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Original Research Article

Validation of Feeding Handicap Index in Adolescents with Cerebral Palsy

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ABSTRACT

Background: Feeding and or swallowing problems tend to persist in adolescents with CP
Objective: To assess feeding and swallowing problems in the physical, functional and emotional domains in adolescents with CP using Feeding Handicap Index (FHI), a tool developed in the Indian context, and to compare the results obtained through FHI with other dysphagia assessment tools.
Methods: Cross sectional study was conducted with a random sample of 15 participants in the age range of 13 to 17.11 years. FHI was administered on the participants to assess the physical, functional and emotional domains of feeding. The functioning of oral structures during feeding was assessed through BASOFF. The different levels and severity of feeding impairments were classified through Eating and drinking ability classification system (EDACS) and Dysphagia outcome and severity Scale respectively (DOSS). Descriptive statistics was done and Spearman correlation was used to find the relationship between FHI and other dysphagia assessment tools.
Results: Administration of FHI on adolescents with CP revealed that they exhibited feeding and swallowing problems in different domains. FHI had high correlation with other western feeding assessment tools.
Conclusions: Hence FHI is an effective subjective feeding assessment tool to assess various domains of feeding in adolescents.

What this paper adds on:

- Documents the feeding and swallowing problems in adolescents with CP
- Tool to assess feeding and swallowing in the physical, functional and emotional domains in adolescents with CP
- Efficacy of the tool in identifying feeding and swallowing problems in adolescents with CP

Key words: Feeding handicap Index, Adolescents, Cerebral palsy, feeding and swallowing

INTRODUCTION

Cerebral Palsy (CP) is a group of permanent non-progressive disorder of brain which leads to disturbances in movement and posture. [1] The incidence of CP is found to be of 3/1000 live births. [2] CP can be associated with various problems among which feeding and swallowing disorders are also predominant. [2-4] CP takes the first place in the list of central nervous system disorders which has a wide range of feeding and swallowing difficulties right from birth. Each of the levels of feeding development are greatly challenging for a child with CP. [1] The prevalence of feeding difficulties in CP varies between 30% to 100%. [5,6]

Oropharyngeal dysphagia is the frequent type of dysphagia noticed in almost 90% of children with CP, which is a major risk factor for survival. [7,1]

Various studies have reported the nature of feeding problems in children with CP. A study in CP individuals reported that participants exhibited difficulties in clearing food, spoon feeding, biting, chewing, cup drinking, straw drinking, swallowing, food and liquid loss. [8] Oral motor dysfunctions are reported to be present in all individuals with CP which could result in feeding problems. Poor feeding scores are reported in individuals with spastic quadriplegic CP and hypotonic CP. [9] However these early feeding problems in children are reflected in later years of life. [10] A few studies on children with CP have included the adolescent group. For instance, a study in CP individuals (aged 4.0 to 16.0 years) reported feeding deficits as a consequence of inefficient oro-facial motor function. [11] Similarly another study also reported poor mean feeding competence score in both children and adolescents with CP. [12] The stability of feeding impairment between childhood and adolescent period in CP population is also reported in the literature. [13] A thorough interview conducted in adolescents and young adults reports that all the participants had difficulties in eating and drinking. Hence the literature indicates that the adolescents with CP exhibit feeding and swallowing problems. [14]

Feeding skills serves as important prognostic indicator for survival in individuals with CP. [15] Feeding and swallowing problems may have negative impact on the quality of life in adolescents with CP and restricts the person from active participation. Hence it is important to assess the feeding and swallowing abilities in adolescents with CP and its impact on different domains of life. [14] There are various subjective feeding assessment tools available such as, Gisel video assessment, [11] Behavioral assessment scale of oral functions in feeding (BASOFF), [16] Dysphagia outcome and severity Scale (DOSS), [17] Dysphagia Disorder Survey, [18] standardized Eating and drinking ability classification system (EDACS) [19] etc. to assess the feeding and swallowing abilities or impairments. All these scales have been developed and standardized on western population. However there is a lack of such validated Indian tools, especially to assess the functional and emotional problems that accompany feeding and swallowing difficulties in adolescents with CP.

Consequently the Feeding Handicap Index (FHI), [20] was developed and standardized on typically developing children, children with CP, Autism spectrum disorder in the age range of 2-10 years and Intellectual disability. FHI has 38 items related to statements related to physical (21), emotional (12) and functional (5) aspects of feeding and swallowing abilities. It has a 3 point rating scale (0, 1 & 2) where '0' indicates the individual 'Never has this problem', '1' indicates 'Sometimes has this problem' and '3' indicates 'Always has this problem'.

A systematic review of the literature suggests that feeding and or swallowing problems tend to persist in adolescents with CP and can have an impact on other domains of life. In the Indian context, such studies investigating these multiple domains in adolescents with CP are limited. Thus it was planned to assess the feeding and swallowing problems in the physical, functional and emotional domainsof feeding using FHI. [21] In addition, also to assess their feeding and swallowing problems with other standardized tools such as BASOFF, [16] DOSS, [17] and EDACS. [19] BASOFF provides the information of how well each oral structures coordinate during feedingprocess. EDACS provides the information of functional ability of feeding interms of safety and efficiency and DOSS provides the individuals' overall severity of dysphagia. The use of a combination of tools would provide a holistic picture of the feeding and swallowing difficulties in adolescents with CP. Keeping this in view, the current study was planned.

Aim: To administer FHI on adolescents with CP to assess their feeding and swallowing problems on physical, functional and emotional domains and to compare the results obtained through FHI with other dysphagia assessment tools used in the western context such as BASOFF, EDACS and DOSS.

METHOD

Participants: 15 participants in the age range of 13 to 17.11 years with the diagnosis of CP made by qualified team of professionals were recruited for the study based on availability of the participants. The participants were recruited from a special school (Spastic society for cerebral palsy, Mysuru), and from the Department of clinical services housed at the All India institute of Speech and hearing, Mysuru. All the participants had undergone Speech - language and physiotherapy intervention programs for a duration ranging from 6 months to 6-7 years. Except three participants, rest of them was enrolled in a special school for more than 9- 10 years. All the participants had different types of CP with varying severity of intellectual disability (ID) and topographic distributions. The characteristics of the participants as described in Table 1.

Table 1 ***Profile of the participants***

Subject	Age/ Gender	Type of CP	Topographic distribution	Intellectual disability
1	15/Male	Spastic	Triplegic	Moderate
2	17.5/Female	Spastic	Quadriplegic	Moderate
3	15/ Female	Spastic	Quadriplegic	Moderate
4	15/ Female	Spastic	Triplegic	Mild
5	14.5/ Male	Athetoid	Quadriplegic	Moderate
6	16/ Male	Mixed (Spastic+Athetoid)	Quadriplegic	Mild
7	14/ Male	Spastic	Hemiplegic	Mild
8	17.8/ Male	Spastic	Quadriplegic	Severe
9	15/ Male	Spastic	Quadriplegic	Severe
10	13/ Female	Spastic	Quadriplegic	Moderate
11	16/ Male	Spastic	Triplegic	Moderate
12	14/ Male	Ataxic	Hemiplegic	Mild
13	15/ Female	Spastic	Quadriplegic	Severe
14	13.5/ Male	Spastic	Diplegic	Severe
15	15/Male	Spastic	Diplegic	Severe

Measures used:

FHI, [20] protocol include 38 items related to various domains such as physical, emotional and functional aspects of feeding with 3 point rating scale (0, 1 & 2) where '0' indicated 'Never has this problem', '1' indicated 'Sometimes has this problem' and '3' indicated 'Always has this problem' (Appendix A).

BASOFF, [16] include sections such as jaw closure, lip closure over spoon, tongue control, lip closure while swallowing, spillage, chewing (tongue /jaw control), sipping liquid, swallowing liquid and solid. The scoring is based on a 4 point rating scale from '0' to '5' where in '0' to '3' indicates passive movements, '4' indicates functional movements and '5' indicates Normal.

EDACS, [19] is a valid measure to assess eating and drinking ability with respect to safety and efficiency in children with CP. This classification system includes five levels as EDACS I to EDACS V where in EDACS level I indicates mild eating and drinking difficulties and EDCAS level V indicates severe eating and drinking difficulties.

DOSS, [17] assess the overall severity of dysphagia. This scale include 7 levels to describe characteristics of dysphagia where in level 7 indicated normal in all situations, level 6 - within functional limits, level 5- mild dysphagia, level 4 - mild to moderate dysphagia, level 3- Moderate dysphagia, level 2- moderately severe, and level 1 - indicated severe dysphagia.

Procedure: Ethical approval was given by the research committee of All India institute of speech and hearing. A written consent was also obtained prior to the testing from the parents of the participants after explaining the purpose of the study. Relatively noise free environment was ensured and participants were made to be seated comfortably in their actual feeding position. The testing was carried out for each participant individually. The demographic details were obtained. The type of CP and the degree of intellectual deficit, if any and other associated problems were also noted. The parents/caregivers were interviewed regarding their wards' feeding and swallowing difficulties using FHI. In addition, the actual feeding process of the participants was observed by asking them to consume some food. Initially solid food (biscuit) was provided followed by thin liquid (water) and semisolid (jelly). The efficiency of the usage of spoon during the feeding was also assessed when they were eating (rice) with their own spoons. There were no risks involved in this, as this assessment only concerned an observation of the natural feeding position. The session was video recorded for later analysis.

To assess how the structures coordinate while feeding, BASOFF was used which was followed by EDACS. The overall severity of dysphagia was graded using DOSS. On 40% of subjects who were selected randomly after one week of the initial data collection, test retest reliability was assessed.

***Scoring*:** Since the scoring pattern was not uniform across the questionnaires chosen for the study, the categories of scoring were changed without disturbing the structure of the questionnaire. The scoring pattern was changed for BASOFF as '5' indicating severe problem and '0' indicating normal movements. Similarly for DOSS, the levels were graded as 1- indicated normal in all situations, level 2- within functional limits, level 3- mild dysphagia, level 4 - mild to moderate dysphagia, level 5- Moderate dysphagia, level 6- moderately severe dysphagia, level 7 - indicated severe dysphagia.

Analysis: The scores obtained from each participant with respect to each protocol were totaled. Since the number of questions was not uniform across for protocols such as FHI and BASOFF, the percentages were calculated. These scores were averaged across all the participants and fed to the computer for statistical analysis using SPSS version 21.0 software. For reliability checking, due to small size the severity matching was performed using Cronbach's Alpha. Descriptive statistics was done to obtain mean, median and standard deviation (SD). Spearman correlation was done to find the correlation between the scores of FHI with severity of dysphagia, oral function during feeding and the scores on EDACS.

RESULTS

1. ***Test retest reliability:*** Test retest reliability indicated that Cronbach's alpha for the physical, functional, emotional domain of FHI was 0.98, 0.95 and 0.85 respectively. The Cronbach's alpha for oral functioning during feeding was 0.98, Eating and drinking ability classification system was 0.96 and for the overall severity of dysphagia was 0.99. Hence the 'α' varied between 0.85 and 0.99 which indicated high test-retest reliability.

2. ***Performance on FHI***

The total scores of FHI for the participants ranged from 10 to 52. The mean, median and the SD obtained on FHI has been presented in Table 2. The mean percentage of physical domain was 47.92 which was greater than the mean percentage of functional domain and emotional domain which was 24.38 and 12.66 respectively. This revealed that the participants had greater issues in the physical domain when compared to functional and emotional domain.

Table 2 ***Mean percentage, median and standard deviation (SD) of physical, functional and emotional domain of FHI***

Domains	Mean	Median	SD
Physical	47.92	47.61	22.80
Functional	24.38	25.00	12.80
Emotional	12.66	10.00	11.62

3. BASOFF and its Correlation with FHI scores

The total scores BASOFF ranged from 12 to 47. It was found that the participants had problems in jaw, tongue and lip movements during feeding. They had difficulty in drinking and sipping liquid, consuming solid food along with presence of cough. The frequently observed problems in most of the participants were initial jaw thrust while encountering a utensil, poor lip closure over the spoon, difficulty in chewing and swallowing, poor sipping skill and excess food and liquid loss (more than 10%). Of the total participants, two participants had a score of less than 15, 5 participants had score between 15 and 20, 6 participants scores ranged between 21 to 30 and 3 participants had a score between 31 and 45. This revealed that majority of the participants had impaired oral functioning.

Descriptive statistics revealed that the mean percentage, median and SD for oral functioning were 37.34, 36.76 and 15.28 respectively. The mean percentage of BASOFF in the current study indicated that majority of participants had mild to moderate degree of feeding and swallowing problems. Spearman correlation between the scores obtained on BASOFF and FHI indicated p<0.00** with correlation coefficient of 0.88 for physical domain, p<0.00** with correlation coefficient of 0.75 for functional domain of FHI respectively indicating positive high correlation. There was no correlation found for emotional domain of FHI and BASOFF. However there was a high positive correlation with the overall total score of FHI and BASOFF during feeding with p<0.0.0** and correlation coefficient of 0.85.

4. EDACS and its correlation with FHI

Descriptive statistics on EDACS revealed that mean, median and SD was 3.00, 3.20 and 0.77 respectively. The overall levels varied between level 1 to level 4 such as 1 participant - *level '1',* 7 participants - *level '2'* and 3 participants - level 3 and 4 particpants - *level '4'.* This indicated that most of the participants had difficulty in feeding and swallowing safely and efficiently. Spearman correlation was done to obtain the relationship between the scores obtained on EDACS and FHI. The results revealed that there positive high correlation with p<0.00** and correlation coefficient of 0.81 for both physical and functional domain and no correlation found for emotional domain of FHI with EDACS. The total score of FHI had positive correlation with EDACS with p<0.00** and correlation coefficient of 0.66.

5. DOSS and correlation with FHI

The severity of dysphagia was assessed using DOSS. The overall DOSS severity rating varied from 1 to 5 for the participants. Among the total participants, 13.3 % had severe dysphagia, 33% had moderately severe dysphagia, 26.6 % had moderate dysphagia', 13.3 % had mild to moderate dysphagia and 13.3% were within functional limits. This result indicated that majority of the participants had moderately severe dysphagia. Descriptive statistics revealed that the mean, median and SD for the scores obtained on DOSS to be 2.86, 3.0 and 1.24 respectively. Spearman correlation between the scores obtained on FHI and DOSS revealed significantly high positive correlation between the FHI total scores and severity of dysphagia. The results are presented in Table 3

Table 3 ***Results of Spearman's correlation between the severity of dysphagia and physical, functional and emotional domain of FHI***

FHI Domains	Correlation coefficient	p value
Physical	0.88	0.00**
Functional	0.67	0.00**
Emotional	-0.27	0.32
Total FHI scores	0.82	0.00**

Note:* indicates 'p' significant at <0.05, ** indicates 'p' significant at <0.01

DISCUSSION

The current study investigated the feeding and swallowing problems in

adolescents with cerebral palsy using FHI and other tools such as BASOFF, EDACS and DOSS. The results revealed several findings of interest. The results of performance on FHI indicated that the participants had greater issues in the physical domain when compared to functional and emotional domain which is in agreement with the literature. Individuals with CP in the age range of 4 to 16 years exhibited longer time for chewing a hard solid food texture than controls and they also had poor functional feeding skills in terms of spoon feeding, biting, chewing, cup drinking, straw drinking etc. [21] Similar to children, adolescents with CP also exhibit various difficulties such as poor spoon feeding abilities, biting, chewing, cup drinking, straw drinking and swallowing abilities. [8] Studies report that as the age of individuals with CP progresses, they have trouble with one or more phases of swallowing, which makes causes inadequate nutrition and hydration. The eating and swallowing impairments may develop or worsen as the age progress in CP individuals. [21] A study in 15-23 year old individuals with CP indicated that participants had problems with swallowing and mastication, which were influenced by food textures, difficulty eating hard and lumpy food, presence of chocking events, difficult in drinking, longer time to chew, difficulty handling utensils, dependence on others during feeding, however the study included both adolescents and adult group. [14]

BASOFF had positive high correlation with physical domain and functional domain of FHI. This indicated that greater the oral functioning related issues, greater were the feeding and swallowing issues. Even though the overall structure of both BASOFF and FHI protocols were different, the items in the physical domain of FHI were similar to some of the items in BASOFF such as lip/jaw closure, sucking/sipping, coughing/ choking, gagging, spillage/loss of food etc. This could have lead to the high correlation seen, especially between the physical and functional domains. However the items in the emotional domain of FHI tapped the emotional aspects surrounding feeding issues, which were not present in BASOFF and hence there was no correlation.

There was also positive high correlation between the scores obtained on the EDACS and FHI (Physical and functional domain). Previous studies have found feeding and swallowing problems in individuals with CP and could classify the impairments of the same into various levels using EDACS. [21] EDACS describes how well an individual eats and drinks with safety and efficiency. [19] Similarly in the current study, the various feeding problems such as coughing, aspiration, gagging was noticed in most of the participants using EDACS which indicated that the feeding process was not safe. Further the oral functioning ability as revealed on BASOFF during feeding was poor which contributed to the poor efficiency while eating. Since the items present in physical and functional domains of FHI also focus on safety and efficiency aspects of swallowing, there was a correlation obtained, however no correlation was found between emotional domain of FHI and EDACS, as the EDACS do not include the emotional aspects of swallowing. This result is also in consensus with the previous studies. Around 93.8% of children with CP had oral phase impairments during eating or drinking leading to poor efficiency. [23]

There was also significant high correlation between scores on DOSS and FHI. According to the previous studies, the degree or severity of feeding problems varies depending on various factors. Studies report around 99% prevalence of dysphagia in individuals with generalized CP with intellectual disability. Their Diet restrictions, feeding dependence, use of adaptive utensils, postural stability, and the use of feeding and swallowing strategies were correlated with the severity of dysphagia. [24] Another study reported that the degree of feeding and swallowing

problems in CP individuals varied from normal to mild category and moderate-severe category. Individuals in moderate to severity category exhibited greater difficulties when compared to mild to moderate category. [8] A moderate level of feeding impairment is reported in the literature which is also in consensus with the current study. [25]

CONCLUSIONS

FHI revealed that adolescents with CP exhibit feeding and swallowing problems similar to that of children as reported in the literature and FHI was effective in identifying the feeding and swallowing problems in different domains. Through the results obtained from the study, it is clear that FHI had high correlation with other western feeding assessment tools. Hence FHI is an effective feeding assessment tool, which assesses the feeding problems in different domains. However, since the sample size was small, one has to exercise caution while generalizing the results. Further, many factors such as the type of CP, the topographic distribution, associated problems and the intervention could have had a differential impact on feeding. Future studies could focus on similar studies incorporating a larger sample and controlling the variables.

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APPENDIX A

Feeding Handicap Index (Swapna & Shabnam, 2017)

Item No.	Domain*	Statement	Never has this problem	Sometimes has this problem	Always has this problem	Remarks
1.	P	My child has/had difficulty in sucking from the feeding bottle/ breast.	0	1	2	
2.	P	My child has difficulty in biting hard food (e.g., biscuit) and/or soft food (e.g., cake)	0	1	2	
3.	P	My child has difficulty in chewing hard food (e.g., biscuit) and/or soft food (e.g., idli, cake)	0	1	2	
4.	P	My child is not able to eat independently with his/her fingers	0	1	2	
5.	P	My child is not able to scoop the food from a bowl/plate with a spoon	0	1	2	
6.	P	My child is not able to clear the food from the spoon with the lips	0	1	2	
7.	P	My child is not able to eat with a spoon independently	0	1	2	
8.	P	My child is not able to drink liquid from a glass/cup when held	0	1	2	
9.	P	My child is not able to drink independently	0	1	2	
10.	P	My child has a problem in drinking through a straw	0	1	2	
11.	P	My child drools while feeding	0	1	2	
12.	P	My child has difficulty in holding the solid/ liquid food in mouth (food/liquid leaks from the mouth)	0	1	2	
13.	P	My child is not able to use the tongue to clear the food particles stuck in between the teeth or between the gums and the cheeks	0	1	2	
14.	P	My child cannot rinse the mouth and spit the water after eating	0	1	2	

Table to be Continued…						
15.	P	My child's weight gain is inappropriate (under/over-weight) and/or has nutritional deficiency due to feeding issues.	0	1	2	
16.	P	My child keeps the food in the mouth without swallowing for a long time	0	1	2	
17.	P	My child has difficulty in swallowing solid/ semi-solid or mashed/ liquid food	0	1	2	
18.	P	The food/liquid comes through the nose during swallowing	0	1	2	
19.	P	My child gags when solid/liquid food is given	0	1	2	
20.	P	My child vomits when solid/liquid food is given	0	1	2	
21.	P	My child chokes while feeding	0	1	2	
22.	F	My child eats less because of the feeding problem	0	1	2	
23.	F	I avoid giving solid food to my child because of the feeding problem	0	1	2	
24.	F	My child spills a considerable 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.*	0	1	2	
25.	F	My child strongly refuses newly introduced food or certain food based on the taste/temperature/ texture/ smell.	0	1	2	
26.	F	My child needs to be placed in a specific position/special chair during feeding	0	1	2	
27.	F	My child requires smaller meals more often due to the feeding problem	0	1	2	
28.	F	I push the food to back of the mouth of my child so that s/he can swallow it easily	0	1	2	
29.	F	My child takes longer to be fed	0	1	2	
30.	F	I pour water/milk to ensure that the food is swallowed	0	1	2	
31.	F	My child needs specific utensils (his/her own spoon, plate, etc.) and/or special feeding equipment/aids (e.g., feeding tube, special feeding bottles etc.)	0	1	2	
32.	F	I pinch my child's nose to make him/her swallow the food	0	1	2	
33.	F	I shake my child/close the lips/jaw for easy swallow	0	1	2	
34.	E	My child refuses to open his/her mouth while feeding	0	1	2	
35.	E	My child exhibits frustration or temper tantrums before/during feeding	0	1	2	
36.	E	My child does not like being dependent on others for feeding	0	1	2	
37.	E	My child feels upset that s/he cannot eat food like other children/does not like to eat with other children	0	1	2	
38.	E	My child feels embarrassed/is not comfortable to eat food in social gatherings	0	1	2	

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

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