Area, as well as surrounding states. Children were enrolled in the study between October 2017 and June 2018. Children met the inclusion criteria if they were between the ages of 2–5 years, diagnosed with a feeding disorder, were English speaking, and consumed some amount of food orally. Children were enrolled in the study ($n = 50$) at the time of their visit. Parents provided informed verbal consent and were provided a $10 gift certificate for compensation for their participation. The MassGeneral Brigham Institutional Review Board approved all study procedures.

Electronic Health Record Abstraction

Following the child's visit, demographic and clinical data were abstracted from the electronic health record (EHR) including sex, age, insurance type, birth history, and ICD-10 codes. We also collected clinical EHR data from the gastroenterologist and speech-language pathologist's notes from the visit that corresponded with the study enrollment date.

Characterizing Medical Diagnosis and Feeding Impairments

The primary medical diagnosis groupings (representing health conditions in the ICF) were developed based on the extant literature [6, 8, 13, 14]. We grouped the diagnoses into four categories: neurologic or genetic disorder (for example, Autism spectrum disorder, Down syndrome, cerebral palsy), gastrointestinal condition, no known diagnosis, or cardiorespiratory condition. We reviewed the ICD-10 codes extracted from the EHR and selected the child's primary medical diagnosis code. We then had a gastroenterologist who was clinically familiar with the children review the diagnosis groupings. Following her review, we changed four (8%) primary medical diagnoses.

For the feeding impairments (representing body function and structure in the ICF), in an iterative and collaborative process, we developed five categories, and corresponding definitions and criterion based on the extant literature [7, 13–15]. The categories, which also aligned with the PFD conceptual framework [4], were: limited volume, oral motor dysfunction, oral sensory processing dysfunction, oropharyngeal dysphagia, and selective food intake (Supplemental Table 1). We iteratively tested and refined the categories and criterion on sample patients until we had working categories, definitions, and criterion. We then sought additional feedback from a speech-language pathologist and psychologist with feeding disorders expertise. Following their input, we made further refinements. Two reviewers who participated in the initial iterative testing and were familiar with the categories and definitions completed medical chart reviews using speech-language pathologists' visit notes. Prior to the review, they were trained by the first author and a document was created with the criterion guidelines. The reviewers then used the criterion guidelines to select children's primary feeding impairments. If they were unable to discern the impairment, they then flagged the child for further review. If there was disagreement between the two reviewers or the child was flagged, a third reviewer then read the speech-language pathologist's note. All three reviewers also read the gastroenterologist's note and discussed until consensus was achieved. Between the two reviewers, they agreed upon 29 (58%) impairments, disagreed upon 6 (12%) impairments, and flagged 15 (30%) children for further review.

Quality of Life and Caregiver Impact Survey Data

At the time of study enrollment, parents completed paper-based surveys and their responses were then inputted into Research Electronic Data Capture (REDCap). The survey consisted of several demographic questions and the Pediatric Quality of Life Generic Core Scales 4.0 (PedsQL) [16] and the Feeding/Swallowing Impact Survey (FS-IS) [12]. The PedsQL measures health-related quality of life for healthy children and children with acute or chronic conditions. The inventory focuses on the core health dimensions as described by the World Health Organization and has four subscales: Physical, Emotional, Social, and School functioning. The PedsQL has 23 questions for children ages 2–4 years and 25 questions for children ages 5–7 years. It uses a 5-point scale for responses and when calculating the scores, the ordinal score is transformed into a 0–100 score with high scores indicating a high quality of life. We calculated a score for each dimension, psychosocial health summary score (combination of Emotional, Social, and School Functioning scales), physical health summary score (Physical Functioning scale), and a total score. We then compared the total score of children with feeding disorders with published Peds-QL scores of children with other acute or chronic conditions. We selected all studies that we found that included children within the age ranges of our study with parent reported scores.

The FS-IS measures the impact of feeding and swallowing issues on caregivers. The instrument has three subscales including Daily Activities, Worry, and Feeding Difficulties and a total of 18 questions. Responses were recorded using a 5-point scale with "5" representing greater caregiver impact than a "1" response. We calculated a score for each subscale and a total score.

Statistical Analysis

We calculated the mean (SD) or count (frequency) for the child and parent characteristics, medical diagnosis grouping and feeding impairment groupings. We then calculated descriptive statistics for the subscales, summary scores, and total score for the PedsQL, as well as for the subscales and total score for the FS-IS. We also calculated t scores ($T = (X - \mu)/[s/\sqrt{(n)}]$) comparing PedsQL scores between our PFD sample and previously reported pediatric conditions/chronic diseases. T scores were compared to the student's t distribution table to determine the p-value and statistical significance, using degrees of freedom (df) = 49 [17]. R (R Core Team, 2013) was used for statistical analysis.

Results

Children were a mean age of 42.8 months and 52% were male. A majority of survey respondents were mothers (86%) and 36% of households had a yearly income of less than $60,000 (Table 1). Table 2 shows the count and frequency of the medical diagnoses and feeding impairments. A majority of children (38%) had a neurologic or genetic disorder followed by children with no known medical diagnoses (34%). 38% of children had oral sensory processing dysfunction followed by limited volume (30%). When stratified by

Table 1 Child, parent, and household characteristics ($n = 50$)

Child characteristics	Mean (SD) or *n* (%)
Child age (months)	42.8(13.8)
Sex	
Male	26(52.0%)
Female	24(48.0%)
Primary insurance	
Public	17(34.0%)
Private	33(66.0%)
Secondary insurance	
Public	12(24.0%)
None	38(76.0%)
Race/ ethnicity	
White, Non-Hispanic	23(46.0%)
Hispanic	12(24.0%)
Asian, Non-Hispanic	7(14.0%)
Black, Non-Hispanic	4(8.0%)
More than one race	4(8.0%)
Birth history	
Full term	28(56.0%)
Preterm	16(32.0%)
Unknown	6(12.0%)
Parent and household characteristics	Mean (SD) or *n* (%)
Parent age (years)	35.5(5.3)
Parent relation to child	
Mother	43(86.0%)
Father	7(14.0%)
Parent education	
High school graduate or less	21(42.0%)
Some college or technical school	18(36.0%)
College graduate	11(22.0%)
Income	
< $60,000	18(36.0%)
> $60,000	23(46.0%)
Unknown	9(18.0%)

Table 2 Groupings by medical diagnoses and impairments of Pediatric Feeding Disorders ($n = 50$)

Medical diagnoses grouping	*n* (%)
Neurologic or genetic disorder	19(38.0%)
No known diagnosis	17(34.0%)
Gastrointestinal condition	9(18.0%)
Cardiorespiratory condition	5(10.0%)
Feeding impairment grouping	***n* (%)**
Oral sensory processing dysfunction	19(38.0%)
Limited volume	15(30.0%)
Selective food intake	8(16.0%)
Oral motor dysfunction	5(10.0%)
Oropharyngeal dysphagia	3(6.0%)

medical diagnoses (Supplemental Table 2), for neurologic and genetic disorders and no known medical diagnoses, oral sensory processing dysfunction was the most common impairment at 42% and 37%, respectively. For gastrointestinal conditions, limited volume was the most common impairment (67%).

We found a mean (SD) total score of 2.33(0.89) on the FS-IS revealing that parents are impacted by their child's feeding disorder (Table 3). The "Worrying" subscale had the highest mean (SD) score of 2.75(1.18) of the three subscales indicating the most impact. On the PedsQL, we found a mean (SD) total score of 72.82(19.21). The "school functioning" subscale had the lowest mean (SD) score of 69.82(22.24) of the four subscales indicating the poorest quality of life in that domain as compared to the physical, emotional, and social functioning domains (Table 3).

When compared to quality of life scores for other pediatric conditions, we found children with feeding disorders had a statistically significant poorer quality of life than children who have had a kidney transplant ($p < 0.01$) or pediatric acute liver failure ($p < 0.01$) [18, 19]. As compared to other conditions, including irritable bowel syndrome ($p < 0.01$) and cancer while undergoing treatment ($p < 0.01$) [20, 21], children with feeding disorders had a better quality of life. No statistically significant differences in quality of life were found between PFD and children who have brain arteriovenous malformations and liver transplants (Table 4) [21–23].

Table 3 Results of quality of life and caregiver impact scales for Pediatric Feeding Disorders

Feeding/ swallowing impact survey[a]	Mean (SD)
Daily activities	2.49(1.25)
Worrying	2.75(1.18)
Feeding child	1.70(0.69)
Total score	2.33(0.89)
Pediatric quality of life inventory[b]	**Mean (SD)**
Physical functioning	73.63(26.55)
Emotional functioning	71.70(18.81)
Social functioning	73.60(22.11)
School functioning	69.82(22.24)
Psychosocial health summary score	72.17(17.69)
Physical health summary score	73.63(26.55)
Total score	72.82(19.21)

[a]Range 1–5. Higher scores indicate greater caregiver impact

[b]Range 0–100. Higher scores indicate better quality of life

Table 4 Comparison of PedsQL scores between the Pediatric Feeding Disorders sample and reported pediatric conditions

References	Condition	Age	Sample Size	PedsQL 4.0, Parent Report, Total Score			
				Mean	SD	Calculated t-score	*p*-value
Varni et al., 2015	Irritable bowel syndrome	2–18 years	$n=43$	60.8	16.2	4.42	<0.01
Alonso, et al., 2010	Cancer (receiving treatment)	2–18 years	$n=180$	67.0	19.9	2.16	<0.01
Abecassis et al., 2016	Brain arteriovenous malformations	2–18 years	$n=26$	71.0	24.0	0.67	NS
Feldman et al., 2016	Liver transplant	2–18 years	$n=261$	75.8	17.9	−1.10	NS
Alonso et al., 2010	Liver transplant	2–18 years	$n=873$	77.3	17.6	−1.63	NS
Anthony et al., 2010	Kidney transplant	2–18 years	$n=23$	78.4	16.6	−2.05	<0.01
Sorensen et al., 2015	Pediatric acute liver failure	2–18 years	$n=36$	78.6	17.5	−2.12	<0.01

The Pediatric Feeding Disorders sample's total score on the PedsQL 4.0 was 72.8. Higher scores indicate better quality of life; *NS* not significant

Discussion

In this study of fifty children with feeding disorders, guided by the PFD Conceptual Framework and the ICF, we found children presented with heterogeneous medical diagnoses and feeding impairments. A majority of children had neurologic/ genetic disorders or no known medical diagnoses; and for impairments, a majority of children had oral sensory processing dysfunction or limited volume. Children with feeding disorders presented with poor quality of life as compared to scores for other pediatric conditions, and their caregivers were negatively impacted by their feeding difficulties. The findings are important for tailoring management approaches to children's feeding impairments, as well as addressing quality of life in treatment.

Although experts have proposed systems for classifying medical diagnoses and impairments, few studies have characterized diagnoses and impairments to empirically examine patient populations [7, 14]. Rommel and colleagues [6] found that the most common diagnoses for children with feeding disorders were gastrointestinal followed by neurologic and genetic. We found the most common diagnoses to be neurologic/ genetic followed by children having no known diagnoses. The differences may be explained by the methods used for classification. Before identifying a medical diagnosis, Rommel and colleagues grouped children by medical, oral, and behavioral and they only reported on diagnoses for children in the medical group, whereas we reported on medical diagnoses for all children. Our finding suggests a growing understanding that children with feeding disorders may not have a primary medical diagnosis and a feeding disorder is not just a symptom of another disorder [4]. Children with no known diagnoses, consistent with our findings, most often present with sensory processing dysfunction, selective food intake, and limited volume [24]. Field and colleagues [13] examined the feeding impairments of children with developmental disabilities. They found the most common impairment to be oral motor delay, whereas we found the most common impairment to be oral sensory processing dysfunction followed by limited volume. The dissimilar findings can be explained by the differences in populations as Field and colleagues only included children with Autism, Down Syndrome, and cerebral palsy. When we examined impairments by medical diagnoses, the most common impairments for children with neurologic/ genetic diagnoses (which included the three diagnoses from the Field et al. study) were oral sensory processing and oral motor dysfunction. Our study in conjunction with previously published studies, affirms the heterogeneity of medical diagnoses and feeding impairments. By better understanding the impairments that fall under the broad term of "pediatric feeding disorders", we can provide best practices for a comprehensive, multi-disciplinary assessment, tailor management approaches accordingly, and ensure coding and documentation reflects the heterogeneity of this population.

Consistent with the literature, we found that caregivers were impacted by having a child with a feeding disorder. Studies have shown that caregivers experience high-levels of stress and parent–child dysfunctional interactions [9, 11, 15]. Studies using the FS-IS have found caregiver impact with total scores ranging from 1.9 to 3.3; our total score findings fall within that range [25–28]. The range of score differences in the studies may be explained by different age groups, differing study populations, or by surgical intervention.

Few studies, though, have examined children's quality of life and our study adds empirical data demonstrating that quality of life is affected. When compared to other pediatric conditions, children with feeding disorders have a lower quality of life than children who have had a kidney transplant or acute liver failure illustrating the far-reaching effects of feeding difficulties [18, 19]. Qualitative studies have shown that the daily life and social participation of children and their families are negatively impacted by feeding problems [3, 10, 25]; the effects on daily life and social participation may help to explain the quality of life impacts. Quality of life impacts are also likely exacerbated by lack of support for families, lack of evidence-based care guidelines, and lack of trained professionals [26]. These findings suggest that

management approaches must not only address impairments but need to incorporate in strategies to address a child and family's well-being.

Our study was guided by the PFD Conceptual Framework and the ICF. The use of the frameworks to characterize feeding disorders at multiple levels can provide guiding principles for clinical practice, research, and documentation and coding; assist in developing standardized assessment and treatment approaches; and help to predict healthcare delivery needs to inform policy [4, 27, 28]. Other studies have begun to also apply the PFD Conceptual Framework to their work [33–35]. These studies have applied the framework to treatment approaches, examined dysfunction in each domain, and reviewed the literature to understand attributes of feeding disorders and associated factors. Applying the framework in empirical studies is a critical step in advancing the PFD knowledge-base. When the data from this study are combined with our previous work on daily life and social participation impacts [3], we have developed a comprehensive overview of the health and functioning of PFD as outlined in the ICF, including health conditions, body functions (impairments), activity, participation, and socio-contextual factors. Additionally, the characterization of the feeding impairments, consistent with the PFD Conceptual Framework, underscore the importance of an interdisciplinary approach as feeding professionals will have varying expertise in diagnosing and treating different impairments [29, 30].

This study presents with limitations, including the lack of comparison group to examine differences for caregiver impact and quality of life. We were also unable to compare differences between the groups with different medical diagnoses or impairments due to statistical power. To help put our findings in context, we did compare quality of life for PFD to other pediatric conditions. The distribution of medical diagnoses and impairments in the study population is reflective of the population at the Center where the study was conducted. These distributions cannot be extrapolated to the PFD population, although, our findings are suggestive of the heterogeneity of this population.

In conclusion, our study that was guided by the PFD Conceptual Framework and the ICF found that children with feeding disorders are heterogenous in regards to their medical diagnoses and impairments. In addition, PFDs negatively impact quality of life as well as caregiver's wellbeing. By understanding medical diagnoses, impairments, and quality of life, assessment and treatment methods can target children's specific needs, as well as address multiple levels of health-related domains to improve child health outcomes.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s00455-022-10455-z.

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Declarations

Conflict of Interest The authors have indicated they have no potential conflicts of interest to disclose.

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Meg Simione PhD

Stephanie Harshman PhD

Christine E. Cooper-Vince PhD

Kelly Daigle MS

Jessica Sorbo MS

Karen Kuhlthau PhD

Lauren Fiechtner MD, MPH