



Demographics of children with feeding difficulties from a large electronic health record database

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Abstract

Background: Feeding difficulties are among the most common concerns expressed by parents in younger children. However, few studies have reported on the characteristics of patients with clinically significant feeding diagnoses. The aim of the current study is to describe the characteristics of patients diagnosed with feeding difficulties including concurrent conditions, age, and sex, sampled nationwide utilizing the Cerner Health Facts Database.

Methods: We identified patients with a diagnosis of feeding difficulties (*ICD-9* 783.3 or *ICD-10* R63.3), age 7 months to 17 years, with an outpatient visit between 2010 and 2017. The demographics and complex clinical conditions of this population were categorized. The cohort was then collapsed into a matrix defining recognized phenotype codes for *ICD-9* and *ICD-10* diagnoses to identify associated conditions.

Results: We identified 39,674 patients (0.95%) representing 101,684 encounters from 68 health systems across the United States; 43% of patients were female. Gastrointestinal conditions were the most common, followed by malnutrition, developmental and behavioral diagnoses, and neurologic conditions.

Conclusions: This study is one of the most robust studies defining the prevalence, demographic characteristics, and phenotypic profiling of patients with feeding difficulties. Our observations have implications on screening and resource allocation to recognize and manage this poorly understood population.

KEYWORDS

ambulatory, comorbidities, enteral nutrition, feeding disorders, gastroenterology, pediatrics, prevalence

CLINICAL RELEVANCY STATEMENT

Patients with feeding disorders represent a heterogeneous population with many different conditions. This is the first report of its kind due to the number of patient encounters and the

diversity of the practices in terms of inclusion of different regions of the country, including both private and publicly insured patients. This is also the first study of its size to report race-based differences in prevalence of feeding difficulties in children.

INTRODUCTION

Up to 25% of children are reported to have some degree of feeding difficulty of whom 3%–10% having more severe feeding disorders.^{1–3} An understanding of the demographic and clinical characteristics of significantly affected patients is critical to focus on at-risk children, a critical aspect is the concurrent conditions prevalent in affected children. The largest published study to date describing chronic comorbid conditions in this group focused on comparison among children in two Midwest states with public and private insurance in setting of inpatient and outpatient care. The authors reported an increased prevalence of respiratory and gastrointestinal conditions in the context of a steady increase in the prevalence of feeding disorders diagnoses.

An earlier, single-center European study of 700 patients also found that gastrointestinal diagnoses were the most common problems identified.⁴ This was also borne out from the findings of an earlier meta-analysis including 11 studies in children with chronic feeding refusal, of which 82% were tube dependent.⁵ A large, parent-survey-based study summarized feeding-related symptoms: voice and swallowing problems and feeding in the US population.⁶ The survey reported on approximately 62.1 million children ages 3–17 years of age. Parents were questioned on the presence of swallowing problems, lasting longer than 1 week, over the course of the past 12 months. Swallowing problems were reported in 1%, and voice problems in 1.4% of those children in the survey. Of the children with swallowing problems, only 13.4% were given a diagnosis for their swallowing problem and 11.1% had contributing neurological problems. Other etiologies mentioned included tissue damage in throat (5.5%), asthma (4%), genetic syndrome (2.9%), congenital malformations (2.9%), prescription medication (1%), or head/neck injury (0.4%).⁶ In contrast, there have been other smaller studies examining the prevalence of feeding difficulties in toddler-age patients reporting a higher, broad range of prevalence from 5% to 30%.^{2,7} The aim of the current study is to describe the characteristics of patients diagnosed with feeding difficulties including concurrent conditions, age, sex, and race in a nationally representative sample across multiple health centers.

METHODS

Cerner Health Facts Database (CHFD) is populated by the daily extraction of discrete electronic health record (EHR) data from participating organizations. These organizations have provided data rights to Cerner and allow the integration of deidentified information into the data warehouse. CHFD data are deidentified to HIPAA standards; text documents and images are not included. Children's Mercy is a contributor to CHFD and has received a copy of the full database to support research. The data are installed in Microsoft Azure and queries are performed with R Studio version 1.3.1093 with R version 4.0.3. This work was performed with the 2018 version of the CHFD with data from 2000 through 2017. Data from 664

facilities associated with 100 nonaffiliated health systems are included in this release. This version of the CHFD data include 68.7 million patients, 506.9 million encounters, 4.7 billion laboratory results, 729 million medication orders, 989 million diagnoses, and 6.9 billion clinical events. The Children's Mercy Institutional Review Board has designated research with CHFD data as nonhuman subjects research.⁸ We sought to utilize this database to characterize patients diagnosed with feeding problems, including concurrent conditions, age, race, and sex.

Utilizing the CHFD, we identified patients with a diagnosis of feeding difficulties and mismanagement (*ICD-9* 783.3) or feeding difficulties (*ICD-10* R63.3) between ages 7 months and 17 years who had an outpatient visit between 2010 and 2017 at one of the participating centers. All diagnosis priorities were included. In order to limit the effect of newborns and young infants with routine feeding difficulties only infants 7 months of age and older were included. Our cohort parameters allowed infants whose feeding problems began during the neonatal period but were severe enough to persist beyond the first 6 months of life. This population was assessed for demographic characteristics and complex clinical conditions. The cohort was collapsed into a matrix defining recognized phenotype codes (PheCodes)^{9,10} for *ICD-9* and *ICD-10* diagnoses to categorize coexisting conditions. This was then further categorized into compound phenotypes through systematic review of phenotype codes, categorized by the primary organ system affected. The categories of compound phenotypes were independently reviewed by three physicians (S.E., M.S., T.A.), to develop the final compound phenotypes. We computed the number of unique patients for each individual ICD diagnosis code and separately for each compound phenotype code for both the base and cohort populations. Prevalences were computed from the patient counts. This process allowed analysis at an aggregate level using compound phenotype codes but with the ability to review results for an individual diagnosis code, if desired. The prevalence of each of the compound phenotypes was identified for the base CHFD pediatric population and the cohort population, that was then used to develop prevalence ratios.

RESULTS

We identified 39,674 patients diagnosed with two feeding difficulties diagnosis codes (*ICD-9* 783.3 and *ICD-10* R63.3) representing 101,684 encounters from 68 health systems, comprising 250 facilities, across the United States (Figure 1). The encounters were predominantly in the Midwest (45.0%), followed by the South (35.3%), West (5.3%), and Northeast (14.4%). There was a male predominance in the cohort with 42.5% being female (M/F = 1.3:1). Figure 2 demonstrates the encounter age distribution. Multiple encounters were noted in 44% of the patients; Figure 3 demonstrates patient trajectories, most patients presenting at a younger age, and in that scenario follow-up appears to be drawn out for longer than the patients who present later. The majority 53.1% of patients were

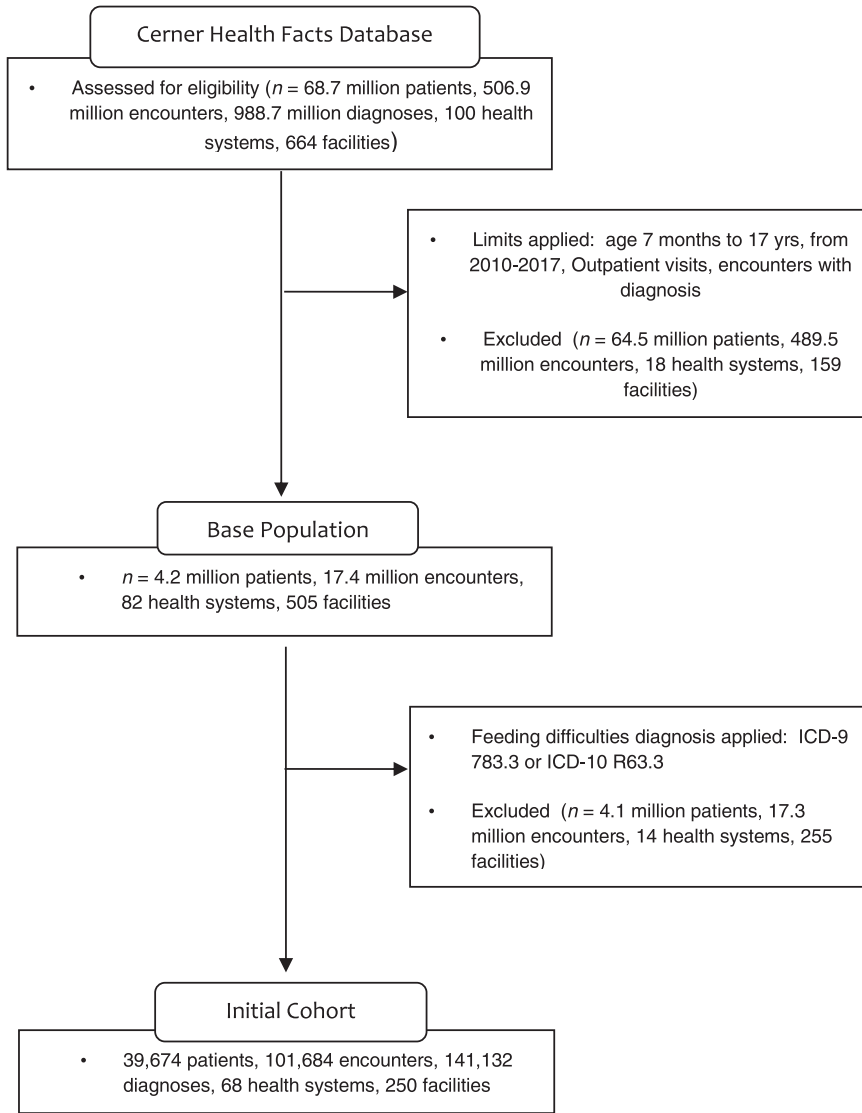


FIGURE 1 Initial cohort

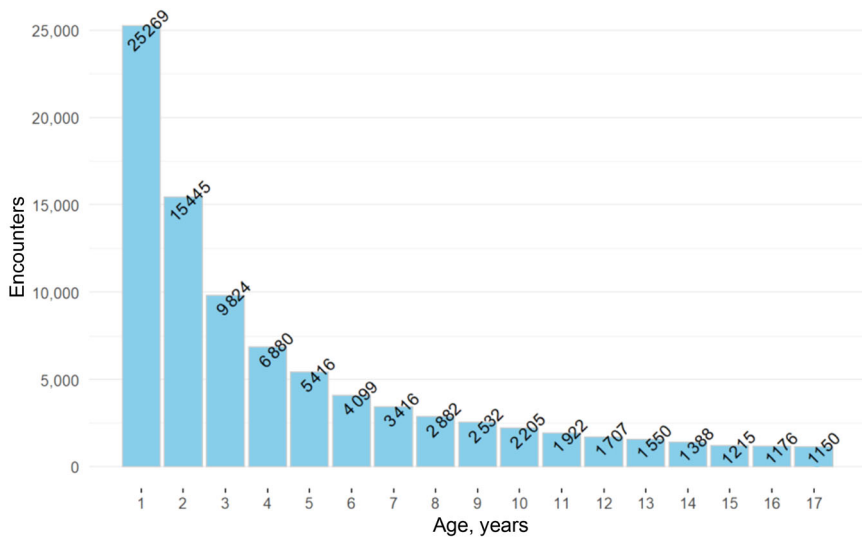
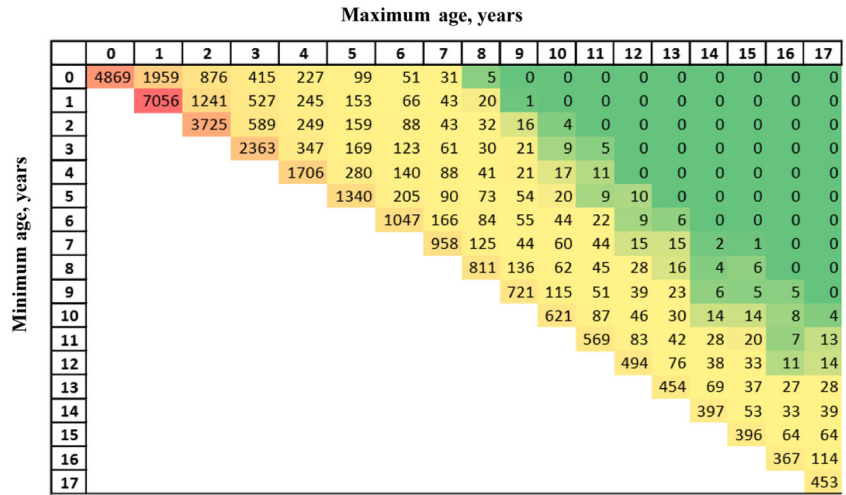


FIGURE 2 Encounter age distribution for children ≥1 year old

FIGURE 3 Patient trajectories. The heat map of our cohort represents the ages at which they were seen and subsequent follow up. For example, “5 patients seen at age 0 are still being seen at age 8 years”. Red colors represent the age at which the largest amount of patients seen progressing to green, which represents ages at which the fewest amount of patients were seen



White, 18.0% African American, 5.1% Hispanic, and 2.6% Asian. There were 4.5% that were mixed race and 16.7% with unknown race. Compared with the general pediatric population,¹¹ Hispanic patients were relatively less likely to be diagnosed with a feeding disorder (relative risk ratio: 0.2198; 95% CI, 0.2101–0.2299, $P < 0.0001$); whereas African American and White patients were significantly more likely to be diagnosed (relative risk: 1.7063; 95% CI, 1.6622–1.7516, and 1.5718: 1.5369–1.6075, respectively, both $P < 0.0001$). The encounter payer mix was 23% commercial, 48% government, 11% other, 2% self-pay, and 15% unknown.

The compound phenotype conditions and their prevalence within the cohort are listed in Table 1, along with prevalence ratios between the cohort and the base population. A prevalence ratio >1 indicates the diagnosis is more prevalent in the cohort than base population. There were 6923 conditions identified in the cohort. These diagnoses were grouped into phenotypes representing 1875 PheCodes^{7,8} identifications, but when there was no mapping of an ICD code to a phenotype, the ICD code was retained in the analysis. The results were then further consolidated by organ system to compound phenotypes. At each stage of aggregation, the number of diagnosis records, encounters, and patients was recorded. In general, encounter and patient counts are not additive because an encounter or patient can have several conditions.

Thirty-two compound phenotypes were identified. ICD codes and phenotype codes that were not considered clinically significant were ignored, such as genetic tests, other activities, polydipsia, or an unspecified accident. The prevalence for the compound phenotypes in the base population and cohort were then compared to generate prevalence ratios. Among the list of compound phenotypes, gastrointestinal conditions was the most common, followed by malnutrition, developmental and behavioral, and neurologic and musculoskeletal. The highest prevalence ratios were identified in those patients with gastrostomy tubes, followed by oral motor skills and malnutrition, failure to thrive, and electrolytes.

The most prevalent compound phenotype was identified as gastrointestinal, which was an aggregate of phenotypes and

associated ICD-9/-10 codes. Details of the makeup of the gastrointestinal compound phenotype can be seen in Table 2. The three most prevalent phenotypes were identified as gastroesophageal reflux, followed by constipation and abdominal pain. There were many diagnoses within the gastrointestinal grouping with prevalence ratios >1 but those with the highest prevalence ratios among the top 25 most prevalent conditions, outside of those related to gastrostomy or enterostomy complications, included gastrointestinal complications ICD-10-CM K91.2 (21.52), gastroesophageal reflux disease (GERD) ICD-10-CM K21.9 (10.59), eosinophilic esophagitis ICD-10-CM K20.0 (8.31), and constipation ICD-9 564.01 (6.68).

DISCUSSION

This is the first publication characterizing the demographics of a large population of children with feeding difficulties in the United States, representing both private and publicly insured patients from multiple medical centers throughout the United States. Previous large studies have been in a single center,³ public insurance from two states compared with privately insured nationwide database,¹ or parent report through the National Health Interview Survey (NHIS).⁵ We report a prevalence of 9.4 out of 1000 pediatric patients within the CHFD who have feeding difficulties. Our report is consistent with the data reported from the national health survey, that cited a prevalence of 9 out of 1000 children ages 3–17 years had a feeding or swallowing problem.⁵ This is lower than the recent prevalence study that demonstrated a prevalence of 16.97–21.43 out of 1000, for those with public insurance and a prevalence of 9.38 out of 1000 in the nationwide privately insured cohort.¹ The privately insured cohort is more consistent with our findings and also represents a national database. It is possible that the higher prevalence for their publicly insured cohort, is an effect of selection bias or a reflection of the greater number of diagnosis codes used in their study as compared with the current study. Their study was also based on inpatient and ambulatory encounters vs the current study which was

TABLE 1 Concurrent conditions

Rank	Compound phenotype	Diagnoses ^a	Encounters ^b	Patients ^c	Prevalence, % ^d	Prevalence ratio ^e
Cohort	Feeding difficulties	101,966	101,684	39,674	100.00	105.25
1	Gastrointestinal	51,811	35,410	14,397	36.29	2.14
2	Malnutrition, FTT, electrolytes	20,398	18,587	9248	23.31	5.88
3	Developmental and behavioral	20,413	18,015	7690	19.38	2.68
4	Neurologic and musculoskeletal	18,783	12,848	6261	15.78	1.03
5	Oral motor skills	9953	9417	5884	14.83	15.39
6	Gastrostomy status	16,161	15,428	5187	13.07	36.25
7	Pulmonology and sleep	13,546	9605	4728	11.92	0.8
8	ENT	9735	7194	3957	9.97	0.4
9	Allergy/immunology	6034	4951	2976	7.50	0.68
10	Hearing and speech	6460	5785	2864	7.22	1.5
11	Dermatologic	4036	3611	2649	6.68	0.35
12	Cardiovascular	7854	5286	2543	6.41	0.8
13	Endocrinology and metabolism	4342	3735	2178	5.49	1.03
14	Perinatal	3773	3048	1777	4.48	3.89
15	Hematologic and lymphatic	3069	2691	1687	4.25	0.84
16	Genetic	3941	3804	1633	4.12	3.03
17	Ophthalmologic	3214	2403	1566	3.95	0.54
18	Congenital anomalies	3599	3330	1471	3.71	5.17
19	Renal/urologic	3213	2288	1418	3.57	0.35
20	Orthopedic	2212	1849	1263	3.18	0.19
21	Psychiatric	2367	1893	1229	3.10	0.52
22	Craniofacial	2217	1972	1119	2.82	1.17
23	Infectious	1457	1280	1037	2.61	0.23
24	Eating disorder	1406	1330	960	2.42	4.66
25	Obesity/bariatric	1251	1129	839	2.11	0.44
26	Hepatology	1098	953	543	1.37	1.7
27	Dental	481	435	405	1.02	0.41
28	Oncologic	677	462	273	0.69	1.44
29	Rheumatologic	237	207	172	0.43	0.06
30	Pharmacology and Toxicology	112	96	92	0.23	0.45
31	Gynecologic	101	96	91	0.23	0.07
32	Nonspecific pain	106	97	80	0.20	0.09

Note: Concurrent Conditions.

Abbreviations: ENT, ear, nose and throat; FTT, failure to thrive.

^aNumber of times diagnosis occurred within our cohort.

^bNumber of unique encounters within our cohort.

^cNumber of unique patients within our cohort.

^dPrevalence of patients with defined compound phenotype, within our cohort.

^ePrevalence of compound phenotype within our cohort as compared with prevalence of compound phenotype within the base population.

TABLE 2 Gastrointestinal compound phenotype

ICD codes	Phenotype	Base patients	Base prevalence, %	Cohort patients	Cohort prevalence, %	Prevalence ratio
ICD-9 530.81	GERD	53,534	1.28	3984	10.04	7.83
ICD-10-CM K21.9	GERD	33,508	0.80	3372	8.50	10.59
ICD-9 564.00	Constipation	99,419	2.38	2625	6.62	2.78
ICD-10-CM K59.00	Constipation	65,156	1.56	2493	6.28	4.03
ICD-10-CM R10.9	Abdominal pain	70,971	1.70	1762	4.44	2.61
ICD-9 789.00	Abdominal pain	124,493	2.98	923	2.33	0.78
ICD-10-CM R11.10	Nausea and vomiting	33,839	0.81	894	2.25	2.78
ICD-9 787.03	Nausea and vomiting	51,556	1.23	856	2.16	1.75
ICD-10-CM K59.09	Constipation	15,290	0.37	658	1.66	4.53
ICD-9 536.42	Complications of gastrostomy, colostomy and enterostomy	2710	0.06	648	1.63	25.17
ICD-9 787.91	Diarrhea	53,831	1.29	525	1.32	1.03
ICD-9 536.40	Complications of gastrostomy, colostomy, and enterostomy	760	0.02	477	1.20	66.06
ICD-10-CM R19.7	Diarrhea	31,964	0.77	347	0.87	1.14
ICD-10-CM K59.01	Constipation	6365	0.15	274	0.69	4.53
ICD-9 536.8	Dyspepsia and other specified disorders of function of stomach	9466	0.23	244	0.62	2.71
ICD-9 787.3	Flatulence	6318	0.15	234	0.59	3.9
ICD-9 564.09	Constipation	7286	0.17	234	0.59	3.38
ICD-10-CM K94.23	Complications of gastrostomy, colostomy, and enterostomy	911	0.02	225	0.57	25.99
ICD-10-CM Z87.19	Personal history of diseases of digestive system	4817	0.12	215	0.54	4.7
ICD-10-CM K20.0	Eosinophilic esophagitis	2685	0.06	212	0.53	8.31
ICD-9 579.3	Gastrointestinal complications	1209	0.03	183	0.46	15.93
ICD-10-CM K91.2	Gastrointestinal complications	851	0.02	174	0.44	21.52
ICD-9 564.01	Constipation	2693	0.06	171	0.43	6.68
ICD-9 530.13	Eosinophilic esophagitis	3137	0.08	149	0.38	5
ICD-10-CM R14.0	Flatulence	3322	0.08	149	0.38	4.72

Note: The gastrointestinal compound phenotype from Table 1 was an aggregation of phenotypes that in turn was an aggregation of the ICD-9/-10 codes shown here. Each compound phenotype in Table 1 could be expanded in the same way.

Abbreviations: GERD, gastroesophageal reflux disease

based on ambulatory encounters only. The study using multiple diagnosis codes used codes that could be seen as etiologies for feeding disorders, such as “dysphagia,” which were included in the concurrent conditions analyze. Unlike the NHIS study, the current study includes those children with feeding difficulties that begin in infancy or as young toddlers. Utilization of the EHR for diagnoses has the potential to provide a more comprehensive and inclusive list of concurrent conditions. Additionally, we included all diagnosis code priorities, as our focus was on evaluating any patient who had a diagnosis of feeding difficulties.

There are very different uses of terminology across all of these studies from diagnoses to disorder and comorbidities, symptoms, and etiologies. All describing very similar conditions but in reality can have very different connotations. Even though there has recently been a formal ICD-10 diagnosis for feeding disorder, this is very new and will help greatly in informing prevalence studies moving forward, but prior to that and for the purposes of our study, no formal “Feeding disorder” diagnosis thus we used the “feeding difficulties” diagnosis for our study, which can include a wide range of interpretations from picky eating, to problem feeder, to severe feeding difficulty and could even include some patients who qualify for an avoidant restrictive food intake disorder (ARFID) diagnosis, as there is much overlap. Having a formal “Feeding disorder” diagnosis will be incredibly helpful for understanding prevalence in years to come.

This is the first large report of race among children with feeding difficulties. We found that Hispanic patients are diagnosed with FD less frequently than others, and in contrast to African American patients who were significantly more likely to be diagnosed. It is unclear if this is a reflection of the delivery of healthcare services to African American families and possibly having increased referral to a tertiary institution, or if this reflects an effect of disparity. With a cohort comprised predominantly of those using government insurance, this could represent a predisposition based on socioeconomic disadvantage or a predisposition based on concurrent conditions. Gastrostomy status would classify a patient as medically fragile, making them eligible for government insurance.

We also evaluated patient trajectories, which is represented in Figure 3. This is a summary of our cohort and the majority of patients are only seen for one visit followed by those followed for a limited number of years. What is unclear is if this indicates more mild disease or a transition of care to a different center outside of the CHFD. It is also important to point out that the first visit in our database may not be the first visit for the patient but our database collectively covers the span from 7 months to 17 years.

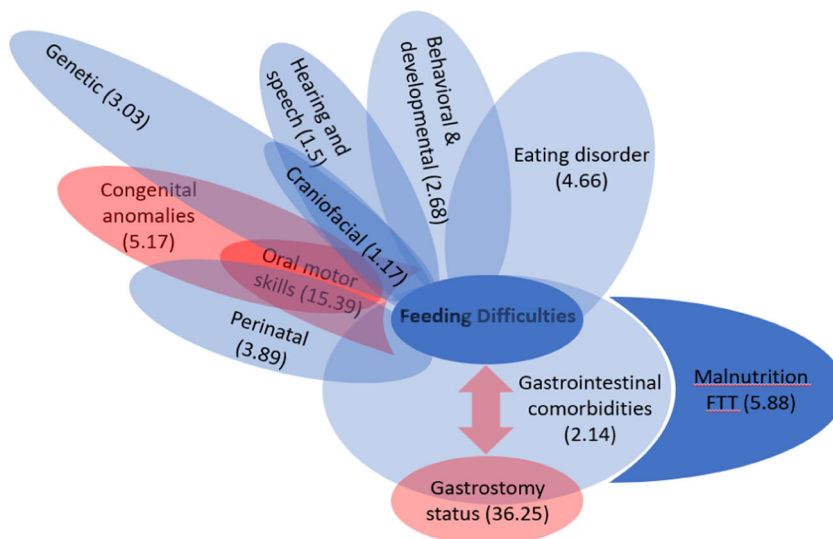
We report the most common concurrent conditions of patients with FD, with the highest relating to gastrointestinal disorders in 36% of our cohort. This aligns with the observations by Rommel et al⁴ and Sharp et al⁵ both 36% and 38% prevalence of gastrointestinal conditions, as well as the most recent pediatric feeding disorder prevalence study that found a high percentage of patients with gastrointestinal conditions.¹ Our observations are also consistent with Rommel's findings of gastroesophageal reflux disease as the

most common etiology among gastrointestinal diagnoses in children with feeding difficulties.⁴ The high prevalence ratios within the gastrointestinal grouping also suggests an association between feeding difficulties with GERD, eosinophilic esophagitis, constipation.

Another US cohort-based report of 143 patients treated with feeding difficulties divided comorbidities into five categories including neurologic, structural/mechanical, cardiorespiratory, behavioral, and metabolic.¹² In this population, neurologic comorbidities were most prevalent and present in 62% of participants. In contrast, 15% of our cohort had neurologic and musculoskeletal comorbidities. In that study, the mechanical/structural category included gastrointestinal etiologies and was found in 53% of their population. These discrepancies could be in part due to the selection bias of different feeding clinics and the heterogeneous population of patients with feeding difficulties. Our report consists of all children in a broadly inclusive cohort with feeding difficulties, reflecting a wider, more inclusive spectrum of patients including mild through severe feeding difficulties. Interestingly, Kovacic et al evaluated the proportion of patients within different groupings of patients with complex chronic conditions who had feeding difficulties and found that those patients with chronic gastrointestinal and respiratory disorders had a higher proportion of patients with a feeding disorder.¹ It is also possible the differences between the findings could relate to the way the diagnoses were grouped. Our study is the first feeding disorder study to use PheCodes to group ICD-9 and -10 diagnoses and then further grouped the PheCodes into broader categories.

We also report on the prevalence ratios between our cohort and the base population. Our observations include some diagnoses that are intuitively anticipated and others that might reveal mechanistic aspects of the evolution to feeding disorders. Hence, the highest prevalent diagnosis was gastrostomy status with the implied interrelationship with FD. This followed by oral motor diagnoses, congenital anomalies and eating disorders. This matches closely with Rommel's report of 16% of their patients with feeding difficulties having a gastrostomy tube⁴ but is greater than the 2.7%–5.6% of patients with feeding disorders who had gastrostomy tubes reported by Kovacic et al.¹ This difference could be a reflection of the use of procedure codes to identify patients with g-tubes vs the use of diagnosis codes in the current study. This is the first report using prevalence ratios, reflecting a potential association with the patient's feeding disorder, including gastrointestinal, malnutrition, developmental and behavioral, neurologic, oral motor, hearing and speech, endocrinologic, perinatal, genetic, congenital, craniofacial, hepatic, and oncologic conditions. This picture (Figure 4) illustrates the complex, heterogeneous population seen within multidisciplinary feeding clinics and the four main etiologies thought to contribute to feeding difficulties—behavioral, oral motor, nutrition, medical or a combination of these. Interestingly, there was not an increased prevalence of those patients with ENT and pulmonologic diagnoses in our cohort. This could be secondary to a high prevalence of ear, nose and throat diagnoses in the general population, including such diagnoses as otitis media and pharyngitis; two common childhood conditions. The results from our study should help with defining the

FIGURE 4 Hypothetical representation of the observed risk relationship between various comorbidities and feeding difficulties, with prevalence listed in parentheses. FTT, failure to thrive



needs for these special vulnerable populations and perhaps increase our awareness of the potential for feeding disorders when dealing with children with these concurrent conditions, specifically those with high prevalence ratios.

As mentioned, eating disorders were noted to have a higher prevalence ratio as well. This category included anorexia nervosa, bulimia, and eating disorder not otherwise specified. ARFID was not included in this study, as it did not become a formal diagnosis until 2018 and CHFD goes through 2017.

The current study has several limitations: a key consideration in any data analysis project is cohort definition and related potential for error; our cohort is defined by a single ICD-9/-10 and therefore susceptible to provider level error; misdiagnosis, misreporting, and coder level error including miscoding. Diagnostic ambiguity, including the inability to discern between the severity of the feeding disorder, may be a factor with the FD diagnosis label and coding error may be increased as nonprimary diagnoses had to be included in the cohort definition. The efforts to define a formal “feeding disorders” diagnosis, as proposed by Goday et al,¹³ further highlights the vague nature of the definition of the feeding difficulties diagnosis. Only as of October 1, 2021, pediatric feeding disorder, acute and chronic, now has an ICD-10 code. Nonetheless published studies specifically addressing cohort accuracy in similar scenarios are reassuring.¹⁴ Additionally we recognize limitations with synthesizing large, nonhomogeneous data as well as the categorization process of such a large number of diagnoses.

This is one of the largest report of its kind and includes a cohort defined as a consequence of medical professional evaluation. This confers a better, more accurate reflection of nationwide patterns of disease prevalence as well as the context, defined by concurrent conditions wherein the diagnosis of FD seems more prevalent. These observations are central to understanding of the true medical impact of feeding difficulties in children, and consequently planning of educational, screening tools and resource allocation to more

effectively recognize and manage this relatively poorly defined group of patients. It is important to note the excitement of a well-defined pediatric feeding disorder diagnosis and ICD-10 code, which will aid in conducting more accurate prevalence studies in the future. Our work, along with others may provide the groundwork toward developing a comorbidity risk assessment tool that would be applied toward identifying at-risk patients and therefore earlier intervention and treatment. Early identification, by virtue of risk profiling based on associated conditions may offer the prospect of early, even presymptomatic identification and thereby intervention that impacts the course of the disease and more advanced clinical manifestations.

AUTHORSHIP STATEMENT

Sarah T. Edwards, Ann M. Davis, Jose Cocjin, and Thomas M. Attard equally contributed to the conception and design of the research; Earl F. Glynn contributed to the acquisition and analysis of the data; Sarah T. Edwards, Michael Slogic, Earl F. Glynn, and Thomas M. Attard contributed to the interpretation of the data; Sarah T. Edwards, Earl F. Glynn, and Thomas M. Attard drafted the initial manuscript. All authors critically revised the manuscript, agree to be fully accountable for ensuring the integrity and accuracy of the work, and read and approved the final manuscript.

CONFLICT OF INTEREST

None declared.

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