



Feeding difficulties and nutritional status of children with cerebral palsy in rural Tamil Nadu

Dr. S Kavitha Maithily¹, G Kowshalya²

¹ Assistant Professor, Department of Home Science, Gandhigram Rural Institute Deemed To Be University, Gandhigram, Dindigul, Tamil Nadu, India

² M.Sc. Food Science and Nutrition, Department of Home Science, Gandhigram Rural Institute Deemed To Be University, Gandhigram, Dindigul, Tamil Nadu, India

Abstract

Cerebral Palsy (CP) is a common neuro-developmental disability noticed among children. It results in feeding difficulties as there is poor co-ordination in sucking, chewing and swallowing the food. The purpose of this study was to understand the feeding difficulties and nutritional status of children with cerebral palsy. The sample of this study constituted 60 children with CP. They were selected by purposive sampling method from rural areas of Dindigul and Virudhunagar districts of Tamil Nadu. Interview method was adopted to collect data from the parents, teachers and care takers of the children with cerebral palsy. Nutritional status of the children was assessed by anthropometric assessments such as height, weight and by calculating Body Mass Index (BMI). Through interview and observation during their meal time feeding difficulties in children were identified. It was found out that children with high feeding difficulties were severely wasted and wasted. Nutritional status of the children with CP decreases with increase in the percentage of disability.

Keywords: cerebral palsy, rural children, feeding difficulties, nutritional status

Introduction

Developmental disabilities are a group of conditions due to impairment in physical, learning, language or behavior areas. These conditions begin during the developmental period, may impact day to day functioning and usually last throughout a person's lifetime [1]. In India, 20.42 lakh children with disabilities are between 0-6years of age. Among them 14.52 lakh children are in rural areas and 5.9 lakh in cities. Of them 11.04 lakh are male and 9.38 are female children. Among them 1.49 children have multiple disabilities. There are more than 5.80 lakh children in this age group with other disabilities such like autism and cerebral palsy. In Tamil Nadu, 62,538 children are disabled [2]. CP is defined as 'a non-progressive lesion or disorder in the brain occurring during the intrauterine life or the perinatal period and characterized by paralysis, spasticity, or abnormal control of movement or posture which is manifest prior to 2 to 3 years of age'[3]. Cerebral palsy is a static neurologic condition resulting from brain injury that occurs before cerebral development is complete. Because brain development continues during the first two years of life, cerebral palsy can result from brain injury occurring during the prenatal, perinatal, or postnatal periods [4].

A call on governments to give persons with disabilities access to adequate, quality and nutritious food was urged in new Sustainable Development Goals. The United Nations' Article 11 on the Right to Adequate Food suggest, measures should be undertaken to ensure that the right to adequate food is especially to be fulfilled for vulnerable population groups and individuals [10]. A article by professor Nora Groce and her colleagues published in Paediatrics and International Child Health states that "Nutrition and disability are intimately

linked: malnutrition can directly cause or contribute to disability, and disability can lead to malnutrition". Children with disabilities are often believed to be incapable of learning to feed themselves and they therefore become reliant on others who may give them less food because it takes time to feed them. Among children with disabilities, girls are often discriminated against and given less and lower-quality foods than boys [5]. Children with CP those who are less active and have trouble getting enough nutrients in their diet due to feeding problems are more likely to have weak, brittle bones with low bone density. This makes their bones more likely to fracture, or break. To keep bones strong, children with CP need to get enough of calcium, vitamin D and phosphorus [6]. Feeding, eating, drinking and swallowing difficulties (FEDS) is commonly present in children with cerebral palsy. Research indicates that up to one third of growing children with CP are poorly nourished due to feeding, eating, drinking, or swallowing difficulties (FEDS). This can result in mealtimes that are much longer or much more effortful than normal. Depending on the severity level of the individual's Cerebral Palsy, his or her digestive challenges and the ability to properly chew, swallow, and self-feed, effective dietary therapy can be devised to meet the individual's unique needs [7]. Malnutrition is highly prevalent among children with cerebral palsy. Considering malnutrition as an important risk factor and it can produce a negative influence on the prognosis of patients with cerebral palsy, so every effort must be taken to improve this condition. This can be done by regular assessment of nutritional status and providing nutritional support [8]. The goal of management of cerebral palsy is not to cure or to achieve normalcy but to increase functionality,

improve capabilities, and sustain health in terms of locomotion, cognitive development, social interaction, and independence. In physical, occupational, speech and behavioral therapies, the goals include enhancing patient and caregiver interactions while providing family support ⁽⁹⁾. Imparting this multidisciplinary approach to the Special schools or institutions is very necessary to provide proper care and guidance to children with cerebral Palsy. In India, 71% of rural children are disabled. Not all the services of the government are reaching rural disabled due to geographical, social and political hierarchies. It is essential to understand the present status especially nutritional status of children with cerebral palsy in rural areas which will be helpful in formulating policies and programs for them. At present not many studies are available about rural children with cerebral palsy, so the study titled “Feeding Difficulties and Nutritional Status of Children with Cerebral Palsy in Rural Tamil Nadu” was carried out.

Objectives

The objective of the study is to understand the feeding difficulties and to assess the nutritional status of the children with cerebral palsy.

Methodology

The study was carried out in four special schools for disabled, located at Virudhunagar and Dindigul districts in Tamil Nadu. In this study 60 children with cerebral palsy were selected by purposive sampling method and they were from the age group of 5 to 18 years. Data were collected from the respondents by interview and observation method. The respondents were class teachers, care takers and parents of the children with CP. The Schedule had questions on the topics such as personal details, birth history, dietary patterns and feeding difficulties of the CP children. During the visit to the school, data about the CP children were collected from class teachers and care takers of both the hosteller and day scholar children. Information was collected from the parents of hosteller and the day scholar students, when they come to visit the hostel students and while pick up the day scholar students. Approximately 30 minutes was needed to fill up the schedule by the investigator. CP children in schools were observed during their meal time. It was done after getting consent from the teachers to observe the children during their meal times. Basic anthropometric measurements such as height, weight and Body Mass Index (BMI) was calculated. BMI was calculated, in order to assess the nutritional status of CP children with the use of World Health Organization’s growth chart especially designed for the age group of 5-19 years old boys and girls. WHO’s growth chart is applicable for worldwide population. BMI was interpreted by using z-scores which are particularly useful to monitor changes in individuals with a BMI above the 99th percentile or below the first percentile. The data collected from the respondents were edited, coded, analyzed and tabulated. Percentage and frequency with variables were used for representing the tables.

Results and Discussion

The profile of the Children, disability related details, feeding

difficulties and nutritional status of the children were discussed under this topic.

Table 1: Personal Details

S. No	Variables	Number (N=60)	Percentage
1	Gender		
	Boys	26	43.3
	Girls	34	56.7
2	Age (in years)		
	5-10	30	50.0
	10-15	22	36.7
	15-20	8	13.3
3	Place of stay		
	Home	42	70.0
	Hostel	18	30.0

Table 1 revealed that girls constituted 56.7 percent of the sample and the rest were boys. The age range of the children studied was between 5-18years. One out of two children was between 5-10 years. 36.7 percent of children were between 11-15 years and 13.3 percent of the children were between 16-20 years. The mean age of children studied was 12.5 years. Seventy percent of children came to school as day scholars and thirty percent were hostellers.

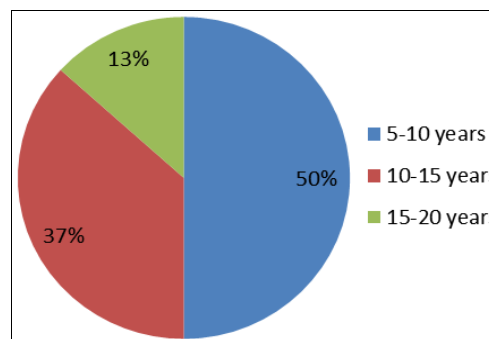


Fig 1: Age Group of the Selected Sample

Table 2: Disability Related Details

S. No	Variables	Number (N=60)	Percentage
1	Type of Disability		
	CP	54	90.0
	CP-MR	6	10.0
2	Percentage of Disability		
	40-60	10	16.7
	60-80	40	66.7
	80-100	10	16.7
3	History of Disability in Family		
	Yes	14	23.3
	No	46	76.7

Table 2 stated the disability related details of children with Cerebral Palsy. Out of 60 children, 54 children had Cerebral Palsy and six children had Cerebral Palsy with Mental Retardation. The percentage of disability of studied ranged from 50-85 percent. Mean percentage of disability was 67.5. The children with the history of familial disability constituted 23.3 percent i-e either the sibling or relative in the family were disabled. In 76.7 percent of children studied no history of disability was noticed in their family.

Table 3: Complications Noticed in Mother and Newborn

S. No	Variables	Number (N =60)	Percentage
1.	Complications noticed in mother during pregnancy		
	Emotional and physical trauma	22	36.7
	Rh incompatibility	10	16.7
	Nutritional deficiencies	4	6.7
	Chicken pox	2	3.3
	No complications	22	36.7
2.	Complications noticed in mother during delivery		
	Prolonged delivery	16	26.7
	Toxemia	4	6.7
	Eclampsia	2	3.3
	No complication	38	63.3
3.	Complications in the child after birth		
	No birth cry	34	56.7
	Convulsion	12	20.0
	Blue baby	4	6.7
	Jaundice	6	10.0
	No complication	4	6.7
4.	Baby admitted in ICU after delivery		
	Yes	38	63.3
	No	22	36.7

Table 3 presented the complications noticed in the mother during pregnancy and delivery and in the newborn. During pregnancy 36.7 percent mothers reported emotional and physical trauma, 16.7 percent mothers reported of Rh incompatibility, 6.7 percent expressed that they had nutritional deficiencies and 3.3 percent had chicken pox. 36.7 percent of the mothers reported that they had no complications during pregnancy period. During delivery, 26.7 percent of mothers experienced prolonged delivery, 6.7 percent had toxemia and 3.3 percent had eclampsia. 63.3 percent of mothers reported that they had no complications during delivery. Around 64 percent of mothers faced complications during pre natal period and 37 mothers had complications in delivery.

In around one out of two children no birth cry was noticed and one fifth of the children had convulsion soon after birth. One tenth of children had jaundice and 6.7 per cent children were

blue babies. While analyzing the babies admitted in ICU soon after birth, it was understood that 63.3 percent children were in ICU soon after delivery either due to no birth cry or convulsion or jaundice. Around 93 percent of children had complications during birth but only 63.3 percent were admitted in the ICU. The complications during pregnancy or birth indicated that the baby had disability.

Feeding Problems

A feeding problem can be defined as a deficit in any aspect of taking nutritional elements that result in under-nutrition, poor growth or stressful mealtimes for children and their caregivers [11]. The feeding difficulties experienced by children with cerebral palsy greatly influence the quality and quantity of food consumed by these children, which in turn affects their nutritional status.

Table 4: Feeding Difficulties in Children with Cerebral Palsy

S. No	Activities*	Feeding Difficulties					
		Easy		Difficult		Very difficult	
		No	%	No	%	No	%
1.	Holding the tumbler	28	46.7	24	40	8	13.3
2.	Drinking liquid foods	20	33.3	40	66.7	-	-
3.	Taking the food with fingers	38	63.3	14	23.3	8	13.3
4.	Taking the food to the mouth	36	60.0	18	30.0	6	10.0
5.	Opening mouth for food intake	60	100.0	-	-	-	-
6.	Taking food with the fork	28	46.7	24	40.0	8	13.3
7.	Eating without spilling	8	13.3	42	70.0	10	16.7
8.	Chewing the food	18	30.0	28	46.7	14	23.3
9.	Swallowing the food	22	36.7	22	36.7	16	26.7

*Multiple responses

Table 4 revealed the problems faced by the CP children while having meals. Forty percent of children had difficulties in holding the tumbler in their hand and 13.3 percent children found it more difficult. 66.7 percent of children had difficulty in drinking liquid foods. 63.3 percent children felt easy to take

food with their fingers. Above one third of the sample population had difficulty in taking food with their fingers. So these children need assistance of the care taker and mother to have their food.

Forty percent of children had difficulty in taking food to the mouth because of lack of co-ordination. 14 percent children would be able to eat with fork and 40 percent had mild difficulty and 13.3 percent had high difficulty in using fork for food intake. Children found it very difficult to eat without spilling the food. Only 13.3 percent children were able to eat without spilling. About 60 percent of children had difficulty in chewing the foods and 30 percent found it easy. 26.7 percent and 36.7 percent children had difficulty in swallowing foods. The problems the child faced while eating vary from child to child based on their percentage of disability and the nature of therapy or training which they receive at the school or home. On the basis of observation it was evident that no children with cerebral Palsy were using any feeding assistive devices such as chairs, spoons or other devices. There was lack of knowledge about the feeding assistive devices in teachers and parents of rural area and they were not aware of it. If they were provided with those assistive devices, the meal times of the children with cerebral palsy would not be much difficult. Feeding difficulties in children were estimated by using scores given to individuals such as easy, difficult and very difficult. For easy, score one was given, for difficult and very difficult option, two and three were given respectively. Scores obtained were in the range of nine to 23, and they were categorized as Low, Moderate and High. Score nine to 13 represent the low feeding difficulty, 14 to 18 and 19 to 23 indicate moderate and high feeding difficulties in children.

Table 5: Feeding Difficulties of Children with Cerebral Palsy

Score	Children	
	Number (N=60)	Percentage
Feeding Difficulty		
Low	24	40.0
Moderate	16	26.7
High	20	33.3

Table 5 revealed the level of feeding difficulties of CP children. Forty percent of the children were had low feeding difficulty. 26.7 percent and 33.3 percent children were reported with moderate and high feeding difficulties respectively. Sixty percent of the children had a tough meal time.

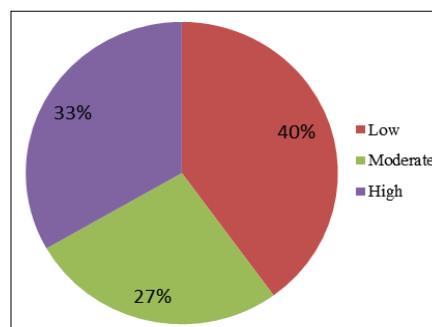


Fig 4: Feeding Difficulties in Children with CP

Table 6: Factors Influencing Feeding Difficulties

Variables	Feeding Difficulties					
	Low		Moderate		High	
	No	Percentage	No	Percentage	No	Percentage
Gender						
Boys(N=26)	10	38.6	8	30.8	8	30.8
Girls(N=34)	12	35.3	8	23.5	14	41.2
Percentage of disability						
40-60 (N=10)	8	80.0	2	20.0	-	-
60-80 (N=40)	14	35.0	14	35.0	12	30.0
80-100 (N=10)	2	20.0	-	-	8	80.0
Place of Stay						
Hostellers (N=18)	4	22.2	8	44.4	6	33.3
Day scholars(N=42)	20	47.6	8	19.0	14	33.3
Type of disability						
CP(N=54)	21	38.9	13	24.1	20	37.0
CP-MR(N=6)	1	16.7	3	50	2	33.3

Table 6 revealed the factors that influence the feeding difficulties in children with cerebral palsy. Feeding difficulty is compared with gender groups, percentage of disability and Hostellers and Day Scholars.

Girls were reported with 41.2 percent high feeding difficulty whereas 30.8 percent boys had high difficulty. 38.6 percent boys were having low feeding difficulty and 30.8 percent had moderate feeding difficulties. 35.3 percent girls had low feeding difficulty and 23.5 percent had moderate feeding difficulties. It was understood that girls were experiencing high feeding difficulties than boys.

Among ten children with 80 to 99 percent disability, eight were reported with high feeding difficulties. In 40 children with 60 to 79 percent disability, 12 had high difficulty and 14

had moderate difficulty. It was clear that feeding difficulty rate was high in children with high and moderate percentage of disability. Lowest score was reported in children with children with low and moderate percentage disability children. Among the hostellers, 33.3 percent children were reported with high feeding difficulties, 44.4 percent with moderate and 22.2 percent with low feeding difficulties. 47.6 percent day scholars were at low level of feeding difficulty whereas 19 percent and 33.3 percent were at moderate and high level respectively. In 54 children with cerebral palsy 21 had low feeding difficulties, 13 had moderate and 20 had high feeding difficulties. Among six children with CP-MR, two had high feeding difficulty, three had moderate and one had low feeding difficulty. It showed that children who were in the

hostel had high feeding difficulties but it might depend on the percentage of disability of the children also.

Nutritional status

Nutritional status is the condition of health of the individual as influence by the utilization of the nutrients. It can be determined only by the correlation of information obtained through a careful medical and dietary history, taking physical measurements of the body, a clinical examination and appropriate laboratory investigation (12). WHO’s 2007 BMI for age growth charts for 5- 19 years were used to assess the nutritional status of CP children.

Table 7: Nutritional Status of Children with Cerebral Palsy

S. No	Nutritional Status	Children with CP	
		Number N=60	Percentage
1.	Severely wasted (< -3)	8	13.3
2.	wasted (< -2)	16	26.7
3.	Normal (-1 to 1)	36	60.0

Table 7 showed the nutritional status of children with cerebral palsy. Among 60 children, 13.3 were severely wasted, 26.7 percent were wasted and 60 percent of the children were normal. Eight children were at the risk of developing severe wasting. No child was noticed as obese or overweight.

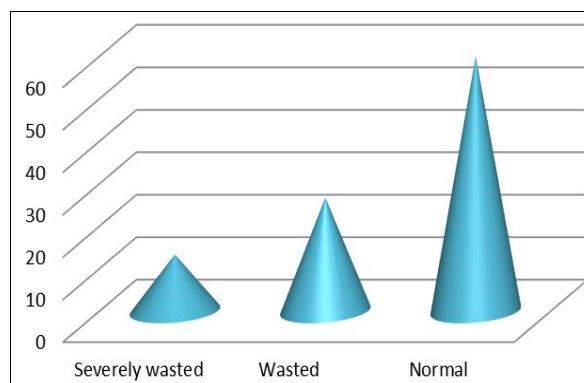


Fig 3: Nutritional Status of Children with CP

Table 8: Factors Influencing Nutritional Status of Children with CP

Variables	Severely wasted (<3)		Wasted (< -2)		Normal (-1 to1)	
	No	Percentage	No	Percentage	No	Percentage
Gender						
Boys(N=26)	4	15.4	10	38.5	12	46.2
Girls(N=34)	4	11.8	6	17.7	24	70.6
Percentage of disability						
40-60(N=10)	-	-	-	-	10	100.0
60-80(N=40)	4	10.0	14	35.0	22	55.0
80-100(N=10)	4	40.0	2	20.0	4	40.0
Place of Stay						
Hostellers(N=18)	2	11.1	10	55.6	6	33.3
Day scholars(N=42)	6	14.3	6	14.3	30	71.4
Type of disability						
CP(N=54)	7	12.9	14	25.9	33	61.1
CP-MR(N=6)	1	16.7	2	33.3	3	50.0

Table 8 revealed the factors influencing nutritional status of children with cerebral palsy.

In boys, 15.4 percent were severely wasted, 38.5 percent were wasted and 46.2 percent were normal. In girls, 11.8 percent were severely wasted, 17.7 percent were wasted and 70.6 percent were normal. About half of the boys were identified as either wasted or severely wasted.

Among ten children with 80 to 100 percent disability, four were severely wasted, two were wasted and four were normal. Among 40 children with the disability percentage of 60-80, 22 were normal, 14 were wasted and four were severely wasted. Ten children with 40-60 percentage disability were normal. There was no children was identified as wasted and severely wasted category with 40-60 percent disability. Therefore it was clear that nutritional status declines with the increase in percentage of disability of the children with CP.

In 18 hostellers, 11.1 percent were severely wasted, 55.6 were wasted and 33.3 were normal. In 42 day scholars, 14.3 percent were identified with severely wasted, 14.3 percent with wasted and 71.4 percent with normal nutritional status. It showed that two third of the hostel students were wasted and was greater than the day scholar population. It might be

related to the percentage of disability of the children. In hostel boys, feeding difficulty rate was also high. About one fourth of the children with CP and CP-MR were evidenced in wasting. 12.9 percent children with CP and 16.7 percent children with CP-MR had high feeding difficulties.

Table 9: Nutritional Status Vs Feeding Difficulties

Nutritional Status	Feeding Difficulties		
	Low	Moderate	High
Severely wasted (< -3)	-	-	8
Wasted (< -2)	-	4	12
Normal (-1to 1)	24	10	2

Table 9 revealed the relation between Nutritional Status and Feeding Difficulties in CP children. Eight children identified with severely wasted, were reported had high feeding difficulties. Among 16 wasted children, 12 were having high feeding difficulty and four had moderate feeding difficulty. Low feeding difficulty was reported in 24 children with normal BMI range. It showed that children who were severely wasted had high feeding difficulties. Children those who are wasted had moderate and high feeding difficulties. All the

children those who had low feeding difficulties were under normal nutritional status. It was understood that as the level of feeding difficulty increases the nutritional status of children with CP decreases.

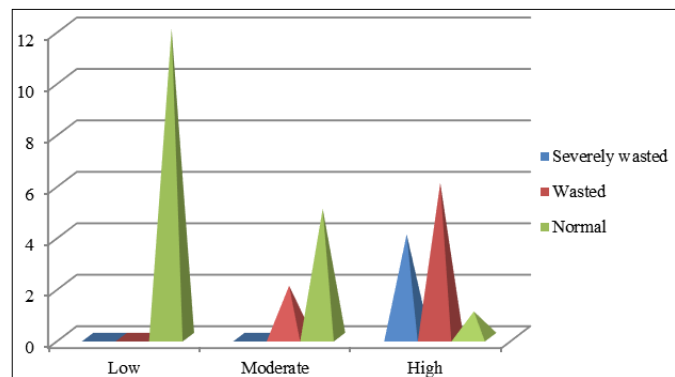


Fig 6: Nutritional Status Vs Feeding Difficulties

Conclusion

Cerebral palsy is one of the developmental disorders which lead to poor motor co-ordination in children. The children with CP experience various feeding difficulties such as holding the tumbler, taking food to the mouth, spilling of food and drinking liquid foods. These feeding difficulties in turn affect the quality and quantity of food intake and influence the nutritional status of the individual. There was a relation between percentage of disability, feeding difficulties and nutritional status. These children need foods which supply maximum nutrients, with suitable food textural modification so that the child could consume without much difficulty. The children should also be supported with assistive devices which could be helpful in eating. The plight of children with cerebral palsy in rural areas could be improved through by giving needed therapies and diet counseling. Schools should be given guidance in planning the meal according to the nutritional requirements for the particular age group of children. Special schools should take attempts to provide food with needed textural modifications, assistive devices and nutrition counseling for the students and parents. On interviewing the parents and caretakers of the children who studied in special schools, it was clear that there were no proper dietary guidelines were given to them to take care of their children. Therefore organizing an inclusive feeding education program to the parents and caretakers in the special schools will be helpful in managing the feeding difficulties experienced by the children with cerebral palsy in rural areas.

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