ORIGINAL PAPER



Clinical Validation of Feeding Handicap Index for Children (FHI-C)

Srushti Shabnam^{1,2} · N. Swapna³

Accepted: 21 July 2022 / Published online: 17 August 2022 © The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2022

Abstract

Children with developmental disabilities (DD) exhibit feeding and swallowing difficulties, which can have an impact on nutritional, developmental, and psychological aspects. The existing tools assess the nature of feeding problems and behaviors only. The present study aimed to assess the physical, functional, and emotional domains in children with DD with feeding issues using Feeding handicap index for children (FHI-C). For clinical validation, FHI-C was administered on the parents/ caregivers of 60 children with cerebral palsy, 61 with autism spectrum disorder, 59 with intellectual disability and 60 typically developing children in the age range of 2 to 10 years. The results revealed that the mean scores (Total FHI-C and FHI-C domain scores) were significantly higher for all three clinical groups than for the control group, which revealed good clinical validity. Also, FHI-C was found to have significantly high test–retest reliability. The study presents a valid and reliable tool for assessing the psychosocial handicapping effects of feeding problems in children with DD. FHI-C provides a holistic picture about the psychosocial impact of feeding problems in children with DD and will assist the clinicians in prioritizing the goals for feeding therapy. The scores obtained can be used as reference for pre and post therapy comparison purposes.

Keywords Autism spectrum disorder \cdot Cerebral palsy \cdot Developmental disabilities \cdot Feeding handicap index for children \cdot Intellectual disability

Introduction

Feeding and swallowing are complex sensorimotor skills, which provide nutrition for normal growth and development (Kummer, 2008). It serves a range of biological, psychological, and social functions in the life of the developing child (Cooper & Stein, 2006). However, feeding is highly sensitive to neurologic dysfunction. Children with developmental disabilities exhibit feeding and swallowing difficulties, which may lead to significant negative nutritional (Schwarz, 2003), developmental (Arvedson, 2006), and psychological sequelae (Learned, 2014). For example, oropharyngeal dysphagia is reported to be present in 90% of children with

 Srushti Shabnam simpleshabnam@gmail.com
 N. Swapna nsn112002@yahoo.com

¹ Nitte Institute of Speech and Hearing, Mangalore, India

- ² All India Institute of Speech and Hearing, Mysuru, India
- ³ Department of Speech Language Pathology, All India Institute of Speech and Hearing, Manasagangothri, Mysuru, India

cerebral palsy (CP) (Benfer et al., 2012, 2013). Children with intellectual disability (ID) and autism spectrum disorders (ASD) are reported to exhibit several feeding issues such as bizarre food habits, food refusal, delay or difficulty in chewing, sucking, or swallowing, delay in self-feeding etc. (Badalyan & Schwartz, 2011; Cermak et al., 2010; Cooper-Brown et al., 2008; Marshall et al., 2014; Nadon et al., 2011; Parry, 1994). Feeding disorder not only impacts eating and drinking ability, but also has an impact on the daily life of children and families and their participation in social gatherings, thus affecting the quality of life of the family (Dondrill & Estrem, 2020).

Parents/caregivers play an important role in feeding the child. Since the parents/caregivers have a first-hand exposure and experience in feeding their child, they are well aware of the child's feeding behaviors and patterns, food-related likes and dislikes, communication behaviors during feeding, use of structures in the mouth for feeding and swallowing; problems faced by the child during feeding and the impact of feeding problems in day-to-day life and on socio-emotional life (Cullinane & Novak, 2013). Consequently, they are the best people to describe the child's feeding problems and can provide a more holistic perspective of their feeding

behaviors (Piazza-Waggoneret al., 2008). Caregiver report has been shown to correspond to direct observation for some feeding behaviors, including meal length and parent coaxing in pediatric populations (Piazza-Waggoneret et al., 2008). Parent-report scales are also a valid means of measuring early child communication skills (Määttä et al., 2012) and behaviours representing developmental risk (Martin et al., 2012).

Though there are a few questionnaires to assess feeding issues in children with developmental disabilities (Table 1), these provide information primarily regarding the nature of feeding problems and behaviors from parents/caregivers' perspective. There are also a few tools developed specifically to assess the quality of life in children with developmental disabilities (Table 1). However, their focus is primarily on overall quality of life and not specific to the psychosocial impact of the feeding problem. These tools do not specifically provide information about the impact of feeding problems on functional and psychosocial aspects.

Though such tools are available to assess adults such as dysphagia goal handicap (DGH, Gustaffson & Tibbling, 1991), SWAL-QOL (McHorney et al., 2002), and the DHI (Silbergleit et al., 2012), but similar tools are not available for children in Indian context. Thus, FHI for children (FHI-C) was developed by Swapna and Shabnam (2017) to assess the nature of feeding problems and their impact on different domains of life in children with developmental disabilities in the age range of 2-10 years. It is a 38-item parent/caregiver reported tool. It consists of physical, functional and emotional domains with 21, 12 and 5 items in each domain respectively. FHI-C was developed by collating the information from the literature and information concerning feeding from the Indian parents of children with developmental disabilities. The questions in the physical domain were formulated based on physical problems manifested by the children while feeding. The questions in the functional domain were formulated based on functional modifications and strategies used by the Indian parents while feeding their children with developmental disabilities. The strategies such as pinching

Table 1 Summary of tools which assesses the feeding problems and quality of life in children

Test	Authors	Description
Tools to assess feeding problems		
About your child's eating (AYCE))-revised	Davies et al. (2007)	AYCE is a parent reported tool to assess the feeding behaviour (Child resistance to eating, positive mealtime environment and parent aversion to mealtime)
Brief autism mealtime behaviour inventory (BAMBI)	Lukens and Linscheid (2008)	BAMBI is an informant reported measure to acquire feed- ing and mealtime behaviour information in children with ASD. The items were categorized under three domains, i.e. limited variety, food refusal and features of autism
Mealtime behavior questionnaire (MBQ)	Berlin et al., (2010)	MBQ is a parent reported tool assesses the feeding behaviour (food refusal/avoidance, food manipulation, mealtime aggression/ distress, and choking/gagging/ vomiting)
Montreal children's hospital (MCH) feeding scale	Ramsay et al., (2011)	MCH is a parent reported tool to assess feeding skills and behaviours (oral motor, oral sensory, and appetite, maternal concerns about feeding, mealtime behaviour, maternal strategies used and family reactions to their child's feeding)
Quality of life tools		
Cerebral palsy quality of life questionnaire for chil- dren (CP QOL-Child)	Davis et al., (2007)	CP QOL-Child is a parent reported tool. It assesses the quality of life of children with CP in term of social well- being and acceptance, functioning, participation and physical health, emotional well-being, pain, and impact of disability
Child health questionnaire (CHQ)	McCarthy et al., (2002)	CHQ contains both self-reported and parent reported form which assesses physical functioning, general health perception and emotional/ behavioral aspect of children with CP
Pediatric quality of life inventory (PedsQL)	Varni et al., (2006)	PedsQL contains both self-reported and parent reported form which assesses physical, emotional, social and school functioning
Caregiver priorities and child health index of life with disabilities (CPCHILD)	Narayanan et al., (2006)	CPCHILD provides the caregivers' perspective on the health status, functional limitation and well-being of children with CP

child's nose to make them swallow, shaking the child's head, pouring water in child's mouth followed by food and pushing back the food in mouth to facilitate swallowing were reported by the parent. Hence, the questions were formulated accordingly and incorporated in the questionnaire. In the emotional domain, questions were formed based on kind of emotional manifestations shown by the children with developmental disabilities due to their feeding difficulties.

The preliminary FHI-C contained 50 items which was given to professionals: seven experienced speech-language pathologists, one nutritionist, one occupational therapist and one psychologist who are working with children with developmental disabilities were considered for content validation and for their feedback regarding the items of FHI-C. After the content validation, the items were reduced to 38 and then FHI-C was subjected to a pilot study. After the pilot study, examples were included in few items (Item no. 3, 24, and 31) for the better understanding of questions by the parents/caregivers. Based on the above, the FHI-C was finalized.

Anil et al. (2019) assessed the issues with physical, functional and emotional aspects of feeding in children with Down syndrome in the age range of 2-7 years using FHI-C and compared them with age match controls. They had considered 17 children with Down syndrome (10 females & 7 males) and 47 typically developing children (20 females and 27 males). The results revealed the following mean \pm SD scores: 10.38 \pm 4.25, 4.12 \pm 2.72, 2.19 \pm 2.10 and 16.69 ± 7.01 for physical, functional, emotional and total FHI respectively for Down syndrome group. For the control group, the mean \pm SD scores obtained were 2.23 \pm 2.62, 1.47 ± 0.86 , 0.93 ± 1.04 and 4.63 ± 3.25 for physical, functional, emotional and total FHI respectively. The results of Mann Whitney U test revealed that Down syndrome group had significantly higher scores compared to typically developing group (p < 0.001). The results suggest that feeding difficulties are predominantly present in children with Down syndrome.

Further, Swapna & Anne Maria (2019) assessed the feeding and swallowing problems in adolescents with cerebral palsy (CP) in the age range of 13–17.11 years using Feeding Handicap Index. Also, the functioning of oral structure during feeding was assessed through Behavioral assessment scale of oral functions in feeding (BASOFF). Eating and drinking ability classification system (EDACS) and Dysphagia outcome and severity scale (DOSS) was used to classify the different levels and severity of feeding impairment. The results revealed the mean \pm SD scores: 47.92 ± 22.80 , 24.38 ± 12.80 , 12.66 ± 10.00 for physical, functional, and emotional respectively for Down syndrome group. Further, the results of Spearman's correlation coefficient revealed that BASOFF have high positive correlation with physical (r=0.88) functional (r=0.75) domains and overall FHI (r=0.85) with p < 0.001. Similarly, EDACS and DOSS found to high positive correlation physical, functional domains and overall FHI with p < 0.001. Hence, this suggests that adolescents with CP exhibit major feeding and swallowing issues. Also, high correlation of FHI with other western feeding assessment tools suggests that it is effective subjective feeding assessment tool.

The above studies support the clinical utility of FHI-C in assessing feeding issues in children with Down syndrome and adolescents with CP. There is a dearth of literature investigating the clinical utility of FHI-C in children with developmental disabilities (cerebral palsy, autism spectrum disorder, intellectual disability). Hence, the present study aimed to assess the physical, functional, and emotional domains in children with developmental disabilities (DD) with feeding issues using Feeding handicap index for children (FHI-C) in the age range of 2–10 years. The specific objective of the study was to compare the performance of the children with developmental disabilities (cerebral palsy, autism spectrum disorder, intellectual disability) and typically developing children on the FHI-C; and to assess the test–retest reliability.

Method

Pilot Study

A pilot study was carried out initially, in which FHI-C was administered on thirty parents/caregivers of children with developmental disabilities (10 with CP, 10 with ASD, and 10 with ID) in the age range of 2 to 10 years with a history of feeding problems. The responses obtained were documented. The sample size was calculated using G*power analysis and sample size was estimated to 60 participants in each group.

Main Study

In the present study, descriptive research with standard group comparison was used. The participants were selected through purposive sampling.

Participants and Procedure

The sample size for the study was calculated using the data from the pilot study and the online sample size calculation software from the website stat.ubc.ca; and the sample size of 60 across each group was estimated. The participants of pilot study were excluded from the main study. The children with the provisional diagnosis of delayed speech and language with cerebral palsy, delayed/inadequate speech and language with Autism spectrum disorder (ASD), and delayed/inadequate speech and language with intellectual deficit; with feeding problems were considered under CP, ASD and ID groups of the clinical group respectively. The children who reported to clinic with feeding problems were in the age range of 2-10 years, this age group was considered. They were diagnosed by a qualified team of professionals including a speech-language pathologist, paediatrician, physiotherapist, and a clinical psychologist. Children with ASD were diagnosed by SLPs by using Indian scale for assessment of autism (ISAA). These children had reported to special clinic for motor speech disorder (MSD) with feeding problems. The feeding problems were assessed using a descriptive protocol used at the MSD clinic by a team of professionals that included a speech language pathologist (feeding specialist), clinical psychologist and nutritionist. The study was carried out in Mysore, a city in Karnataka state of India. The majority of the participants belonged to Karnataka and Kerala states of India, located in southern part of the country.

The FHI-C was administered to the parents/caregivers of 60 children with CP (21 females and 39 males), 61 children with ASD (15 females and 46 males), and 59 children with ID (23 females and 36 males) in the age range of 2–10 years. In the CP group, all the children had associated intellectual disability ranging from borderline intellectual deficit to severe intellectual deficit. In ID group, seventeen children had associated Down syndrome. A group of sixty typically developing children (29 females and 31 males) matched for age and socioeconomic status were considered as the control group. These children were selected from the Mysuru city, Karnataka, India. Those with no history of neurological, oro-motor, communicative, cognitive, or sensorimotor, and academic impairment were selected which was ensured using the 'WHO Ten-question disability screening checklist' (Singhi et al., 2007). All the participants in this study belonged to the middle class socio-economic status which was ascertained using the NIMH socioeconomic status scale developed by Venkatesan (2011).

FHI-C was administered to parents/caregivers of all the participants in one-to-one setup in a relatively noise-free environment with minimum distractions. A rapport was established with the parent/caregiver and the purpose of the administration was explained. Initially, the demographic details were obtained and then the FHI-C was administered. The examiner read out the questions and possible responses to the parent/caregiver. The responses were obtained orally and were marked on the questionnaire by the examiner. The responses were scored on the 3-point rating scale by the examiner. The rating scale to indicate the overall severity of the problem was also carried out both by the examiner and the parent/caregiver. The time taken to administer the tool was approximately 30 min.

The present study was a part of AIISH Research Funded project; hence the proposal was presented before the Research Advisory Committee of the Institute and approval was received for the same. The study complied with the 'Ethical Guidelines for Bio-Behavioural Research Involving Human Subjects' of the Institute for participant selection and their participation. Before testing, written consent was obtained from the parents of the participants after explaining the purpose and method of the study.

Assessment of Test-Retest Reliability

To assess the reliability of the final version of the tool, the tool was administered again on ten participants selected randomly from each of the groups. This was done one week after their initial responses were obtained.

Analyses

The scores obtained from each participant in the clinical groups and the control group were totalled. A total score on the FHI-C and domain-specific scores were obtained. A higher score on FHI-C indicated greater feeding problems. The data obtained were subjected to the statistical analysis using IBM SPSS version 20. Descriptive statistics were used to obtain the median and interquartile range (IQR) of scores obtained for all the groups. A Chi-square test was used to measure the significance level of each question. Cronbach's alpha was used to determine the test–retest reliability. Kruskal–Wallis test and Mann–Whitney U test were used to compare the control and the clinical groups.

Results and Discussion

The results have been presented and discussed under different sections below:

I. Comparison of Clinical Groups with the Control Group

The groups of children with CP, ASD, and ID were compared with the control group for the total FHI-C scores and FHI-C domain (Physical, Functional & Emotional) scores. The median and interquartile range (IQR) obtained have been depicted in Table 2. On comparison, it was seen that the mean scores (Total FHI-C and FHI-C domain scores) were higher for all the three clinical groups than for the control group. Mann–Whitney U test revealed a significant difference between all the three clinical groups and the control group. The /z/ values and p values have been depicted in Table 3.

The results indicated that children with CP, ASD, and ID exhibited a greater extent of feeding problems than the control group. These results are in agreement with the studies done by previous studies (Gangil et al., 2001; Rajshree

Table 2Median andinterquartile range (IQR) valuesof FHI-C for the three clinicalgroups and the control groupfor the FHI-C domains and totalFHI-C scores

Domains	FHI value	s						
	CP group		ASD group		ID group		Control group	
	Median	IQR	Median	IQR	Median	IQR	Median	IQR
Physical	17.00	13.00	8.00	9.00	8.00	9.00	1.00	2.00
Functional	5.00	6.00	3.00	3.00	2.00	3.00	1.00	2.00
Emotional	1.00	2.00	2.00	5.00	2.00	3.00	0.00	1.00
Total	22.00	18.75	14.00	10.00	13.00	10.00	2.50	5.75

Table 3Comparison betweenall three clinical groups with thecontrol group using the Mann–Whitney test

FHI-C scores	CP group		ASD group	ASD group		ID group	
	/z/ values	p values	/z/ values	p values	/z/ values	p values	
Total	8.98*	0.00	8.15*	0.00	7.60*	0.00	
Physical	8.79*	0.00	7.00*	0.00	7.68*	0.00	
Functional	6.32*	0.00	6.01*	0.00	4.73*	0.00	
Emotional	2.93*	0.01	5.67*	0.00	4.93*	0.00	

 $^{^*}p < 0.001$

& Manjula, 1991; Stallings et al., 1996; Trier & Thomas, 1998), where they have found that feeding difficulties are seen in the majority of the children with cerebral palsy. Researchers have also reported that children with ASD eat a very narrow range of food items (Badalyan & Schwartz, 2011; Bandini et al., 2010; Marshall et al., 2014; Nadon et al., 2011), which is in agreement with the results of present study. The feeding problems are reported in around 30–80% of children with ID (Matson et al., 1991; Palmer et al., 1975; Perske et al., 1977), which is again in consensus with the results of the present study. These results suggest that FHI-C shows a clear demarcation between control group and children with developmental disabilities and the tool can be used to assess the feeding problems and their impact.

II. Frequency of Different Responses on Each Item of the FHI in the Three Clinical Groups and the Control Group

The responses obtained from the parents/caregivers under the three response categories viz. 'never', 'sometimes', and 'always' for each item were totalled for different participants in the three clinical groups. To investigate whether significant differences, if any, existed between each of the three clinical groups and the control group for each item in the index, the Chi-square test was used. For the CP group, the chi-square values ranged between 0 and 82.94. The results of the test revealed that there was a significant difference between the CP group and the control group on all items except the items 17, 18, 19, 20, 24, 30, 31, 35, and 37. This suggests that majority of the items 29 out of 38 were affected in children with CP showing the severity of feeding problems in these children. Similarly, the results of the chi-square test in the ASD group revealed that there was a significant difference on all the items between the two groups except items 1, 2, 6, 8, 11, 19, 21, 28, 31, and 33; and ID group also revealed that there was a significant difference on all items except on items 2, 6, 8, 19, 20, and 33 between both the groups. This indicated that 28 out of 38 items for ASD group and 32 items out 38 in ID group were affected; suggesting that even children with ASD & ID face multiples issues related to feeding. Table 4 depicts the chi-square values obtained for each item for all the three clinical groups. The results of Chi-square test reveals that which kind of feeding related issues predominate in which particular group, that has been discussed further:

It was found that 61% of children with CP exhibited difficulty in drinking using a straw, rinsing, spitting and usage of the tongue to clear the food particles in the mouth which indicated that these were the most commonly occurring problems in them. The difficulties with sucking, chewing, eating with fingers, drinking using glass/cup, inadequate weight gain, inadequate amount of eating, avoidance of solid food, and longer feeding time was reported by approximately 33% of the children. Difficulty in using the tongue to clear the food particles stuck in between the teeth or between the gums and the cheeks was found to be affected in more than 70% of the children with CP. Nasal regurgitation, vomiting, choking, usage of special utensils, and feelings of embarrassment or sadness due to the feeding problem were not reported to be present in these children. These findings were in consensus with the previous studies (Gangil et al., 2001; Rajshree & Manjula, 1991; Stallings et al., 1996; Trier & Thomas, 1998).

 Table 4
 Comparison between each of the three clinical groups and the control group for each item of the FHI-C

Item No	Chi square val	ues (df=2)	
	CP group	ASD group	ID group
1	25.45***	7.31	6.43*
2	18.46***	7.31	4.21
3	31.13***	15.24***	12.81**
4	11.70*	25.70***	21.49***
5	34.89***	39.03***	35.86***
6	52.72***	0.44	2.91
7	27.47***	44.55***	37.96***
8	55.31***	1.07	3.03
9	25.45***	9.56**	18.79***
10	40.09***	29.04***	23.02***
11	49.67***	1.53	7.62*
12	24.00***	6.21*	11.11**
13	22.29***	30.99***	39.27***
14	82.94***	45.48***	44.02***
15	10.49**	16.40***	17.45***
16	82.82***	7.31*	5.31*
17	4.14	6.21*	9.57**
18	2.14	5.03*	1.54
19	4.39	2.47	5.35
20	3.78	6.19*	2.22
21	16.41***	0.99	8.79*
22	11.91**	6.95*	8.79*
23	17.22***	12.24**	12.29**
24	4.03	22.74***	33.61***
25	24.00***	72.99***	44.51***
26	17.18***	15.13**	17.63***
27	26.28***	19.08***	19.80***
28	8.14*	2.36	8.99*
29	12.11**	40.99***	30.57***
30	_	10.72**	12.33**
31	4.13	2.00	8.72**
32	11.88**	20.01***	22.23***
33	14.58***	0.99	_
34	6.33*	0.01*	7.77*
35	4.14	23.57***	22.99***
36	7.73*	13.52**	14.92**
37	3.89	31.29***	6.43*
38	8.94*	25.92***	9.94**

p < 0.05, p < 0.01, p < 0.01

In children with ASD, it was found that approximately 40% of their parents/caregivers reported difficulty in the usage of finger and spoon by the child for eating, drinking using a straw, usage of the tongue to clear the food

particles in the mouth, and ability to rinse and spit, neophobia and avoidance of specific food items, longer mealtime, and avoidance of feeding in social situations. Difficulty in chewing, inappropriate weight gain, spillage of food by children, and dislike to be dependent on others for feeding were reported by 18% of the parents/caregivers. Gagging while eating, refusal to open his mouth to eat, and temper tantrums while feeding were found only in 5% of the children with ASD. These results were in agreement with the previous studies (Badalyan & Schwartz, 2011; Bandini et al., 2010; Marshall et al., 2014; Nadon, et al., 2011).

The parent/caregiver responses obtained from the ID group revealed that approximately 38% of the children displayed difficulties in independent eating, drinking using a straw, rinsing, spitting, and usage of the tongue to clear the food particles in the mouth. They also exhibited and inappropriate weight gain and avoidance of specific food items. 21% of the children had difficulty in chewing, usage of fingers to eat, retention of food in the mouth, spillage of food by children, and dislike to be dependent on others for feeding. 9% of them were unable to drink independently, refused to eat, and threw temper tantrums while feeding. These results agree with the studies reported in the literature (Matson et. al 1991; Palmer et al., 1975; Perske et al., 1977).

In the control group, the responses to almost all the items were 'never' for all the children which indicated that there were no major problems in feeding the children. However, the responses to item numbers 6, 8, and 32 were 'Always' for a few of the parents/caregivers. Item number 6 and 8 dealt with the usage of a spoon for eating and two parents/ caregivers of the typically developing children had reported problems with these items. Item number 32 dealt with the duration of feeding and around 13% of the parents/caregivers reported that their children took a long time to complete the meal. However, they reported that this was only seen when they watched television while eating.

III. Agreement Between Overall Severity Rating of the Examiner and Parent/Caregiver

The overall severity of the feeding problems was assessed by the investigating examiner as well as by the parent/caregiver of the children using a customized seven point rating scale. These severity ratings were divided into four categories, i.e. 1 = normal, 2 and 3 = mild, 4 and 5 = moderate and 6 and 7 = severe. The rating scale is incorporated at the end of the FHI-C questionnaire (Appendix 1). When the agreement between the ratings by the examiner and the parent/caregiver was assessed, it was seen that there was a poor agreement in all the three disorder groups (CP, ASD, and ID). The Kappa coefficient values were 0.09, 0.15, and 0.19, p > 0.05 for CP, ASD and ID groups respectively. This result suggested that most of the parents/caregivers of children were not sensitive to the feeding issues present in their children. The parents/ caregivers of these children seemed to be more concerned about their speech and language, cognitive and behavioural deficits as these were more predominant than the feeding problems. The support for these findings can be drawn from a few studies. Adamo and Brett (2013) suggested that the diet quality of children these days are sub-optimal and parent perception may not reflect the actual reality precisely. Another study by Harvey et al (2015) assessed the relationship between parental report of children's feeding problems and the child's nutritional intake in a non-clinical population. The results revealed no significant correlation between parent perception and the child's intake. Hence the results of present and previous studies suggest that although parents play an integral role in feeding of children, they may not be sensitive enough to judge the extent of feeding problems of their children.

Test-Retest Reliability

The test-retest reliability was determined for 33% of the samples from the three clinical groups using Cronbach's alpha. The alpha values for the total FHI-C scores and scores for FHI-C domains in the CP group were found to be high (Total FHI = 0.95, Physical = 0.95, Functional = 0.94, Emotional = 0.94), which indicated significantly high test-retest reliability. The alpha values for the total FHI-C scores and its domains in the ID group were also found to be high (Total FHI = 0.95, Physical = 0.95, Functional = 0.89, Emotional = 0.94), which indicated significantly high test-retest reliability. The alpha values in the ASD group too was found to be high (Total FHI = 0.95, Physical = 0.95, Functional = 0.90, Emotional = 0.93), which again indicated a high test-retest reliability. Kappa coefficient indicated a good test-retest reliability for Parent-reported severity (p < 0.001, k = 0.71). The alpha values for the total FHI-C scores and scores for FHI-C domains for the control group were also found to be high (Total FHI = 0.95, Physical = 0.95, Functional = 0.96, Emotional = 0.96) which indicated significantly high test-retest reliability. Similar results were obtained for Dysphagia Handicap Index for adults, where they obtained strong test test-retest reliability (Intraclass correlation coefficient ranging between 0.75 and 0.86) for total DHI and subscales of DHI (Silbergleit et al., 2012).

Limitation of the Study

The responses were restricted to three choices, which restrict the variability in the parent's response. Also, information regarding the cognitive and motor impairment of the children, i.e. reports from clinical psychologist and physiotherapist were not covered in the present study which can give a deep insight about the attributes to feeding problems in these children.

Conclusion

In sum, the results indicated that the total FHI-C scores and scores for each domain were significantly higher for all the three clinical groups in comparison to the control group. This indicated a good clinical validity for the tool developed. The high alpha values obtained also indicated good test-retest reliability. This study presents a psychometrically validated, reliable new tool for assessing the psychosocial handicapping effects of feeding problems in children with developmental disabilities. FHI-C provides with holistic information on the physical, functional, and emotional aspects related to feeding. This tool can be used in both clinical and research settings alike. The quantitative scores obtained from the tool will strengthen the clinical findings made by speech-language pathologists and also provide an insight into the impact of feeding problems on other domains of functioning. This will also assist the speech-language pathologists in prioritizing the goals taken up during feeding therapy. Since quantitative scores are obtained, this tool can be used to monitor the progress achieved during feeding therapy. Future studies could include the validation of the tool on adolescents with developmental disabilities. Also, research can be carried out to assess the parent's perception regarding the feeding problems in children with developmental disabilities, as information concerning this is very much limited in the literature.

Appendix 1

Feeding Handicap Index-Children (FHI-C)



Age/ Gender:

Date of birth:

Date of evaluation:

Provisional Diagnosis:

Examiner:

Item No.	Domain*	Question	Never has this problem	Sometimes has this problem	Always has this problem	Remarks (Please specify)
1.	1. P Did/does your child have difficulty in sucking from the feeding bottle/ breast?		0	1	2	
2.	Р	Does your child have difficulty in biting hard food (e.g., biscuit) and/or soft food (e.g. cake)?	0	1	2	
3.	Р	Does your child have difficulty in chewing hard food (e.g., biscuit) and/or soft food (e.g., idli, cake)?	0	1	2	
4.	Р	Does your child have difficulty in eating independently with his/her fingers?	0	1	2	
5.	Р	Does your child have difficulty in scooping food from a bowl/plate with a spoon?	0	1	2	
6.	Р	Does your child have difficulty in clearing the food from the spoon with the lips?	0	1	2	
7.	Р	Does your child have difficulty in eating with a spoon independently?	0	1	2	
8.	Р	Does your child have difficulty in drinking liquid from a glass/cup when held?	0	1	2	
9.	Р	Does your child have difficulty in drinking independently?	0	1	2	
10.	Р	Does your child have difficulty in drinking through a straw?	0	1	2	
11.	Р	Does your child have drooling while feeding?	0	1	2	
12.	Р	Does your child have difficulty in holding the solid/ liquid food in mouth? (food/liquid leaks from the mouth)	0	1	2	
13.	Р	Does your child have difficulty in clearing the food particles stuck in between the teeth or between the gums and the cheeks with his/her tongue?	0	1	2	
14.	Р	Does your child have difficulty in rinsing the mouth and spitting the water after eating?	0	1	2	
15.			0	1	2	
16.	Р	Does your child keep the food in the mouth without swallowing for a long time?	0	1	2	
17.	Р	Does your child have difficulty in swallowing solid/ semi-solid or mashed/ liquid food?	0	1	2	
18.	Р	Did/does the food/liquid comes through the nose during swallowing?	0	1	2	

19.	Р	Does your child gag when solid/liquid food is given?	0	1	2	
20.	Р	Does your child vomit when	0	1	2	
20.	•	solid/liquid food is given?	Ū	1	-	
21.	Р	Does your child choke while feeding?	0	1	2	
22.	F	Does your child eat less because of the	0	1	2	
		feeding problem?				
23.	F	Do you avoid giving solid food to your	0	1	2	
		child because of the feeding problem?				
24.	F	Does your child spill a considerable	0	1	2	
		portion of the solid food/liquid during				
		feeding? (E.g. spilling the food near the				
		mouth or spilling the food while taking				
		it from the plate). Specify the quantity of				
		food spilled in percentage.				
25.	F	Does your child strongly refuse newly	0	1	2	
		introduced food or certain food based				
		on the taste/temperature/ texture/				
	-	smell?				
26.	F	Does your child need to be placed in a	0	1	2	
		specific position/ special chair during				
27	г	feeding?	0	1	2	
27.	F	Does your child require smaller meals	0	1	2	
28.	F	more often due to the feeding problem?	0	1	2	
28.	Г	Do you push the food to the back of the mouth of your child so that s/he can	0	1	2	
		swallow it easily?				
		swallow it easily?				
29.	F	Does your child take longer time to	0	1	2	
		complete a meal?				
30.	F	Do you pour water/milk into the mouth	0	1	2	
		of the child in order to ensure that the				
		food is swallowed?				
31.	F	Does your child need specific utensils	0	1	2	
		(his/her own spoon, plate, etc.) and/or				
		special feeding equipment/aids (e.g.,				
		feeding tube, special feeding bottles				
32.	F	etc.)? Do you pinch your child's nose to	0	1	2	
32.	Г	make him/her swallow the food?	0	1	2	
33.	F	Do you shake your child's head/face or	0	1	2	
55.	1	close the lips/jaw for easy swallow?	0	1	2	
34.	Е	Does your child refuse to open his/her	0	1	2	
51.	Ľ	mouth while feeding?	Ū	1	-	
35.	Е	Does your child exhibit frustration or	0	1	2	
		temper tantrums before/during feeding?				
36.	Е	Does your child not like being	0	1	2	
		dependent on others for feeding?				
37.	Е	Does your child feel upset that s/he	0	1	2	
		cannot eat food like other				
		children/doesnot like to eat with other				
		children?				
38.	Е	Does your child feel embarrassed/is not	0	1	2	
		comfortable to eat food in social				
		gatherings?				

*P-Physical, F-Functional, E-Emotional

Other Significant Findings

Rating Scale for Parent/Caregivers

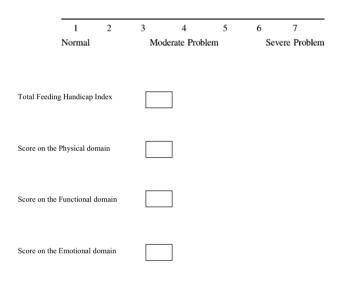
1	2	3	4	5	6	7
Normal		Мо	derate Prob	Se	vere Problem	

Please circle the number that matches the severity of your child's feeding difficulty (1- no difficulty at all; 4- some problem is present; 7- the worse problem my child could have).

Domains	FHI values						
	CP group (n=60)	ASD group (n=61)	ID group (n=59)	Control group (n=60)			
Func- tional	5.45 <u>+</u> 4.43	3.89 <u>+</u> 3.82	3.41±2.972	1.35±1.31			
Emotional	1.31 ± 1.52	3.30 ± 3.77	2.05 ± 1.888	0.56 ± 0.87			
Total	22.65±12.67	15.59±9.95	14.76±9.956	3.53±3.35			

Values are given as Mean±SD

Rating Scale for the Examiner



Appendix 2

Mean and standard deviation (SD) values of FHI-C for the three clinical groups and the control group for the FHI-C domains and total FHI-C scores

Domains	FHI values							
	CP group (n=60)	ASD group (n=61)	ID group (n=59)	Control group (n=60)				
Physical	15.91±8.79	8.41±6.42	9.31±6.571	1.68±2.20				

Declarations

Conflict of interest We declare no conflict of interest in the paper titled "Clinical Validation of Feeding Handicap Index for Children (FHI-C)."

References

Adamo, K. B., & Brett, K. E. (2013). Parental perceptions and childhood dietary quality: Who holds the reins? *Diet Quality* (pp. 177–197). Humana Press.

- Anil, M. A., Shabnam, S., & Narayanan, S. (2019). Feeding and swallowing difficulties in children with Down syndrome. *Journal of Intellectual Disability Research*, 63(8), 992–1014.
- Arvedson, J. C. (2006). Swallowing and feeding in infants and young children. *GI Motility Online*. https://doi.org/10.1038/gimo17
- Badalyan, V., & Schwartz, R. H. (2011). Feeding problems and GI dysfunction in children with asperger syndrome or pervasive developmental disorder not otherwise specified: Comparison with their siblings. *Open Journal of Pediatrics*, 1, 51–63.
- Bandini, L. G., Anderson, S. E., Curtin, C., Cermak, S., Evans, E. W., & Scampini, R. (2010). Food selectivity in children with autism spectrum disorders and typically developing children. *The Journal* of *Pediatrics*, 157, 259–264.
- Benfer, K. A., Weir, K. A., Bell, K. L., Ware, R. S., Davies, P. S., & Boyd, R. N. (2013). Oropharyngeal dysphagia and gross motor skills in children with cerebral palsy. *Pediatrics*, 131, e1553–e1562.
- Benfer, K. A., Weir, K. A., & Boyd, R. N. (2012). Clinimetrics of measures of oropharyngeal dysphagia for preschool children with cerebral palsy and neurodevelopmental disabilities: A systematic review. *Developmental Medicine and Child Neurology*, 54, 784–795.
- Berlin, K. S., Davies, W. H., Silverman, A. H., Woods, D. W., Fischer, E. A., & Rudolph, C. D. (2010). Assessing children's mealtime problems with the mealtime behavior questionnaire. *Children's Health Care*, 39, 142–156.
- Cermak, S. A., Curtin, C., & Bandini, L. (2010). Food selectivity and sensory sensitivity in children with autism spectrum disorders. *Journal of the American Dietetic Association, 110*, 238–246.
- Cooper, P., & Stein, A. (2006). Childhood feeding problems and adolescent eating disorders. Routledge.
- Cooper-Brown, L., Copeland, S., Dailey, S., Downey, D., Petersen, M. C., Stimson, C., & Van Dyke, D. C. (2008). Feeding and swallowing dysfunction in genetic syndromes. *Developmental Disabilities Research Reviews*, 14, 147–157.
- Cullinane, D., & Novak, P. (2013). Parent's/caregiver's relationship and the impact on nutrition. *ICAN: Infant Child, & Adolescent Nutrition, 5*, 311–314.
- Davies, W. H., Ackerman, L. K., Davies, C. M., Vannatta, K., & Noll, R. B. (2007). About your child's eating: Factor structure and psychometric properties of a feeding relationship measure. *Eating Behaviors*, 8, 457–463.
- Davis, E., Nicolas, C., Waters, E., Cook, K., Gibbs, L., Gosch, A., & Ravens-Sieberer, U. (2007). Parent-proxy and child self-reported health-related quality of life: Using qualitative methods to explain the discordance. *Quality of Life Research*, 16, 863–871.
- Dodrill, P., & Estrem, H. H. (2020). Quality of life assessment in children with feeding and swallowing disorders. *Multidisciplinary management of pediatric voice and swallowing disorders*. Springer.
- Gangil, A. K., Patwari, S., Aneja, B., & Ahuja, and Anand, V. K. (2001). Feeding problems in children with cerebral palsy. *Indian Pediatrics*, 38, 839–846.
- Gustafsson, B., & Tibbling, L. (1991). Dysphagia, an unrecognized handicap. *Dysphagia*, 6, 193–199.
- Harvey, L., Bryant-Waugh, R., Watkins, B., & Meyer, C. (2015). Parental perceptions of childhood feeding problems. *Journal of Child Health Care*, 19, 392–401.
- Kummer, A. (2008). *Cleft palate & craniofacial anomalies: Effects on speech and resonance* (2nd ed.). Cengage Learning.
- Learned, S. (2014). Understanding dysphagia: The social and emotional Impact. University of Arkansas.
- Lukens, C. T., & Linscheid, T. R. (2008). Development and validation of an inventory to assess mealtime behavior problems in children with autism. *Journal of Autism and Developmental Disorders*, 38, 342–352.

- Määttä, S., Laakso, M. L., Tolvanen, A., Ahonen, T., & Aro, T. (2012). Developmental trajectories of early communication skills. *Journal* of Speech Language, and Hearing Research, 55, 1083–1096.
- Marshall, J., Hill, R. J., Ziviani, J., & Dodrill, P. (2014). Features of feeding difficulty in children with autism spectrum disorder. *International Journal of Speech Language Pathology*, 16, 151–158.
- Martin, A., Razza, R. A., & Brooks-Gunn, J. (2012). Specifying the links between household chaos and preschool children's development. *Early Child Development and Care*, 182, 1247–1263.
- Matson, J. L., Gardner, W. I., Coe, D. A., & Sovner, R. (1991). A scale for evaluating emotional disorders in severely and profoundly mentally retarded persons: Development of the diagnostic assessment for the severely handicapped (DASH) scale. *British Journal* of Psychiatry, 159, 81–89.
- McCarthy, M. L., Silberstein, C. E., Atkins, E. A., Harryman, S. E., Sponseller, P. D., & Hadley Miller, N. A. (2002). Comparing reliability and validity of pediatric instruments for measuring health and well-being of children with spastic cerebral palsy. *Developmental Medical Child Neurology*, 44, 468–476.
- McHorney, C. A., Robbins, J., Lomax, K., Rosenbek, J. C., Chignell, K., Kramer, A. E., & Bricker, D. E. (2002). The SWAL–QOL and SWAL–CARE outcomes tool for oropharyngeal dysphagia in adults: III documentation of reliability and validity. *Dysphagia*, *17*, 97–114.
- Nadon, G., Feldman, D. E., Dunn, W., & Gisel, E. (2011). Mealtime problems in children with autism spectrum disorder and their typically developing siblings: A comparison study. *Autism*, 15, 98–113.
- Narayanan, U., Fehlings, D., Weir, S., Knight, S., Kiran, S., & Campbell, K. (2006). Initial development and validation of the caregiver priorities and child health index of life with disabilities (CPCHILD). Developmental Medical Child Neurology, 48, 804–812.
- Palmer, S., Thompson, R. J., & Linscheid, T. R. (1975). Applied behavior analysis in the treatment of childhood feeding problems. *Developmental Medicine and Child Neurology*, 17, 333–339.
- Parry, J. B. (1994). Merycism or rumination disorder: A historical investigation and current assessment. *British Journal of Psychiatry*, 165, 303–314.
- Perske, R., Clifton, A., McClean, B. M., & Stein, J. I. (1977). *Mealtimes for severely and profoundly handicapped persons: New concepts and attitudes*. University Park Press.
- Piazza-Waggoner, C., Driscoll, K. A., Gilman, D. K., & Powers, S. W. (2008). A comparison using parent report and direct observation of mealtime behaviors in young children with cystic fibrosis: Implications for practical and empirically based behavioral assessment in routine clinical care. *Children's Health Care*, 37, 38–48.
- Rajshree, S., & Manjula, R. 1991. Assessment Scale for cerebral palsied. A dissertation submitted as a part of fulfillment of Master's degree (Speech Language Pathology), University of Mysore
- Ramsay, M., Martel, C., Porporino, M., & Zygmuntowicz, C. (2011). The Montreal children's hospital feeding scale: A brief bilingual screening tool for identifying feeding problems. *Paediatrics & Child Health*, 16, 147–151.
- Schwarz, S. M. (2003). Feeding disorders in children with developmental disabilities. *Infants and Young Children*, 16, 317–330.
- Silbergleit, A. K., Schultz, L., Jacobson, B. H., Beardsley, T., & Johnson, A. F. (2012). The dysphagia handicap index: Development and validation. *Dysphagia*, 27, 46–52.
- Singhi, P., Kumar, M., Malhi, P., & Kumar, R. (2007). Utility of the WHO ten questions screen for disability detection in a rural community—the North Indian experience. *Journal of Tropical Pediatrics*, 53, 383–387.
- Stallings, V. A., Zemal, B. S., Davies, J. C., Cronk, C. E., & Charney, E. B. (1996). Energy expenditure of children and adolescents with

severe disabilities: A cerebral palsy model. *The American Journal of Clinical Nutrition*, 64, 627–634.

- Swapna, N., & Anne Maria, A. (2019). Validation of feeding handicap index in adolescents with cerebral palsy. *International Journal of Health Science and Research*, 9(9), 206–214.
- Swapna, N., & Shabnam, S. (2017). Manual of Feeding Handicap Index in children (FHI-C). All India Institute of Speech and Hearing
- Trier, E., & Thomas, A. G. (1998). Feeding the disabled child. Nutrition, 14, 801–805.
- Varni, J. W., Burwinkle, T. M., Berrin, S. J., Sherman, S. A., Ba, K. A., Malcarne, V. L., & Chambers, H. G. (2006). The PedsQL in pediatric cerebral palsy: Reliability, validity, and sensitivity of the generic core scales and cerebral palsy module. *Developmental Medicine & Child Neurology*, 48, 442–449.
- Venkatesan, S. 2011. Socio Economic Status Scale-2011. Mysore: AIISH. Revised version of "NIMH Socio Economic Status Scale-1993". NIMH

Wardle, J., Guthrie, C. A., Sanderson, S., & Rapoport, L. (2001). Development of the children's eating behaviour questionnaire. *The Journal of Child Psychology and Psychiatry and Allied Disciplines*, 42, 963–970.

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Springer Nature or its licensor holds exclusive rights to this article under a publishing agreement with the author(s) or other rightsholder(s); author self-archiving of the accepted manuscript version of this article is solely governed by the terms of such publishing agreement and applicable law.