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ORIGINAL ARTICLE

Impact of Children's Feeding/Swallowing Problems: Validation of a New Caregiver Instrument

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Abstract The impact of caring for children with deglutition disorders is poorly understood and tools to measure the unique concerns of these caregivers are lacking. The aims of this investigation were to develop and validate The Feeding/Swallowing Impact Survey (FS-IS) as an instrument designed to measure and improve understanding of caregiver issues. Demographic, economic, and dysphagic data were provided by the primary caregivers of 164 children (median age: 14 months, male: 78, female: 86) presenting for initial outpatient feeding/swallowing evaluations. Caregivers completed the PEDS-QL$^{\text{TM}}$ Family Impact Module (PEDS-QL$^{\text{TM}}$ FIM) and the FS-IS. A principal component analysis was conducted on the FS-IS to identify appropriate subscales. Concurrent validity was assessed by examining correlations between the FS-IS and PEDS-QL$^{\text{TM}}$ FIM. Caring for children with feeding/swallowing problems adversely impacted the Health-Related Quality of Life (HRQoL) of their caregivers. The FS-IS had a strong 3-factor solution to indicate 3 subscales: Daily Activities, Worry, and Feeding Difficulties. All three subscales and total score of the FS-IS correlated with PEDS-QL$^{\text{TM}}$ FIM. The FS-IS was validated as an instrument that may help clinicians detect specific factors that influence caregiver HRQoL, identify caregivers who might benefit from additional support, and ultimately improve the care of their children with feeding/swallowing disorders.

Keywords Deglutition · Deglutition disorders · Dysphagia · Child · Pediatric · Health-related quality of life · Caregiver experiences

The incidence of feeding/swallowing disorders in children is reported to be increasing secondary to improved survival rates of children born with histories of prematurity (<37 weeks gestation), low birth weights and complex medical conditions, and the improved life expectancy of children with developmental disabilities [1, 2]. Given the inextricable relationship between feeding and swallowing during infancy and early childhood, the generic term feeding/swallowing will be used in this text unless distinguishing between feeding and swallowing is relevant to the discussion [3]. Importantly, disruptions in either process can result in a complex and heterogeneous group of

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problems [1]. Affected children are at increased risk for aspiration-induced lung injury, sequelae associated with malnutrition, and stressful interactions with their caregivers [1, 4–9]. Understanding the concerns of caregivers has not kept pace with the recent medical advances, which have improved the ability to identify dysphagia in children and manage the associated respiratory and nutrition consequences [6, 7, 10, 11].

The importance of caregiver well-being is underscored by its influence on disease course and health outcomes in children with other medical conditions [12, 13]. In addition, the impact of quality of life has been implicated in the noncompliance to recommendations of caregivers for adults with dysphagia [14]. Health-Related Quality of Life (HRQoL) has been established as an important gauge of patient-based health outcomes and a recommended endpoint in all clinical trials [15]. An understanding of the caregiver's concerns in the outpatient setting is particularly important given that recent health care cost containment measures have shifted services from inpatient to ambulatory care settings, and thereby increased the burdens placed upon the caregivers of affected children [16, 17]. Existing tools, which measure the generalized HRQoL of caregivers, may lack sensitivity for the detection of the unique concerns associated with caring for children with specific medical conditions [18]. Given the limitations associated with generalized HRQoL measures, "condition-specific" instruments are needed to identify and track the unique concerns of caregivers for children with deglutition disorders.

The primary aims of this investigation were to develop and validate the Feeding/Swallowing Impact Survey (FS-IS) as an instrument designed to measure the impact of children's feeding/swallowing difficulties on their caregivers. Understanding the specific concerns of these caregivers may provide health care providers, educators, and funding sources with information on which to base management recommendations and ultimately improve the care provided to affected children.

Methods

Participants

This was an observational cross-sectional study that included data gathered from caregivers of children presenting for the first time for a feeding/swallowing evaluation at the outpatient Johns Hopkins Pulmonary Feeding and Swallowing Clinic between August 2008 and February 2010. A convenience sample of parents or legal guardians were recruited and consented to participate in the Johns Hopkins Pediatric Pulmonary Registry. Inclusion requirements are (1) child presenting for the first time for an outpatient feeding/swallowing evaluation and (2) an accompanying parent or legal guardian who was able to provide informed consent for participation in the study. The protocol for this study was approved by the Institutional Review Board of The Johns Hopkins Medical Institution. Of the 191 subjects consented, 23 participants did not answer all 18 items on the FS-IS and 4 children did not have a recorded height or weight at the clinic visit, resulting in a total of 164 participants having complete data. Since this study was examining the scoring and psychometrics of the measure, we did not impute any missing data which might bias the results.

Table 1 Study sample demographics, clinical characteristics, and diagnostic conditions

	Study sample $n = 164$
Demographics	
Sex, n (% female)	86 (52)
Race/ethnicity, *n* (%)	
Hispanic	8 (4.8)
African American	43 (26.3)
Caucasian	93 (56.8)
Asian	5 (3.0)
American Indian	2 (1.2)
Mixed	13 (7.9)
Clinical characteristics	
Age at clinic visit (months), median (IQR)	14 (7, 35)
Adjusted age for preterm births (months), median (IQR) $n = 66$	9.9 (5, 32)
Weight for age percentile, median (IQR)	45.3 (8.5, 90.4)
Height for age percentile, median (IQR)	47.1 (6.9, 87.9)
Weight for height percentile, median (IQR)	55.6 (22.6, 91.0)
Weight for height perentile <5 % failure to thrive, *n* (%)	20 (12 %)
Feeding tube, *n* (%)	77 (47.0)
Diagnostic conditions	
GI/digestive/nutritional disorders	123 (75)
Developmental delays	113 (69)
Pulmonary disorders	84 (51)
Nervous/neuromuscular disorders	50 (30)
Anatomic/structural disorders	41 (25)
Known genetic/syndromic disorders	38 (23)
Environmental exposures/social concerns	17 (10)
Cardiac disorders	16 (10)
Allergy/immune/systemic processes	12 (7)

Procedures

Caregivers provided demographic data, medical histories, and socio-economic data. Research assistants (RAs) were trained to follow a script that explained the project to caregivers and provided caregivers with specific instructions about how to complete forms. RAs were available to answer any questions. To minimize time constraints associated with the completion of forms, caregivers were able to return completed forms by mail if they were unable to complete them on the day of the visit. Clinical characteristics were provided by caregivers and extracted from the medical records. (Table 1) Household incomes were estimated from residential zip codes using the most recent (2007-2011) 5-year survey estimates available from the American Community Survey (www.census.gov/acs).

Given the paucity of validated quality of life measures for parents of young children, caregivers completed The PEDS-QL^{TM} Family Impact Module (PEDS–QL^{TM} FIM) which has been reliable and validated in caregivers of medically fragile children between 2 to 19 years of age [19, 20]. Each caregiver's HRQoL is assessed by scoring the caregiver's self-reported functioning (physical, emotional, social, and cognitive functioning, communication, and worry) and the functioning of their families (daily activities and family relationships). Items are scored on a 0–100 scale and higher scores indicate better functioning.

Caregivers completed an 18-item Feeding/Swallowing Impact Survey (FS-IS). The items on the FS-IS were developed in 3 phases. In phase 1, content was extracted from caregiver input during visits to this feeding/swallowing clinic over the past 20 years. In phase 2, content was reviewed and revised per consensus of clinical experts (e.g., speech-language pathology and pulmonary medicine) who care for children with feeding/swallowing problems. In phase 3, items on FS-IS were grouped into 3 major categories to parallel general subsets from other QoL measures (e.g., PEDS-QL^{TM} FIM) and included caregivers' perceptions of time demands on daily activities, worry about the children's well-being, and challenges related to the delivery of care specific to feeding/swallowing needs. All items included the stem, "In the past ONE month, as a result of your child's feeding/swallowing problems, how often have you had problems …?" Response options were assessed on a 5-point Likert scale ranging from a score of "1" indicating never to a score of "5" indicating almost always. Items within each subscale were added together then divided by the total number of items in the subscale to create an average subscale score. All 18 items were summed and then divided by 18 to create an average overall total score." Items on the FS-IS were tested for readability and scored a Flesh-Kincaid Grade Level of 6.1. (see online appendix)

Statistical Methods

Descriptive frequencies of sociodemographic characteristics were generated using means and proportions as appropriate. We conducted a principal component analysis with promax rotation for the 18 items to evaluate these subscales. To evaluate concurrent construct validity, we computed correlations between the FS-IS and the PEDS-QL^{TM} FIM using Pearson correlation coefficients. We hypothesized that higher FS-IS scores (worse problems) would correlate with lower ratings of HRQoL as assessed by the PEDS-QL^{TM} FIM. To test for discriminative properties of the FS-IS, we examined mean differences on the FS-IS by the presence/absence of key medical and demographic variables using t-tests. Given the wide range of developmentally appropriate feeding behaviors in young children, we examined the FS-IS for mean differences among three age groups: (1) <12 months old, (2) 12–18 months old, and (3) >18 months old, based on corrected gestational age as applicable. Participants with incomplete survey data were excluded, with the exception of the four families who did not have household income information. All analyses were 2-sided and *p*-values of less than 0.05 were considered to be statistically significant. Analyses were performed using SAS 9.3 (SAS System, Cary, NC).

Results

Participants

Caregivers accompanying the 164 children to the clinic visit provided data for this study. (Table 1) Of the caregivers, 138 (84 %) identified themselves as mothers, 18 (11 %) fathers, and 8 (5 %) others (e.g., grandmother, aunt, stepmother). Median age of presentation was 14 months (mean: 32 ± 44 months). Prematurity (<37 weeks gestation) was reported for 66 (40 %) patients. Medical/developmental conditions were grouped into the nine diagnostic-based categories displayed in Table 1. This group was medically complex with 144 (88 %) having conditions in more than one of the diagnostic-based categories. Additionally, 77 (47 %) of the children had feeding tubes (73 gastrostomy, 1 gastrojejunostomy, 1 nasogastric, and 3 nasojejunostomy), 32 (20 %) had fundoplications for reflux, and 7 (4 %) required some means of respiratory support (e.g., supplemental oxygen or BiPap). Using census data, 122 (76 %) families were above mean (SD) median U.S. household income of $72,608 (±27,317), with four families not reporting.

Principal Component Analysis of the FS-IS and Internal Reliability

A principal components extraction using promax rotation was conducted. Three factors were extracted, which corresponded to the three subscales (daily activities, worry, and feeding difficulties). As indicated by the squared

Table 2 Caregiver reported Feeding/Swallowing Impact Survey (FS-IS) factors

Item	Factor 1 (Feeding)	Factor 2 (Worry)	Factor 3 (Daily activities)
It is hard for me to do my job, go to school, or work around the house			0.74
It is hard for me to get help from others because they are scared to feed or take care of my child			0.78
It is hard for me to leave my child because I am scared to have other people feed or take care of my child			0.69
It is hard for my family to make plans or go out to eat			0.79
I am too tired to do the things I want or need to do			0.84
I worry about my child's general health		0.72	
I worry that my child does not get enough to eat or drink		0.60	
I worry about how others will react to my child's feeding/swallowing problems		0.52	
I worry about how my child breathes when feeding or whether my child will choke		0.57	
I worry that my child will never eat or drink like other children		0.76	
I worry about whether I am doing enough to help with my child's feeding/ swallowing problems		0.76	
I worry about how my child's feeding /swallowing problems affect others in my family		0.49	
It is hard to feed my child because it takes a long time to prepare liquids or foods the "right" way	0.61		
It is hard to feed my child because I don't know how to prepare liquids or foods	0.75		
It is hard to feed my child because others give my child liquids or foods that are not allowed	0.70		
It is hard to feed my child because I don't know how long these feeding/swallowing problems will last	0.76		
It is hard to feed my child because family members or professionals have different opinions about how to take care of my child's feeding/ swallowing problems	0.69		
It is hard to feed my child because I do not get enough information about how to get my child to eat or drink like other children	0.69		
Variance explained	3.41	3.64	3.66

multiple correlations (SMC), all factors were internally consistent and well defined by the variables, with 0.79 as the lowest SMC for factors from the variables. All variables loaded on only one factor using a cutoff of factor loadings at 0.4. (Table 2) All three factors correlated with each other with a range from 0.36-0.46 indicating that a promax rotation was appropriate. Internal reliability was very good with Cronbach alphas all above 0.7 (Total score = 0.89, daily activities = 0.88, worries = 0.85, and feeding difficulties = 0.85).

Concurrent Construct Validity of the FS-IS

To assess concurrent construct validity, we evaluated the correlations between the FS-IS and the PEDS-QL^{TM} FIM, and other demographic and anthropometric variables. Means (SDs) for each HRQoL measure are shown in Table 3 with the correlation coefficients shown in Table 4. Items on the FS-IS were summed to create subscales identified in the principal component analysis above. All three of subscales on the FS-IS (1) Daily Activities, (2) Worry, and (3) Feeding Difficulties as well as the Total Score were significantly associated with the PEDS-QL^{TM} FIM total score and subscales.

Discriminative Properties of the FS-IS

The FS-IS was able to discriminate between children with and without more significant deglutition difficulties as implied by the presence of a feeding tube. Feeding tube presence was associated with significantly greater interference with caregiver completion of daily activities ($p < 0.006$) with a trend for the overall FS-IS total score ($p < 0.08$). There were no significant differences on any subscale or total score of the FS-IS between white and non-white families, above and below median household income, and caregivers of developmentally delayed and typically developing children. There were no mean differences on any of the subscales of the FS-IS among the three age groups (see Table 3).

Discussion/Summary

This investigation reports on the validation of a new instrument, the FS-IS, to measure the impact of children's feeding/swallowing problems on the HRQoL of their caregivers. These children are medically complex and their care substantially impacts the physical and emotional well-being of their caregivers. The FS-IS fills a significant gap in the literature and holds the potential of identifying and tracking the specific needs of caregivers of affected children. Such information is particularly important given that health care

Table 3 Means (SDs) of caregiver impact and PEDS-QL$^{\text{TM}}$ Family Impact Module (FIM) measures

	Total Mean (SD) $n = 164$	Mean (sd) children <12 months $n = 75$	Mean (sd) children 12–18 months	Mean (sd) children >18 months	Cronbach α
Feeding/Swallowing Impact Survey (FS-IS)					
Daily activities	1.8 (1.0)	1.8 (0.9)	2.0 (1.0)	1.8 (1.0)	0.88
Worry	2.5 (1.0)	2.5 (1.0)	2.7 (0.9)	2.4 (1.0)	0.85
Feeding	1.3 (0.6)	1.3 (0.6)	1.5 (0.8)	1.3 (0.6)	0.85
Total	1.4 (0.5)	1.4 (0.5)	1.5 (0.5)	1.3 (0.6)	0.89

Table 4 Concurrent validity of Feeding/Swallowing Impact Survey (FS-IS) Sum Scores with PEDS-QL$^{\text{TM}}$ Family Impact Module (FIM), anthropometric measures, and demographic and socio-economic characteristics

	Mean (SD)	FS-IS			
		Daily activities	Worry	Feeding	Total score
PEDS-QL$^{\text{TM}}$ FIM					
Physical	65.1 (24.9)	−0.43*	−0.27*	−0.23*	−0.38*
Emotional	70.0 (26.3)	−0.51*	−0.35*	−0.34*	−0.48*
Social	71.2 (28.7)	−0.72*	−0.41*	−0.39*	−0.62*
Cognitive	76.6 (26.5)	−0.42*	−0.26*	−0.28*	−0.38*
Communication	72.6 (27.3)	−0.62*	−0.40*	−0.39*	−0.56*
Worry	61.2 (23.9)	−0.39*	−0.57*	−0.30*	−0.54*
Daily Activities	59.8 (31.5)	−0.59*	−0.39*	−0.29*	−0.54*
Family relationships	76.5 (26.3)	−0.57*	−0.38*	−0.44*	−0.53*
Total Score	68.2 (21.6)	−0.61*	−0.43*	−0.38*	−0.58*
Anthropometric measures					
Weight for age percentile		0.06	0.04	0.12	0.07
Height for age percentile		−0.06	0.01	0.04	−0.02
Weight for height percentile		0.12	0.09	0.17	0.12
Demographic and socio-economic characteristics					
Age in months		−0.03	−0.03	−0.04	−0.04
Median household income by zip code		−0.05	−0.04	−0.01	−0.05

* $p < 0.05$ for Pearson correlations

providers are increasingly reliant upon the caregivers for the improved health outcomes of medically complex children [12, 16] and lower HRQoL has been reported for caregivers of children with other chronic conditions [21–23].

To our knowledge, there exists one unpublished (at the time of manuscript preparation) scale that captures information about the impact of feeding/swallowing problems on children's caregivers. Redle [10] developed and piloted a 44-question scale, and found that caregivers of affected children reported greater challenges and stresses than those experienced by caregivers of typically developing children [10]. In comparison to the current investigation, Redle's caregivers represented a demographically and racially limited subgroup of the population, and cared for older children. It is likely that children in our study were younger because our data were captured only at the time of the first outpatient visit for feeding/swallowing problems.

Our caregivers' responses to the Daily Activities, Worry, and Feeding Difficulties subscales of the FS-IS correlated with the broader measures of HRQoL on the PEDS-QL$^{\text{TM}}$ FIM. Caregivers may be especially vulnerable to factors that adversely impact their HRQoL because of the stressful child–caregiver interactions and social isolation associated with feeding/swallowing disorders [23, 24]. They reported that caring for affected children resulted in time and economic challenges as well as worries about children choking or getting enough to eat and the impact of these problems on other family members [10].

Consequently, they confirmed previous reports about the challenges associated with the caring for children with special needs, including those with gastrostomy tube feedings and complex feeding problems [6, 24–26].

Approximately one-half of the children in our sample were younger than 12 months of age at the time of their first outpatient clinic visit. Understanding the needs of caregivers of young children is particularly important given that greater time and attention demands have been reported by caregivers of younger versus older children with other conditions [26, 27]. Our subjects were comparable to previous studies for the frequency of prematurity, developmental delays, and use of feeding tubes [1, 28–32].

We were surprised that caregivers' responses did not differ on the basis of the presence of a feeding tube, a history of prematurity, age group, or a diagnosis of developmental delay. Given the cross-sectional nature of our investigation, with data accrued from one point in time, we are unable to determine if caregivers had sufficient time to adjust to their children's feeding/swallowing problems or the management of the feeding/swallowing and medical problems before the first outpatient clinic visit. Ray [33] reported that it took approximately six months for families to be comfortable with the technical aspects of their children's care, regardless of the complexity of the care. [33] Prospective longitudinal studies are needed to determine whether the concerns expressed by our caregivers are modified by time, therapeutic interventions, the severity of the feeding/swallowing impairments, the persistence of co-morbidities, or changes in their children's medical or health status.

Primary limitations of this study are related to factors associated with a sample derived from a single clinic, the cross-sectional nature of our data, and the use of census-derived income. Biases associated with data collected from one center are well known. In addition, there may be a selection bias in those who came to this clinic because it is geared toward the evaluation of children with feeding/swallowing concerns thought to have a medical basis. Consequently, we may attract younger and fewer children with feeding disorders associated with the developmental delay spectrum. Nevertheless, the inclusion of all children presenting for the first time to an outpatient feeding/swallowing clinic, may have been reduced some sample biases related to selective underlying conditions or specific populations. Although, differences in feeding/swallowing concerns have been reported by caregivers of children with versus without these problems [10], our data do not allow us to determine whether some of the concerns expressed in our study (e.g. "I worry that my child does not get enough to eat or drink") are ubiquitous and true for many caregivers of young children regardless of feeding/swallowing status. Likewise, we are not able to determine whether caregiver concerns are related to problems with deglutition, co-occurring medical conditions, or some combination of factors. Another limitation is related to the use of the PEDS–QL$^{\mathrm{TM}}$ FIM because it had not been validated on children younger than two years of age. At the time of our data collection, we were unable to find any other validated quality of life tools for caregivers of younger children.

The above limitations point to the need for further investigations to establish internal validity and determine whether our findings are generalizable to caregivers of children with characteristics (e.g., older children or those diagnosed with chronic conditions [e.g., cerebral palsy]) that differ from those reported in this investigation or who present to other settings. To address internal validity, we need to compare our findings with data obtained from a control group of caregivers of children with typical feeding/swallowing development. We are currently investigating HRQoL and FS-IS in relation to quantitative assessments of the severity of swallowing impairments in young children to determine whether caregiver concerns are modified dysphagia severity.

Our findings suggest that caregiver demands associated with the caring for children with feeding/swallowing problems in the outpatient setting should not be underestimated. We recommend that health care providers support caregivers by discussing how many children improve with time and the resolution of medical problems that either cause or are caused by the feeding/swallowing impairments [34]. Whenever possible, families should be given realistic expectations about the time commitments so that they can make appropriate plans. Family-centered multidisciplinary centers may improve the HRQoL of caregivers by lessening some of time burdens, decreasing days lost from employment, and fostering the development of their coping and mastery skills [24, 35, 36].

Conclusions

The FS-IS is a new instrument developed and validated to measure the impact of feeding/swallowing disorders in children on their caregivers. Subscales of the FS-IS correlated with the broader measures of HRQoL on PEDS-QL$^{\mathrm{TM}}$ FIM. Caring for these children adversely impacted the HRQoL of caregivers. Clinicians can deliver better services by identifying and paying appropriate attention to factors that influence the HRQoL of caregivers of children with feeding/swallowing disorders.

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Conflict of interest All authors disclose that they have no financial interests in the subject of this manuscript.

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