DEVELOPMENT AND VALIDATION OF FEEDING HANDICAP INDEX FOR CHILDREN

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CERTIFICATE

This is to certify that this dissertation entitled "**Development and Validation of Feeding Handicap Index for Children**" is a bonafide work submitted in part fulfilment for the Degree of Master of Science (Speech Language Pathology) of the student (Registration No.: 12SLP028). This has been carried out under the guidance of a faculty of this institute and has not been submitted earlier to any of the University for the award of any other Diploma or Degree.

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CERTIFICATE

This is to certify that this dissertation entitled "**Development and Validation of Feeding Handicap Index for Children**" has been prepared under my supervision and guidance. It is also certified that this has not been submitted earlier in other University for the award of any Diploma or Degree.

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DECLARATION

This is to certify that this dissertation entitled "**Development and Validation of Feeding Handicap Index for Children**" is the result of my own study under the guidance of Dr. Swapna N., Reader in Speech Pathology, Department of Speech-Language Pathology, All India Institute of Speech and Hearing, Mysore, and has not been submitted earlier in other University for the award of any Diploma or Degree.

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Introduction

Feeding is a skill present from the early infancy which provides nutrition for normal growth and development. The satisfaction of hunger and maintenance of homeostasis is achieved through the feeding process. Feeding also provides opportunities for sensory and motor stimulation, mother-child bonding and oro-motor skill development (Kummer, 2008). The development and acquisition of feeding skills is a gradual process. During early infancy, children are only able to suck and swallow liquids and these preliminary feeding skills are very essential to their existence. As the children grow, the sucking and swallowing action is followed by biting, chewing, eating from a spoon, drinking from a cup and a straw which are more mature feeding behaviors. The active movement of the oral structures during feeding helps oro-motor skill development which provides a basis for the development of more mature feeding skills (Morris & Klein, 1987). These developments occur as the higher cortical centers gain more control.

Feeding is a complex sensory motor act. Feeding and swallowing involves the oral structures, pharynx and esophagus. The swallowing mechanism of our body consists of four phases: The oral preparatory phase, the oral transport phase, pharyngeal phase and the esophageal phase (Logemann, 1998). During the oral preparatory phase, the food is manipulated in the mouth in an attempt to make it ready to be swallowed. This action requires sufficient lip closure, tongue and jaw movement. In the oral transport phase, the prepared food is pushed into the oropharynx and then into the hypopharynx. Tongue is the key structure for this phase. In the pharyngeal phase, the bolus is directed toward the esophagus; also a few mechanical adjustments are made to make sure that the airway and nasal cavities are protected from the food particles, so

that it will not lead to aspiration or nasal regurgitation. During the esophageal phase, the pharyngo-esophageal sphincter opens and the food goes through the esophagus into the stomach. These actions during the process of deglutition occur in quick succession (Arvedson & Brodsky, 1993).

In most children, these individual acts during feeding and swallowing occur normally enabling them to take in food with ease. However, in some children the problems in feeding or swallowing can arise due to structural or functional deficits in the oral, pharyngeal or esophageal region since the food passes through these regions after ingestion before reaching the stomach. Cerebral palsy, one of the most common conditions leading to developmental disability in children due to neurological impairment, is frequently associated with a variety of feeding problems. It is a permanent and non-progressive condition which occurs due to a lesion in the developing nervous system resulting in a disorder of the movement, posture, balance and coordination. This heterogeneous group of motor disorders varies in the nature of dysfunction and localization based on the site of neurological involvement. Other associated problems such as disturbed mental development, convulsions, growth retardation, impaired auditory, visual or tactile sensation and speech difficulties may complicate the condition (Pohl & Cantrell, 2006).

In the survey done in India by National sample Survey Organization (NSSO) in 1991, it was found that 31 children out of 1000 in the rural areas and 9 children out of 1000 in the urban areas had a developmental delay. A later survey by the same organization (NSSO, 2002), revealed that for every 1, 00,000 number of persons with disability, there were 1008 individuals afflicted with a locomotor disability. The recent statistics reported by Indian Academy of Cerebral Palsy (IACP, 2011) revealed that the incidence of CP was up to 3 cases per 1000 live births**,** making it the most common cause of disability.

Cerebral palsy is the most common cause of congenital neurogenic dysphagia (Christenson, 1989). The children with cerebral palsy are at risk for feeding problems, dysphagia, gastro esophageal reflux disease and aspiration. The feeding problems seen in children with cerebral palsy could be consequent to several problems such as the abnormal oral muscle tone and strength, abnormal general body posture, hypersensitive areas inside and outside the mouth regions, hyperactive gag reflex, restricted temporo-mandibular joint, persistence of the primitive reflexes such as suckle-swallowing, rooting, gagging, biting, asymmetrical tonic neck reflex, lack of tongue lateralization, instability of the lower jaw, and phasic biting etc. (Ottenbacher, Bundy, & Short, 1983; Rogers, Arvedson, Buck, Smart, & Msall, 1994; Arvedson & Brodsky, 2002). Mastication and deglutition are relatively complex motor behaviors in the repertoire of infant motor activity, and therefore are highly sensitive to neurologic dysfunction. Dysphagia may be an early and even sometimes seen as an isolated sign of brain injury (Love & Webb, 1992).

Research indicates that these feeding problems are prevalent in children with cerebral palsy. Sullivan, Lambert, Rose, Ford-Adams, Johnson, and Griffiths (2007) reported that feeding problems were prevalent in children with cerebral palsy: 89% needed help with feeding, 56% choked with food; 20% of their parents described feeding as stressful and not enjoyable. Prolonged feeding times (3h/day) was also reported. These feeding problems in turn can lead to health related problems such as growth failure, poor weight gain and nutrition related problems. Hung, Hsu, Wu, and Leong (2003) found that 41.3% of 75 children with spastic CP were undernourished. Sjakti, Syarif, Wahyuni, and Chair (2008) reported the prevalence of undernourishment and severe malnutrition in children with spastic cerebral palsy to be 66% and 11% respectively.

Several studies have also been carried out to identify the nature of feeding problems in children with cerebral palsy. In a longitudinal study of 33 children with cerebral palsy between the age range of 4 weeks and 6 months, it was found that weak sucking was seen at 4 weeks of age and more feeding difficulties were seen at 6 months of age. Also, feeding difficulties at 4 weeks of age was associated with the pattern of functional impairment at 4 years of age (Motion, Northstone, Emond, Stucke, & Golding, 2002). In another study by Wilson and Hustad (2009), the parents of children with cerebral palsy reported that there was more difficulty in self-feeding, increased frequency of choking and coughing during feeding and later introduction of solid food.

Clancy and Hustad (2011) carried out a longitudinal study to track the changes in feeding between 4 years to 7 years of age in children with cerebral palsy. They found that the children who had severe oro-motor involvement had marked and pervasive feeding difficulties which showed some fluctuations with time, but were generally stable. Those children who had mild to moderate oro-motor involvement showed little to no change over time and had fewer problems in comparison to the severe group.

In a study done in Pakistani children with moderate to severe cerebral palsy in the age range of 3-15 years, the parents reported that their children had difficulty in getting food off spoon with lips, were taking longer time to swallow the bites of food, liquid leaked out of corners of the mouth and had coughs when receiving liquids or pressed tongue forward while swallowing. The study suggested that 90% of parents were conscious about the feeding problem in their children with cerebral palsy (Ghayas & Sulman, 2013).

Diwan and Diwan (2013) found maximum inadequate feeding skills present in spastic quadriplegic type of CP (75.0%). Problems found were related to sucking and swallowing,

inability to self-feed (48.5%), prolong feeding time (mean feeding time was 22.42 minutes) (95%), improper feeding positions, coughing and choking during feeding (6.1%), vomiting (3.0%), recurrent chest infections, oral motor dysfunction, drooling and cry / strong extensor thrust during feeding.

These feeding problems that are seen in children with cerebral palsy can cause a negative impact on the life of children and their parents/caregivers. Although studies have been conducted to assess the impact of cerebral palsy itself on the quality of life (QOL) of the child and his/her parents/caregivers and the nature and extent of feeding problems, there are limited studies which investigate specifically the impact of feeding problems on the child. Commonly used instruments to assess quality of life in children due to cerebral palsy include the Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child, Davis, Waters, Mackinnon, et al., 2007), the Child Health Questionnaire (CHQ, McCarthy, Silberstein, Atkins, Harryman, Sponseller, & Hadley-Miller, 2002) a European generic health related quality of life questionnaire (KIDSCREEN, Ravens-Sieberer, Gosch, Rajmil, et al., 2005), the Pediatric Quality of Life Inventory (Varni, Burwinkle, Berrin, et al., 2006), the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD, Narayanan, Fehlings, Weir, Knight, Kiran, & Campbell, 2006), the Lifestyle Assessment Questionnaire (Mackie, Jessen, & Jarvis, 2002), the modified Caregiver Questionnaire (Schneider, Gurucharri, Gutierrez, & Gaebler-Spira, 2001) and the Pediatric Outcomes Data Collection Instrument (Daltroy, Liang, Fossel, & Goldberg, 1998). All these questionnaires are disability specific, meant to assess the QOL in parents/caregivers of children with cerebral palsy.

Further, there have been tools developed to study the quality of life and the extent of handicap in adults with dysphagia such as Dysphagia Goal Handicap (DGH, Gustaffson &

Tibbling, 1991), SWAL-QOL (McHorney et al., 2002), and the Dysphagia Handicap Index (Silbergleit, Jacobson, Beardsley, & Johnson, 2012). These are patient reported outcome tools which provide information regarding the patient's swallowing difficulty and the severity of it.

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 behavior to indicate hunger or deny food etc., problems faced by the child during feeding if any, mode of food intake, their ability to us the structures in the mouth efficiently for feeding and swallowing etc. Consequently they are the best people to describe their child's feeding problems. Meyer, Coll, Lester, Boukydis, McDonough, and Oh (1994) reported that the behaviors of both caretaker and infant during feeding contribute significantly to the overall success of the feeding interaction as well as feeding performance.

Need for the study

A look into the literature revealed that feeding problems are quite common in children with cerebral palsy and vary according to the type and severity of cerebral palsy. Further several studies have been carried out to identify the nature of feeding problems which report of problems in either the oral, pharyngeal or esophageal phase in these children. It is possible that these problems in feeding faced by the child have a negative impact on the life of the child, which may in turn hinder the progress of the child during intervention. The feeding problems could affect the social and emotional life and he/she could perceive the feeding problems as a big handicap. Hence a need was felt to develop a questionnaire to assess the extent of impact of the feeding problem on the child in three domains, viz., physical, functional and emotional. It was felt that

this will provide an insight into the impact of feeding problems on the day to day functioning of the child and on the emotional development of the child.

Further such information will provide valuable input to the speech-language clinician during the treatment of feeding problems in children. The clinician will be aware of the extent of child's feeding problems in greater detail and its impact on different other domains. This would help the speech-language clinician in prioritizing the goals during therapy depending on which aspect needs immediate attention. The information from the questionnaire will also serve as baseline information which can be used to make comparisons with the post therapy performance. The information will also help in counseling the caregivers, deciding the success or failure of feeding therapy and thereby help in predicting the prognosis of the child.

In the present scenario there are assessment scales available to assess the nature and extent of feeding problems and the impact of cerebral palsy on the quality of the life of the child. Although there are scales which assess the parents' feeling about dealing with feeding problem, there are no tools to assess the parents' perception of the child's physical, functional and emotional problem related to feeding. There are also no tools available to assess the extent of impact of the feeding problems on the life of children especially in the Indian context. Thus a need was felt to develop a feeding handicap index, that is easy to administer and less time consuming, to measure the impact of the feeding difficulties on the day to day activities and other socio-emotional aspects. Keeping this in view, the present study was planned with the aim of developing a feeding handicap index that would measure the handicapping effect of feeding problems in children with cerebral palsy.

Aim of the study

The present study aimed at developing a feeding handicap index for children with cerebral palsy in the age range of 2-10 years and standardizing the same. The specific objectives of the study included:

- To assess the content validity of feeding handicap index
- To assess the test- retest reliability
- To assess the sensitivity of the tool by administering it on children with cerebral palsy
- To compare the performance of the children with cerebral palsy and typically developing children on the feeding handicap index
- To compare the performance of the lower vs. higher age group of children on the feeding handicap index and to check for variations if any, with respect to the different types and topographical distribution of cerebral palsy.
- To investigate the relationship between oro-motor abilities and feeding problems seen in children with cerebral palsy.

Chapter-2

Review of Literature

Feeding is an important skill which provides nutrition for normal growth and development. The satisfaction of hunger, maintenance of homeostasis and the energy release in the body to carry out various activities is achieved through the feeding process. Feeding in children provides opportunities for sensory and motor stimulation, mother-child bonding and oro-motor skill development. The tactile input to the mouth initiates both rooting and sucking reflex in neurologically intact infant and the sucking reflex represents the primary requisite in the initiation of the suck- swallow-breath synchrony central to the infant feeding process. The mother spends time holding and cuddling the infant during feeding which improves the mother-child bonding, also the mutual eye contact and vocalization of the parent help the infant gain some of the pre-requisite skills for communication. Meyer, Coll, Lester, Boukydis, McDonough, and Oh (1994) reported that the behaviors of both caretaker and infant during feeding contribute significantly to the overall success of the feeding interaction as well as feeding performance. The physical act of sucking also requires the active use of the jaw, cheeks, lips, and tongue. The active movement of these oral structures during feeding helps oro-motor skill development which provides a basis for the development of more mature feeding skills (Morris & Klein, 1987).

Feeding is the process for intake of food, including both its gathering and preparation. Feeding is defined as placement of the food in mouth; the manipulation of the food in oral cavity prior to the initiation of the swallow including mastication, and the oral stage of swallow when the bolus is propelled backward by the tongue (Logemann, 1998). The process of feeding is

complex and a sensory motor act which links the physical process of eating with learned social interactions. The physical process requires a coordinated series of steps from the voluntary process of oral management to the swallowing reflex and involuntary esophageal peristalsis. At the time of feeding, lips are used to transfer liquid and solid and retain the food in the oral cavity throughout chewing or mastication (Guyton, 1986; Lund, 1987). The lips and cheeks also help the tongue in ensuring the alternate movement of food between the teeth during chewing (Logemann, 1986). Once the food is masticated, the swallowing or deglutition occurs to transport materials from the oral cavity to the stomach without allowing entry of substances into the airway. Thus the process of deglutition and feeding differ from each other, although both are complex and interrelated. Swallowing is just one process in the broader context of feeding.

Phases of feeding and swallowing

The swallowing mechanism of our body consists of four phases: the oral preparatory phase, the oral transport phase, pharyngeal phase and the esophageal phase.

Oral preparatory phase

This phase is voluntary in nature and the duration of it depends on the texture of the food. Food is manipulated and bolus is formed in this phase. Further, it is divided into two phases i.e. transfer phase and reduction phase. During the transfer phase, the tongue arranges the bolus and moves it posterior to a position where it can be chewed. In normal individuals, the transfer phase usually results in the food being placed in region of the molar teeth. After this, the reduction phase takes over and the food is chewed, ground, and mixed with saliva to form the bolus, which eventually is swallowed. Lip closures during these phases are important as it prevent the bolus or liquid from spilling. After the bolus is prepared, it is held in between the tongue and hard palate before the voluntary swallow initiates. Also, to prevent the liquid from entering the pharynx, the

soft palate is lowered which takes place by the contraction of the palatoglossus muscles. At the same time, both larynx and pharynx are at rest and airway is open and breathing continues until swallow is produced. During, this phase, factors such as taste, temperature, viscosity, and size of bolus are sensed and appropriate lip, tongue, buccal and dental manipulations are carried out to prepare the bolus for the next phase.

Oral phase

This is also a voluntary phase, which starts with propulsion of food bolus to the back with the help of tongue and ends with the production of swallow but the final phase is involuntary in nature. The voluntary phase of it includes manipulation of bolus which includes rise of the tongue, then posterior intended movement ensuing in peristaltic movement. This will lead to sequential contact to hard and soft palates and forward motion of food into pharynx, meanwhile soft palate is raised against the posterior pharyngeal wall. Also, to prevent nasopharyngeal reflux at the time of swallowing nasopharynx is sealed off. Oral phase remains for 1 second in normal human beings. It had been found that swallow is elicited at the level of the anterior faucial arches. According of Storey (1968), this region is covered by posterior tongue when the oral phase is initiated, as the bolus goes through the fauces into pharyngeal region of epiglottis which forms the area of initiation of swallow. Infants usually produce an oral and then a pharyngeal swallow similar to that of an adult for a small amount of liquid bolus.

Pharyngeal phase

This phase starts when the bolus reaches the anterior tonsillar pillars. It involves the complex action of tongue elevation, velopharyngeal closure, elevation of larynx, and relaxation of cricopharyngeus musculature, all of which contribute to the movement of bolus through the pharyngeal segment. It is considered to be involuntary phase. To protect the airway the larynx is

closed. The airway is protected by the larynx in two ways: During swallowing, the main action is the complete and automatic closure of glottis. Then epiglottis is pulled down over the glottis to divert the bolus laterally and posterior toward the upper esophageal sphincter. Another important protective role of the larynx is the production of cough reflex which is triggered by sensitive receptors stimulated by the vagus nerve in both the larynx and subglottic space. Shaker, Dodds, Dantas, Hogan, and Arndorfer (1990) have noted four sequential actions related to laryngeal closure i.e,

i. Adduction of the true vocal folds associated with the horizontal approximation of the arytenoids cartilage
ii. Vertical approximation of the arytenoids to the base of the epiglottis
iii. Laryngeal elevation, and
iv. Epiglottis descent

In the oropharyngeal swallow sequence, the primary action is the onset of the vocal fold adduction. The presence of little amount of liquid in mouth leads to partial adduction of the vocal folds, which suggests the presence of sensory afferent fibers in the oral cavity activates the protective system. This action might be a oro-glottal reflex or might entail higher brain stem centers. Shaker et al., (1990) have noticed that in the oropharyngeal swallow sequence, true vocal fold closure is the primary action to happen which persists throughout the sequence.

The pharyngeal swallow in the infants is similar to that of the adults with two exceptions. Laryngeal elevation is much reduced; since larynx is anatomically elevated under the tongue base does not need to move upward. In normal infants, the posterior pharyngeal wall is often seen to move much further anterior during swallow than is observed in adults.

Esophageal phase

In this phase, the bolus to the stomach is carried by an automatic peristaltic wave, which reduces the possibility of gastroesophageal reflux from esophagus to pharynx. The peristalsis movement ends when the food passes through the gastroesophageal junction. In infants, occasionally refluxes are present in small amount which is considered to be normal and they are known as "spit up" or "wet burp". There is more pressure in the esophagus which is primary mechanism to prevent reflux of stomach content at birth. These anatomic mechanisms of closure at the gastroesoghageal juncture mature fast after few weeks of birth. After that, the peristalsis movement is same in infants, children and adults. Studies have found that, swallow induced peristalsis normally propagates at about 2 to 4cm/sec and transverse the entire body of the esophagus in 6 to 10 sec (Arvedson & Brodsky, 1993).

Development of feeding

The development and acquisition of feeding skills is a gradual process and each infant has its own pace. There are several reflexes associated with swallowing which are controlled by different cranial nerves which disappear at a certain age. The reflexes which are directly related to swallowing are gag reflex, phasic bite reflex, transverse tongue response, tongue protrusion and rooting response. As gag reflex diminishes at about 6 months of age, which generally is manifested by the onset of chewing; and in turn allows for swallowing of solids. Tongue protrusion begins to diminish by 4 to 6 months of age, permitting introduction of solids and a spoon. Bosma (1986) explained suckling as a distinctive act that involves all the oral-motor structures. The tongue, lower lip, mandible and hyoid act as a single motor unit. It diminishes by 6 to 12 months of age as transition feeding begins. Therefore, the fundamental actions of thriving feeding is insured from the beginning through strong feeding reflexes, the rooting, suck-swallow,

bite and gag reflexes (Gallender, 1979). These reflexes are present in the fetus and are active in the utero. From the initial stage itself, the typical baby demonstrates some flexibility in this extremely reflexive behavior and the ability to regulate to a diversity of feeding situations. The feeding process gets modified and matures as the child grows.

Feeding development is related to the development of oral structures, upper limbs and other skills which determines the pattern of feeding. During early infancy, infants are only able to suck and swallow liquids and these preliminary feeding skills are very essential to their existence. As the child grows, the sucking and swallowing action is followed by biting, chewing, eating from a spoon, drinking from a cup and a straw which are more mature feeding behaviors. These developments occur as the higher cortical centers gain more control (Arvedson & Brodsky, 1993).

Breast feeding

Suckling from the breast of the mother is what the infant learns to do first. During breast feeding, the tip of the tongue stays behind the lower lip and over the lower gum, while the rest of the tongue cups around the areola of the breast. The mandible moves the tongue up, allowing the breast areola to be compressed against the infant's alveolar ridge. Milk is then expressed into the oral cavity (Arvedson & Brodsky, 1993).

Suckling and sucking

In infant development, there are two distinct phases of suck i.e., suckling and sucking. The first pattern developed is suckling, which involves a definite backward and forward movement of the tongue. Liquid is drawn into the mouth through a rhythmical licking action of the tongue, combined with pronounced opening and closing of the jaw. Sucking is the second

intake pattern to develop between 6 and 9 months. In this type of feeding pattern, the tongue body raises and lowers with strong movement of its intrinsic muscles, and thus jaw makes a smaller vertical departure (Morris & Klein, 1987).

Transitional feeding

The transitional feeding phase typically starts at 4 to 6 months of age in normal infants. The inclination for different textures after several months of suckle feeding is primarily related to changes in the central nervous system along with some anatomical changes. There is an increase in intraoral space as the mandible grows downward and forward. The oral cavity also elongates in the vertical dimensions. The hyoid bone and larynx shift downward, so the breathing and swallowing coordination becomes a factor during feeding, and breathing and swallowing truly become mutual activities (Arvedson & Brodsky, 1993).

Eruption of teeth may be the most notable change in the peripheral anatomic structures. Deciduous teeth erupt between 6 to 24 months after birth, with all 20 deciduous teeth usually present by the end of the second year in healthy children. Mandibular incisors usually erupt 6 to 8 months after birth, but the process may be as late as 12-13 months in some normal children (Moore, 1988). Molars erupt from 12-24 months and the canines from 16 to 20 months. The erupted teeth are probably more important as sensory receptors than for motor purposes, because biting and chewing during the transitional period can be accomplished effectively with no teeth. Bosma (1986) has suggested that the sensory inputs of teeth may be significant in the development of central nervous system control of the feeding process. In this phase the buccal cavity space increases, food is manipulated between the tongue and the buccal wall. It is especially common for infants to move toward their first spoon experiences with suckling movement of tongue. Sometimes, these movements may appear to be tongue thrusting.

Progressively the lateral tongue action becomes steadier along with the rotary jaw action required for efficient oral stage.

The tongue continues to be a primary structure for oral feeding. As infants mature toward semi-firm food, the tongue moves the food to the lateral buccal area where it is mashed by vertical motion of the tongue and jaw. These manipulations probably are a prelude to molar chewing. The motions of chewing occur with or without erupted molars in young children. In the course of development, the vertical movements happen to be related with alternating lateral motor feature of mature mastication. Mastication coordination becomes fully mature between 3 to 6 years age (Vitti & Basamajian, 1975).

While the skill to manipulate varied food textures increases, parallel gains occurs in speech development as well as in trunk, head and neck stability. As the brain develops throughout the first several months of life, sensory inputs pertinent to feeding extend into the midbrain, cerebellum, and thalamus and to the cerebral cortex (Arvedson & Brodsky, 1993). The sense of taste and smell also has a significant role in feeding. Bosma (1986) has stated that the increasing variety of taste and smell of the foods offered to infants may be one of the major factors in the achievement of transitional feeding.

Developmental milestones relevant to normal feeding

According to Pridham (1990), feeding skills were found to be very important for the development of infant's capacity for self regulation throughout the first year of life. It begins with hunger and satiety pattern at the age of 2-3 months. Till the age of 4-6 months, infants receive all the nourishment from nipple feedings. The table 2.1 depicts the normal developmental milestones for self feeding skills from birth to 24 months:

Table 2.1

Normal developmental milestones for self- feeding skills (source: Arvedson & Brodsky, 1993)

Age (months)	**Skill level**
0-5	Hand to mouth begins
2-4	Hand on bottle during feeding
4	Spoon feeding introduced
4-6	Cup drinking introduced
5-6	Both hands to hold the bottle
5-7	Semi solids from spoon
6	Cracker to mouth briefly
6	Lip closure around the spoon
6	Munching begins- vertical jaw action
7	Chewing begins- rotary jaw action
6-8	Liquids suck from cup
8-9	Assisting with spoon
9	Cracker to mouth- deliberately reaches for spoon
9-10	Drinks from the cup held by the caregiver
10-11	Pincer grasp for finger feeding
12	Self-feeding by grasping spoon with whole hands
12	Holds cup with 2 hands; 4-5 consecutive swallows
12	Holds and tips bottle by self
15-24	Skills refined for independent self-feeding

Stevenson and Allaire (1991) studied the development of feeding and swallowing and they put forward the following findings:

i. The normal development of feeding and swallowing skills essentially depends on structural integrity i.e. there is an association between anatomic changes taking place and growth in the feeding function.
ii. During infancy, feeding is reflexive in nature and is under brainstem control. Along with development, these brainstem mediated reactions gradually come under voluntary control.
iii. At infant stage, swallow does not involve voluntary oral-preparatory phase and oral phase while a mature swallow is consists of voluntary oral-preparatory phase, voluntary oral phase, and involuntary pharyngeal and esophageal phases.
iv. Neural control of swallowing entails sensory afferent nerve fibers, motor efferent fibers, paired brainstem swallowing centers and supra-bulbar neural inputs. Normal feeding development requires the integration of these sensory and motor functions.
v. Along with neural and structural development, feeding also depends on learned behaviors which is controlled by oral sensation, fine and gross motor development, and experimental chances.
vi. Feeding is also affected by person's nature, interpersonal connections, upbringing and culture.
vii. The major objective of feeding is the attainment of sufficient nutrition required for age adequate growth and development.

Feeding development does not occur in isolation. There are many other skills such as cognitive and sensory motor skills that develop simultaneously in the child which would in turn

facilitate feeding skills. Averdson and Brodsky (1993) compiled the developments in all the above mentioned areas which have been depicted in the table 2.2 below:

Table 2.2

Neurodevelopmental milestones relevant to normal feeding (Source: Arvedson & Brodsky, 1993)

Age (Months)	**Cognitive skill**	**Sensory Motor skill**	**Feeding skill**
Birth to 2	Visual fixation and tracking	Balanced flexor and extensor tone of neck and trunk	Promotion of parent-infant interaction during feeding. Maintenance of semiflexed posture during feeding
3 to 4	Visual recognition of parents	Head maintained primarily in midline and aligned with trunk in supported sitting	Parents preferred for oral feedings Upright supported position for spoon feeding
5 to 9	Visual interest in small objects Extended reach and grasp Object permanence Stranger anxiety	Independent sitting Extended reach pincer grasp and grasp	Feedings more frequently in upright position Initiation of finger feeding Parents preferred for feedings
18 to 24	Use of tools Increasing attention and persistence in play activities Independence from parents	Refinement of upper extremity coordination	Use of feeding utensils Prefer to feed self over longer periods of time Imitate others during meals

Factors influencing the development of feeding

Oral feeding skill may be different in different individuals. It is influenced by the levels of alertness, stress, illness, and fatigue as well as actual motor coordination in the oral pharyngeal system. Also, the cultural pattern along with social factors within the family, have an effect on the feeding skills. The transitional feeding phase is the time, when the dietary pattern and preferences are acquired, and many of these preferences are carried over into adulthood (Arvedson & Brodsky, 1993). The aspects of anatomy, embryology, and physiology a human embraces also influence the feeding development. In addition, it is influenced by behavioral and social factors (Miller, 1991).

Neurodevelopmental aspects in feeding

Maturation of the central nervous system (CNS) plays an important role in the acquisition of normal swallowing or feeding skills. Both feeding and swallowing require intact functioning of the central and peripheral nervous systems and the intricate coordination of actions of multiple muscles of the oral cavity, pharynx and esophagus (Miller, 1982). A child's neurodevelopmental status determines the development of feeding and swallowing. Any abnormalities of developing brain or structural or functional deficits in the oral, pharyngeal or esophageal region commonly results in a spectrum of cognitive, communicative, behavioral, and motor abnormalities that are often associated with feeding and swallowing disorders. Even a small injury to the developing brain can have a magnified negative effect on the rest of the sequence of the developing brain leading to congenital malformation and other related abnormalities (Lenn, 1991).

Feeding/swallowing problems can be seen in a variety of syndromic conditions, disorders such as cleft lip and/or palate, congenital malformations, prolonged respiratory illness, cardio respiratory problems, motor disabilities that affect the development of muscle tone, posture, and

movements etc. (Davis, 1987). For e.g., Pierre Robin syndrome which is a craniofacial anomaly described by micrognathia, glossoptosis and a U-shaped cleft palate leads to difficulties such as choking and aspiration of liquid. Down syndrome is also associated with oral motor dysfunction leading to difficulties like poor sucking, difficulties in chewing, and uncoordinated swallow leading to choking and gagging (Cooper-Brown, Copeland, Dailey, Downey, Petersen Stimson, & Van Dyke, 2008). Children with cleft lip/palate exhibit difficulty in developing negative pressure required for nipple feeding due to the inability to seal the nasal cavity and nasophaynx from the oral cavity and oropharynx. They also exhibit nasal regurgitation, bloating, choking, gagging, fatigue with feeding, prolonged feeding times that contributes to spitting up and emesis.

There are a few other conditions where children have normal oral motor skills and swallowing function but they might have gastrointestinal issues which will affect feeding. Here, the children will refuse or will not tolerate oral feedings because of the negative consequence (i.e. respiratory distress, pain) associated with the movement of food from esophagus to the intestine. Disorders such as vascular ring, esophageal atresia, gastro esophageal reflux etc. are associated with gastrointestinal problems (Hall, 2001). Conditions like choanal atresia, midface hypoplasia, laryngeal anomalies, apnea etc. where breathing is compromised will lead to feeding problems (Hall, 2001). Any injury to the CNS of children before, during and after the birth may cause feeding and/or swallowing difficulties which is accompanied by developmental delays and behavioral issues. Cerebral palsy is one of the most common disorder caused by an injury to the central and peripheral nervous system (Batshaw & Perret, 1992).

Cerebral palsy

Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, balance and coordination causing activity limitation, that are attributed to non-progressive disturbances that occur in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour; by epilepsy, and by secondary musculoskeletal problems (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2006). CP is frequently associated with a variety of feeding problems.

Incidence and prevalence of cerebral palsy

The incidence of CP in the western countries is reported to be 2-2.5/1000 live births (Reddihough & Collins, 2003) and the prevalence estimates of CP based on population-based studies from around the world ranges from 1.5 to more than 4 per 1,000 live births or children of a defined age range (Winter, Autry, Boyle, & Yeargin-Allsopp, 2002; Surveillance of CP in Europe, 2002; Paneth, Hong, & Korzeniewski, 2006; Bhasin, Brocksen, Avchen, & Van Naarden Braun, 2006; Arneson, Durkin, Benedict, Kirby, Yeargin-Allsopp, Van Naarden Braun, & Doernberg, 2009). Over the years, although improvements in medical technology with respect to improvements in perinatal and obstetric care have helped reduce the number of babies who develop CP, there has been an increase in the survival rates of premature, low birth weight babies and a number of multiple births cases, who are more likely to develop CP (Odding, Roebroeck, & Stam, 2006). Therefore the incidence of CP has not declined and the overall prevalence has increased during the last 2-3 decades.

In the Indian scenario too the incidence estimates are nearly the same. In a survey done in India by National sample Survey Organization (NSSO) in 1991, they found that 31 children out of 1000 in rural area and 9 children out of 1000 in urban areas had a developmental delay. According to NSSO (2001) survey, there are 18.5 million disabled people in India. Also, in Delhi itself there are 1, 00,000 disabled people, out of which 6600 had cerebral palsy. Hence, the prevalence rate is 48 per 1 lakh persons. According to the NSSO (2002), for every 1, 00,000 number of persons with disability, there are 1008 individuals afflicted with a locomotor disability. In a study by Nair, George, Padmamohan, Sunitha, Resmi, Prasanna, and Leena (2009) done in Alappuzha District, Kerala, they found that 311 children out of 12520 in the age range of 0-5 years had developmental delay, deviation, deformity or disability making a prevalence of 2.5%. The prevalence was 2.31% in 0-2 years and 2.62% in 2-5 years age range. The recent statistics reported by Indian Academy of Cerebral Palsy (IACP, 2011) revealed that the incidence of CP is up to 3 cases per 1000 live births, making it the most common cause of disability.

Etiology of cerebral palsy

CP can be caused by a number of injuries to the brain at various stages from several weeks after conception (prenatal period), through birth (perinatal period), to early childhood (postnatal period). The major prenatal causes include insult during the first trimester as a result of maternal viral infection such as rubella, influenza, toxoplasmosis etc., ingestion of teratogenic drugs, radiation exposure, chromosomal abnormalities and so on. The major perinatal causes include birth complications during labour and delivery and the postnatal causes include birth asphyxia, neonatal jaundice, and sepsis (Batshaw & Perret, 1981). CP can also be caused due to the maldevelopment of the brain. There are also some well documented reports of CP being

genetically transmitted. Most common nervous system anomalies found such as anencephaly, hydrocephaly, microcephaly and spina bifida imply that they are genetically related (Denhoff & Robinault, 1960).

In addition several risk factors have been identified that can lead to CP which could be grouped under different categories (Minear, 1956; Denhoff & Robinault, 1960; Shyamala, 1987) based on the period during which the injury occurs. The risk factors in the prenatal period include diabetes or hyperthyroidism, high blood pressure, high blood sugar levels, poor maternal nutrition, seizures or mental retardation, trauma/fall, incompetent cervix (premature dilation) leading to premature delivery, bleeding in the third trimester, infection (TORCH), severe toxemia, exposure to toxic/poisonous substances, drug abuse, use of alcohol or tobacco, trauma, multiple pregnancies, age above 40 years, and placental insufficiency. The risk factors in the perinatal period include premature delivery (less than 37 weeks gestation), low birth weight (<1.5 kg), prolonged and difficult labour, vaginal bleeding at the time of admission of labour, prolonged rupture of the amniotic membranes for more than 24 hours leading to fetal infection, umbilical cord around the neck, abnormal presentation such as breech, face, or transverse lie, vacuum delivery which makes for a difficult delivery, Rh or ABO blood type incompatibility between mother and infant, delayed birth cry, asphyxia, severely depressed fetal heart rate during labor, indicating fetal distress, and a low Apgar score. The risk factors in the postnatal period include infections to the brain such as meningitis, encephalitis etc., seizures, hypoxia, hyperbilirubinemia, trauma, interventricular hemorrhage (I. V. H.) – bleeding into the interior spaces of the brain or into the brain tissue), periventricular encephalomalacia (P.V.L.) – damage to the brain tissue located around the ventricles (fluid spaces) due to the lack of oxygen or problems with blood flow). All the above mentioned factors can occur during the first two years

of life and cause a damage to the brain. In this case the child will be known to have congenital CP. However an injury to the brain can also occur due to a fall or a motor vehicle accident, infections such as meningitis after two years of life, especially during the early childhood which could lead to acquired CP (Arvedson & Brodsky, 1993).

Clinical manifestation of cerebral palsy

The neuromuscular manifestations may be regarded as the most obvious symptom of CP. Depending on the areas of the brain that have been damaged, individuals with CP may experience one or more of the following: muscle tightness or spasm or floppy muscles, involuntary movement and disturbance in gait and mobility. Children with CP present with three types of motor problems: primary, secondary and tertiary impairments. The primary impairments of muscle tone, balance, strength and selectivity are directly related to the damage in the central nervous system. Abnormal muscle tone, disturbance of balance mechanisms, muscle weakness and loss of selective motor control lead to an inability to stretch the muscles. Secondary impairments of muscle contractures and deformities develop over time in response to the primary problems and musculoskeletal growth. Tertiary impairments are adaptive mechanisms and coping responses that the child develops to adapt to the primary and secondary problems (Berker & Yalçın, 2010). Many clinical signs and symptoms are not readily visible at birth, except in some severe cases, and may appear within the first three to five years of life as the brain and the child develops. Some of the signs and symptoms exhibited by children with CP are listed under the following categories:

***Primary impairments*:** Due to the primary impairment, the following signs and symptoms may be seen:

- Delay in reaching key growth milestones, such as controlling head, rolling over, reaching with one hand, sitting without support, crawling, or walking.
- Persistence of "primitive" reflexes, which normally disappear 3-6 months after birth.
- Development of handedness before 18 months of age which indicates weakness or abnormal muscle tone on one side, which may be an early sign of CP.
- Abnormal tone in muscles. The muscles may be very stiff or unusually relaxed and "floppy." Limbs may be held in unusual or awkward positions.
- Abnormal involuntary movements which may be unusually jerky or abrupt, or slow and writhing. They may appear uncontrolled or without purpose.
- Muscle weakness.
- Problems with balance and coordination.
- Delay in developing speech and language milestones and unintelligible speech due to poor respiratory control, laryngeal, velopharyngeal and articulatory dysfunction.

Secondary impairments: These secondary impairments develop in response to the primary impairments. The following secondary impairments can be seen in children with CP:

- Skeletal deformities: Individuals with CP on only one side may have shortened limbs on the affected side. If not corrected by surgery or a device, this can lead to tilting of the pelvic bones and scoliosis (curvature of the spine). Muscle contractions in the hip area can lead to hip dislocations or fractures in children with CP.

- Joint contractures: People with spastic CP may develop severe stiffening of the joints because of unequal pressures on the joints exerted by muscles of differing tone or strength.

Tertiary impairments: These impairments are the result of the coping mechanism which children with CP use to adapt to the primary and secondary impairments. Tertiary problems include dynamic deformities of the musculoskeletal system that tend to become fixed with time. For e.g., a child with spastic CP may develop secondary ankle plantar flexion contractures because of which they may use knee hyperextension in stance as an adaptive mechanism which is considered as tertiary impairment.

Associated problems in cerebral palsy

As highlighted in both the definitions, there are several problems that could occur along with the primary impairments. 25-80% of the children with CP could have additional impairments (Odding, Roebroeck, & Stam, 2006). These could increase with an increase in severity of the condition. Few of the associated problems that can be seen in children with CP are listed below:

- Mental retardation: Two-thirds of individuals with CP have mental retardation (Odding et al., 2006). Mental impairment is more common in spastic type compared to other types of CP. Among the spastic type those with spastic quadriplegia tend to have mental retardation more often than spastic diplegics or hemiplegics (Sharma, Sharma, & Kabra, 1999). Generally, the more severe the retardation, the more severe the disability overall. In dyskinetic type of CP, however no such relationship between degree of intellectual impairment and type of cerebral palsy was found (Fennell & Dikel, 2001).

- Seizures: Seizures are present in 20-40% of the population of CP; it is most common among the hemi and tetraplegics (Odding et al., 2006). Seizures may appear early in life or years after the brain damage that causes CP. The physical signs of a seizure may be partly masked by the abnormal movements of a person with CP. In a study done by Ashwal, Russman, and Blasco (2004), epilepsy was seen in 28-35% hemiplegic, 19-36% tetraplegic, 14% diplegic, 13-16% ataxic and 8-13% dyskinetic CP.
- Swallowing problems: Swallowing is a very complex function that requires precise interaction of many groups of muscles. People with CP who are unable to control these muscles will have problems in sucking, eating, drinking, and controlling their saliva. They may drool. An even greater risk is aspiration, the inhalation of food or fluids into the lungs from the mouth or nose. This can cause infection or even suffocation. They may also have problems in the muscles of the lips, jaw and tongue which may result in feeding difficulties.
- Hearing loss: The child with CP may have hearing loss that range from mild to severe range. The loss could be unilateral or bilateral. Children born prematurely are at risk for developing hearing loss. Sensorineural hearing loss affecting the inner ear is common in most children with CP.
- Vision problems: Schenk-Rootlieb, Nieuwenhuizen and van der Graaf (1992) reported that around 70% of the children with CP have low visual acuity. Three percent of people with CP have strabismus (Pigassou-Albouy & Fleming, 1975). This is due to weakness of the muscles that control eye movement. These people are often nearsighted. If not corrected, strabismus can lead to more severe vision problems over time. The other problems include

nystagmus, refractive error, amblyopia , optic atrophy, cortical visual impairments, blurred vision, hemianopia etc.

- Tactile problems: Yekutiel, Jariwala, and Stretch (1994) found that 44-51% of the children with CP had deficits in stereognosis and two-point discrimination. Cooper, Majnemer, and Rosenblatt (1995) suggested that 90% of the hemiplegic have considerable bilateral sensory deficits where stereognosis and proprioception were mainly affected. Also, they found that there was no correlation between sensory and motor impairments. They also may have hypersensitivity or hyposensitivity to touch. They may exhibit impaired sensation for pain, touch and temperature. These problems may be restricted to the face and the mouth in some children.
- Dental problems: Children with CP tend to have more cavities than usual due to the defects in tooth enamel and difficulties in brushing the teeth. They may also have abnormal alignment of the teeth or delayed development of the teeth which in turn results in speech problems.
- Gastrointestinal problems such as GERD (Gastro esophageal reflux disease): There could be problems such as inadequate intake of food, frequent vomiting with aspiration occurring because of gastro esophageal reflux.
- Bowel and/or bladder control problems: These are caused by lack of muscle control. The common problems include bed-wetting, uncontrolled urination during physical activities, or slow leaking of urine throughout the day. These children also could have constipation which could occur as a result of being confined to bed or due to insufficient intake of fluids.

- Sleep disturbances: Some children with CP have difficulty in falling asleep. Sometimes the children fall asleep at the proper time but wake up after a few hours.
- Emotional disturbances: There could be withdrawal and insecurity in these children. Frustration is one of the most common problems. The inability to communicate may also cause disruption associated with emotional problems and CP.
- Behavior problems: Problems such as increased irritability or hyperactivity could be seen in some children. They may also be inattentive and distractive.
- Perceptual problems: Some children with CP may not be able to perceive the auditory or visual signals (auditory or visual agnosia) and therefore they may exhibit processing problems. Some may also have problems with depth perception.

Types of cerebral palsy

The effect of CP varies from one child to another. The effects can range from complex physical and cognitive involvement to a barely noticeable limp. The severity and location of brain damage play a major role in the manifestation of CP. Many CP classifications are used today. A few of the popular classifications are listed below (Minear, 1956; Boone, 1972; Shyamala, 1987).

I. **Based on the neuromuscular symptoms, CP can be classified into the following types:**

a) ***Spastic cerebral palsy:*** In this type of CP, there is a release of the postural stretch reflexes and there is exaggerated muscle tone, which may vary from mild hypertonicity to extreme rigidity depending on the exact site of lesion and the extent of involvement of the extrapyramidal system, due to increased excitation from other neural areas. There is also an interruption of normal phasic muscle responses in these individuals. Whenever a movement

is initiated, resistance to movement by antagonists which are normally inhibited increases enormously and prolonged involuntary muscular spasms are created which make the limbs stiff, rigid, and resistant to flexing or relaxing. Most of the children with spasticity show strong extensor spasticity in supine position and flexor spasticity in prone position (Bobath & Bobath, 1954). The motoric symptoms exhibited by these children vary depending on the severity of the spasticity. A severe spastic child will walk with a dysrhythmic, jerky, scissored gait, where in the legs would be turned inward, hips rotated, the knees adducted, the heel lifted from the ground, the arms flexed against gravity and the wrist and fingers flexed. But in mild cases the symptoms may be limited to strabismus, drooling, hyperactivity and distractibility. Other conditions associated with spastic CP may include an exaggerated response to startle stimulation, a degree of mental impairment, and weak respiration. The arms and legs are commonly affected. Besides, the tongue, mouth, and pharynx can also be affected which will lead to impaired speech, eating, breathing, and swallowing. This type of CP accounts for 70% to 80% of CP cases (Stanley, Blair, & Alberman, 2000). The injury to the brain occurs in the pyramidal tract and is called as upper motor neuron damage.

b) ***Rigidity****:* Rigidity is similar in some respect to spasticity except that the muscle stiffness appears equally in the agonist and the antagonist muscles and the attempts to move a limb are often described as similar to bending a lead pipe. In this form of CP, the child assumes a very rigid or stiff posture when awake or stimulated, but usually relaxes during sleep. Here the resistance is greater to slow motions than to rapid motion, whereas in spasticity there is greater resistance to rapid motion. Reflexes are diminished or absent. All extremities are involved in rigidity. Because of the simultaneous contractions of agonists and antagonists,

children with rigidity are capable only of slow movements within a restricted range. It is considered as the extreme form of spasticity.

c) ***Atonic cerebral palsy****:* Lesion in lower motor neuron pathways or peripheral nerves leads to atonic CP. This type of CP is characterized by lack of tone and failure of muscles to respond to volitional stimulation. The muscle lacks the firmness or turgor of the normal relaxed muscle. They exhibit either absence of reflexes or weak reflexes. Atonia in most instances does not describe a type of CP, but the outstanding symptom.

d) ***Ataxic cerebral palsy:*** The motor deficits exhibited by children with ataxic CP are ascribed to lesions in the cerebellum and/or to the pathways which conjoin it with cerebral cortex and brainstem. The main characteristics of ataxic CP are lack of equilibrium and coordination in voluntary muscle activity, shakiness, poor balance and an unsteady broad based gait. These children have difficulty with movements that are quick or require a great deal of control. The incoordination in these children is found to result from an inability to integrate the components of direction, force and rate in the muscular synergy. In pure ataxics the muscle tone is permanently reduced. But in practice, ataxics fluctuates from hypotonicity to hypertonicity since they also share features of other type of CP like athetosis.

Reaching for objects can initiate an "intention tremor" in these children. The tremor gets worsened as the child's hand gets closer to the object he/she is trying to reach. Tremors also occur when the child attempts actions requiring specific muscle control, such as writing. Difficulties with motor skills become much more pronounced when the child with ataxic CP attempts motor specific tasks for longer time duration. Depth perception is also usually affected. The entire body is involved rather than just certain limbs or muscle groups which includes the

muscles of the face as well. The most common facial ataxic symptoms are jerky speech patterns and abnormal eye movements called nystagmus. About 5-10% of cases of CP are of this type.

e) ***Athetoid cerebral palsy****:* Athetoid CP involves involuntary, abnormal movement of the skeletal musculature and is characterized chiefly by twisting, writhing and worm like movements. Generally the extrapyramidal system or basal ganglia is considered as the site of lesion in children with athetoid CP. The muscle tone is usually increased, but it might fluctuate between normal tone and hypotone. Reflexes in this type of CP are exaggerated and primitive. The abnormal postural patterns exhibited by athetoids are almost similar to that exhibited by spastics. The posture changes almost constantly, but certain postures recur so frequently and regularly that they may be considered typical. For example, the fingers are generally hyperextended and abducted, wrists flexed, the forearm bent forward so that the palm of the hand is down, the plantar section of the sole of the foot is flexed and inverted, the head often is retracted and rotated to one side, facial grimaces may be constant, the mouth often is open and the tongue is protruded. Besides, slow, writhing worm like movements progressing from proximal to distal areas in wave like fashion are present in hands and arms. These movements are accentuated by voluntary effort and emotional tension. They are absent during sleep. A child with athetoid CP will have trouble tying his shoes, buttoning his shirt, cutting with scissors, and doing other tasks that require fine motor skills. He might walk with his feet farther apart than normal and have trouble with his balance and coordination. The gait would be writhing, lurching and stumbling with overflow of arms when he moves. These children may also suffer from “intention tremors,” a shaking that begins with a voluntary movement. For example, when a child with athetoid CP tries to reach for a toy, his hand and

arm will start to shake. As he gets closer to the toy, the tremor worsens. Cognitive deficits are usually not present in children with athetoid CP.

f) Dystonia: This type of CP occurs due to a lesion in the extrapyramidal system. It is considered as an extreme form of athetosis. The child with this type of CP has involuntary movements which are characterized by involuntary contractions of muscles of torso, neck and face. The contractions increase relatively slowly in intensity, and result in grotesque posture due to extremely forceful contraction of the involved muscles before relaxation.

g) Tremor: The muscle tone and reflexes in such type of CP are normal. These children exhibit repetitive, rhythmic involuntary contractions of flexor and extensor muscles. These tremors may be either intentional or non-intentional. Intentional tremors are not present during rest, but appear with voluntary or 'intended' movement. Non intentional tremors are present during rest and continue with the intentional movement. Tremors in the lower extremities may throw the child off balance. Tremors in the upper extremities interfere with the development of hand skills. Some tremors interfere with the performance of precise movements to such a degree that it is impossible for the child to develop skills such as writing. Tremors can also be seen in the tongue, especially when protruded. However, the tremor type of CP does not develop any deformities. Tremor is usually associated with other types of CP.

h) Ballismus*:* This type of CP results from a lesion in the subthalamic nucleus. The involuntary movements seen in the extremities are rapid, violent, and flailing. If the lesion is in the contralateral side, the condition is called hemiballismus. This type is associated with dyskinesia or other types of CP.

i) ***Myoclonus:*** Involuntary movements are present due to rapid, abrupt, twitching unsustained muscle contractions in large and small groups of muscles. The lesion here is in the extrapyramidal system. There could be two types of myoclonus seen (a) synchronous myoclonus in which a number of muscle groups jerk or contract at the same time or one after the other and (b) asynchronous myoclonus in which a number of muscle groups contract at different times. The involuntary movements can be present in the pharyngeal, laryngeal or palatal regions which could affect the speech.

j) ***Chorea:*** This occurs due to a lesion in the extrapyramidal system. The involuntary movements seen in chorea are described as quasi purposive, that is, these movements resemble movements of a high order (although they achieve no purpose). They resemble fragments of purposive movements following one another in a disorderly fashion, e.g., the eyes may be rolled from one side to another, The head may turn in the same direction. The tone fluctuates between hyper and hypotone.

k) ***Mixed cerebral palsy:*** Some children with CP exhibit combinations of neuromuscular characteristics. This type of CP is the result of injury to both the extrapyramidal and pyramidal areas of the brain. Their overall appearance will be determined by the type of neuromuscular characteristic which predominates. For example, some children with athetoid CP may have mild spasticity in their lower extremities. Such children may exhibit involuntary movements of athetoid CP as well as tight muscle tone of spastic CP.

II. CP can be classified on the basis of topography i.e., according to the number and location of limbs which are involved.

i. ***Hemiplegia:*** This is the most common type of CP. In this type of CP, abnormalities of motor control are localized to one side of the body. Here arms are involved to a greater extent than legs. It is usually seen in spastic CP and occasionally athetoid CP. A delay in walking or an early hand preference may be the first noticeable sign of mild hemiplegia.

ii. ***Paraplegia****:* Both legs are involved, but there is no involvement of the arms. Individuals with paraplegia are likely to be of the spastic type.

iii. ***Quadriplegia (Tetraplegia):*** In this type of CP all the four extremities are involved. Quadriplegics may be spastics, athetoids, tremors, rigidities or ataxics. When legs are most involved, it is usually seen in spastic quadriplegic whereas, greatest involvement in arms is usually seen in dyskinetic, including athetoid quadriplegic. When all four extremities are significantly involved with the legs more so than with the arms, but with considerable limitation of hand use, it can be referred to as tetraplegia (because the head and trunk are also usually involved) or total involvement (because the face, swallowing, and speech may be affected). Seizures and significant cognitive impairment are common with this type of CP. Major musculoskeletal problems with the hips and spine are seen in this type. Oral-motor and feeding problems are usually a significant component of quadriplegic CP.

iv. ***Diplegia:*** In this type of CP there is an involvement of all the four extremities; however, the legs are primarily involved and there is only slight involvement of the arms. Hand function is generally not significantly affected. Diplegics are usually spastics. Motor involvement in diplegia is often about the same on both sides of the body. Strabismus (crossed eyes) is commonly seen in diplegics. Sensory, perceptual, and learning problems are also observed in such children. If in diplegics, one side of the body is

significantly more involved than the other (asymmetrical involvement), we can categorize it as diplegia with a hemiplegia (sometimes referred to as triplegia).

v. ***Triplegia:*** In this type of CP, three extremities, more often both legs and one arm are involved. It is usually seen in spastic CP.

vi. ***Monoplegia:*** In this type of CP, only one limb is affected and this condition is extremely rare.

vii. ***Double Hemiplegia:*** Spastic quadriplegics whose arms are more involved than their legs can be referred to as double hemiplegics. Besides quadriplegics whose one side is more involved than the other side can also be described as double hemiplegics rather than quadriplegics.

Causes of feeding problems in children with cerebral palsy

Feeding problems are very frequent in CP (Gisel, 2008). The children with CP are at risk for feeding problems, dysphagia, GERD and aspiration. The feeding problems or dysphagia seen in children with CP is consequent to the abnormal oral muscle tone and strength, general body posture etc. (Arvedson & Brodsky, 2002). Mastication and deglutition are relatively complex motor behaviors in the repertoire of infant motor activity, and therefore are highly sensitive to neurologic dysfunction. Dysphagia may be an early and even sometimes seen as an isolated sign of brain injury (Love & Webb, 1992). Lack of tongue lateralization, instability of the lower jaw, restricted temporo-mandibular joint and phasic biting can severely limit the individual's ability to chew, position, and swallow a food bolus safely (Rogers, Arvedson, Buck, Smart, & Msall, 1994).

Prolonged retention of the reflexes could be another cause of feeding problems. The reflexes may remain obligate and become more prominent, that is, each time the sensory input is

received the reflex occurs outside of voluntary control. This can further inhibit normal neuromotor development and, in turn normal feeding patterns. According to Ottenbacher, Bundy, and Short (1983) the persistence of the primitive reflexes such as suckle-swallowing, rooting, gagging, biting, asymmetrical tonic neck reflex etc. can interfere with a child's eating skills. Further the swallowing reflex may be completely absent or more often delayed (Morris, 1989). This could lead to aspiration due to poor coordination of swallowing. When the neuromotor coordination of swallowing is deficient, there may be gagging in some cases with associated vomiting or aspiration, choking, and pneumonia. These unpleasant sensations cause further eating problems by triggering avoidance behaviors.

GER (Gastroesophagial reflux) is the movement of food or acid from the stomach into the esophagus. This may be associated with an unpleasant burning sensation. This can make the child associate feeding with pain; and he or she, in turn will avoid feeding entirely. Studies have shown an incidence of GER as high as 75% in children with severe CNS dysfunction (Byrne, Euler, Ashcraft, Nash, Seibert, & Golladay, 1982). The possible etiological factors could include supine positioning, scoliosis, and kyphosis causing diaphragmatic distortion, spasticity, abnormalities of lower esophageal spinchter tone, motility disorders, and seizures. The feeding problems could also be due to hypersensitive areas inside and outside the mouth regions, hyperactive gag reflex, restricted temporo-mandibular joint etc.

The feeding problems in spastic cerebral palsy is generally linked to improper movements of tongue, such as forward sucking, or to difficulty in lifting the lip or using lateral movements. It could also be due to the stiffness of the muscles which could interfere with gathering the food and taking it to mouth in self-feeding. Sometimes, facial paralyses may also be present at the time of birth leading to feeding problems (Denhoff & Robinault, 1960).

Children with hypertonicity, show extensor pattern of head, trunk, and limb leading to limited oral and thoracic movement (Ottenbacher et al., 1983). Athetoid CP mostly comes with the symptom of poor sucking and frequent vomiting. The severe conditions are frequently associated with lack of expressiveness of the face, grimacing and drooling, and also by difficulties in chewing and swallowing (Denhoff & Robinault, 1960). The involuntary movements could often interfere with feeding in athetoid CP (Arvedson & Brodsky, 2002). Children with developmental disabilities are frequently associated with abnormal development of muscle tone which leads to drooling, uncoordinated breathing and inability to initiate, grade, or sustain oral patterns (Ottenbacher, Bundy, & Short, 1983). In children with hypotonia, the low tone affects posture and neuromuscular coordination. There is frequently an open mouth posture with drooling, poor truncal stability, and difficulties in oromotor coordination resulting in dysphagia. They lack the ability to stabilize their head and trunk which will lead to problems in breathing and swallowing. Children with fluctuating tone exhibit irregular breathing patterns, impaired coordination of swallow, and coughing and choking.

Prevalence of feeding problems in children with cerebral palsy

Research indicates that the feeding problems are prevalent in children with cerebral palsy. The prevalence rate of feeding difficulties in children with CP ranges from 40% to 90% (Gisel & Patrick, 1988; Reilly, Skuse, & Poblete, 1996; Stallings, Zemal, Davis, Cronk, & Charney, 1996; Trier & Thomas, 1998). Reilly et al. (1996), in their study included 49 children in the age range of 12-72 years with cerebral palsy. They administered a standardized procedure to assess the feeding and oro- motor difficulties. They found that during the first year of life, sucking problem was present in 57% of the children, swallowing problem in 38% , and 80% were fed non-orally no less than once. Oro-motor dysfunction was seen in more than 90% of the

children. They also found that individuals with spastic quadriplegia had the greatest motor difficulties and up to 85% of them had severe feeding difficulties.

Gangil, Patwari, Aneja, Ahuja, and Anand (2001) considered 100 parents of children with CP in the age range of 1 to 9 years. They were questioned for their perception regarding their child's feeding difficulties. The difficulties listed by the parents have been mentioned in table 2.3. The first column indicates the feeding problems, second column includes the percentage of the parents who reported the complaint in the initial examination and third column represents the percentage of parents who reported the problem on further probing by the examiner. They asserted that it is essential to assess the feeding problems and nutritional status at regular intervals of time.

Table 2.3

Feeding difficulties seen in children with cerebral palsy (Source: Gangil, Patwari, Aneja, Ahuja, & Anand, 2001).

Feeding Problems	**Presenting problems (%)**	**Observed/Reported by parents (%)**
Inability to self feed	16	90
Inadequate/absent tongue lateralization	—	84
Chewing problem	11	81
Swallowing problem	19	63
Cough/choking during feed	4	62
Drooling	20	52
Hypertonic tongue	10	43
Inability to take solid food	12	33
Restricted temporomandibular joint movement	10	29
Constipation	13	25
Recurrent chest infections	3	23
Sucking problem	14	23
Vomiting/regurgitation	4	23
No closure of lips around spoon	5	20
Inappropriate wide mouth opening	4	14
Cry/extensor dystonia during feeding	4	10

Sullivan, Lambert, Rose, Ford-Adams, Johnson, and Griffiths (2007) conducted a cross sectional study to estimate the prevalence and severity of feeding and nutritional problems in children with neurological impairment. They sent a validated questionnaire to 377 parents of children (aged 4 to 13 years) on the Oxford Register of Early Childhood Impairments with oro-

motor dysfunction. From those 377 questionnaire they got 72% of them back. Of those, 93% had cerebral palsy; 47% were unable to walk; 78% had speech difficulty; and 28% continuous drooling. Also, gastrointestinal problems were frequently seen, i.e., 59% had constipation, 22% had vomiting and 31% had suffered from chest infection however once in the last 6 months. Feeding problems were prevalent: 89% needed help with feeding and 56% choked with food; 20% of parents described feeding as stressful and not enjoyable. Prolonged feeding times (3h/day) was also reported. Furthermore, they found that 38% of the children were underweight but 64% of them never had their feeding and nutritional assessment. This suggests that feeding problem in children with neurological impairment is frequent and severe and parents should be concerned about it.

Consequences of feeding problems in children with cerebral palsy

The feeding difficulties can lead to health related problems such as growth failure and nutrition related problems. Hung, Hsu, Wu, and Leong (2003) investigated the nutritional status in children with spastic CP. They included 75 children with spastic CP who underwent anthropometric assessment (includes body weight, recumbent length and knee height), assessment of functional status, medical condition and feeding status. It was found that 41.3% of 75 children with spastic CP were undernourished and 3 of them were overnourished. They also noticed that there was no significant connection between undernutrition and seizure or pneumonia history. Food loss during eating, presence of more than one feeding problem and variety of food textures were significantly associated with undernourishment.

Sjakti, Syarif, Wahyuni, and Chair (2008) in their cross-sectional study assessed nutrition and feeding difficulties in 55 children with CP in the age range of 1-10 years. A single standard weighting scale with 0.1 kg accuracy was used for weighting the children. CDC-NCHS (Centers

for Disease Control and Prevention- National centre for Health and Statistics) 2000 growth curve was used to plot the ratio of actual body weight to ideal body weight for a given height. CP growth curve by Krick was used for spastic quadriplegic children. Nutritional status was decided by the ratio of body weight to body height using Waterlow classification (nutritional status less than 70% were considered as severe malnutrition, 70-90% undernourished, 90-110% well nourished, 110-120% overweight, more than 120% obesity) was used. Caloric intake was evaluated using dietary analysis. Feeding difficulties were found from the case history, physical examination and observation of feeding skills during assessment. Around 90% of the spastic quadriplegic and 65% of spastic diplegic had inadequate caloric intake. They found that malnutrition was seen in 76% of the children who had spastic quadriplegic CP and feeding difficulties were seen in 76%, where half of them were spastic quadriplegic CP and 38% were spastic diplegic. Also, 38% of the parents whose children had feeding difficulties were unaware of these difficulties. Hence, the prevalence of undernourishment and severe malnutrition in children with spastic CP was found to be 66% and 11% respectively.

Nature of feeding problems in children with cerebral palsy

Reily, Wisbeach, and Carr (2000) and Pohl and Cantrell (2006) reported that the feeding problems seen could either occur in the oral phase, pharyngeal phase or in the esophageal phase in children with CP. The common oral phase problems include discoordinated tongue movement patterns, poor chewing, poor /absent bolus formation, poor /absent manipulation of bolus, oral pocketing of food, slow oral transit time (slow transportation of bolus), premature spill into the pharynx, hypersensitivity in and around mouth and prolonged subsistence on pureed foods. The common pharyngeal phase problems include delayed/absent swallow reflex, slow pharyngeal transit time, residue in the pharynx after a swallow (incomplete clearance), pooling of food in the

valleculae or pyriform sinus, aspiration/penetration before, during or after swallow, nasal regurgitation, gagging, increased frequency of choking and coughing, respiratory distress during meals and poorly coordinated ventilatory cycle and swallowing. The common esophageal phase problems include vomiting, esophageal dysmotility, delayed gastric emptying, GERD, oesophagitis, aspiration of GERD (Reily, Wisbeach, & Carr, 2000; Pohl & Cantrell, 2006).

Several studies have been carried out to identify the nature of feeding problems in children with CP. In Avon a longitudinal study of Parents and children with CP by Motion, Northstone, Emond, Stucke, and Golding in 2002 was carried out. Children residing in Avon Health Authority area, born between 1st April 1991 and 31st December 1992 were enrolled for the study. When the children were 4 to 5 years of age, different tools and procedures were used to diagnose the children with CP. The 51 short listed children were reviewed in 1996, when they were approximately 4 years old and were examined by pediatrician. The functional motor impairment, oro-motor dysfunction and communication impairment were assessed using a standard recording of central Motor deficit form (Evans, Johnsons, Mutch, & Alberman, 1989). The established pattern of CP, the extent of oro-motor dysfunction and weight of each child was recorded at the age of 7 to 8 years using a questionnaire which was completed by the school doctor. They found that 33 children with CP at the age of 4 weeks had weak sucking and more feeding difficulties were seen at 6 months of age. Also, feeding difficulties at 4 weeks of age was associated with the pattern of functional impairment at 4 years of age.

Wilson and Hustad (2009) considered parents of 37 children with CP with the mean age range of 41 months and a questionnaire was administered on them regarding present and past feeding abilities of their child. Children with CP were divided into two groups i.e., children who had oro-motor involvement and who did not have oro-motor involvement. The parents of

children with CP who had oro-motor involvement reported that there was more difficulty in self-feeding, increased frequency of choking and coughing during feeding and later introduction of solid food in comparison to children with no oro-motor involvement.

Clancy and Hustad (2011) carried out a longitudinal study to track the changes in feeding between 4 years to 7 years of age children with CP. They included parents of 23 children with CP who were in the mean age of 4.53 years and had no hearing loss. The children with CP were divided into 3 groups i.e. (i) children with normal oro-motor skills, (ii) children with mild-moderate oro-motor difficulties and (iii) children with severe oro-motor difficulties by perceptual evaluation. Questions regarding feeding were asked to the parents using informal feeding and swallowing questionnaire. Results indicated that there was a significant difference across three groups for parameters such as usage of feeding tube, thickened liquids, use of special feeding techniques and feeding therapy. However there was no significant difference across parameters such as choking and coughing. They found that the children who had severe oro-motor involvement had marked and pervasive feeding difficulties which showed some fluctuations with time, but were generally stable. Those children who had mild to moderate oro-motor involvement showed little to no change over time and had fewer problems in comparison to the severe group.

A study done in Pakistani population, 122 parents of children with moderate-severe CP in the age range of 3-15 years were included in the study. Nutritional Perception Assessment and Parenting Stress Index- Short Form (Abidin, 1995) was administered on the parents which assessed the feelings of the parents regarding feeding their child, their nutritional knowledge and confidence and parenting stress respectively. Behavioral pediatric feeding assessment scale was also used to elicit information about the child's feeding behavior during mealtime and parent's

feelings at the same time. The questionnaires were administered in an interview. Parents reported that their children had difficulty in getting food off spoon with lips, were taking longer time to swallow the bites of food, liquid leaked out of corners of the mouth and had coughs when receiving liquids or pressed tongue forward while swallowing. The study suggested that 90% of parents were conscious about the feeding problem in their children with CP (Ghayas & Sulman, 2013).

In a survey study by Diwan and Diwan (2013), 33 children with confirmed diagnosis of CP (7 – 96 months) were assessed for oro-motor functions. An interview of parent was taken for detailed feeding history and feeding habits. Feeding skill assessment was based on Gisel and Patrick's feeding behavior skill score. A score of 4 or less was considered as normal, score of 5-8 as marginal problem and score of 9 and more as inadequate feeding skills. Also, oro-motor and feeding skills were observed during the feeding session. Feeding assessment was done mostly during the natural feeding time. The severity of CP was assessed using GMFCS. The results indicated that feeding issues were prevalent in children with cerebral palsy. They found maximum inadequate feeding skills present in spastic quadriplegic type of CP (75.0%). Problems found were related to sucking and swallowing, inability to self-feed (48.5%), prolonged feeding time (mean feeding time was 22.42 minutes) (95%), improper feeding positions, coughing and choking during feeding (6.1%), vomiting (3.0%), recurrent chest infections, oral motor dysfunction, drooling, cry / strong extensor thrust during feeding.

Several studies have also concluded that the greater the degree of motor impairment, the greater was the likelihood of having feeding difficulties (Thommessen, Heiberg, Kase, Larsen & Riis, 1991; Dahl, Thommessen, & Rasmussen 1996). Venkateswaran and Shevell (2008)

reported that children with microcephaly with more severe functional involvement and spastic quadriplegia required additional support for feeding.

Feeding assessment in children with cerebral palsy

Feeding assessment is very important as it is a multifaceted heterogeneous disorder where every individual will have different difficulties which vary with severity.

Assessing the nature and extent of feeing difficulties

There are different feeding assessment scales that have been developed which tries to describe the child's feeding issue. Developmental Pre-feeding checklist (Morris & Klein, 1987) is a tool that can be used for children of any age group but it mainly assesses the developmental skills emerging between birth to 24 months of age. It provides qualitative and quantitative description of feeding performance, brief history of the feeding problem and detects any abnormal oral pattern if present. It assesses feeding through bottle or breast, liquid by cup, semi-solid and solids.

Multidisciplinary Feeding Profile developed by Kenney, Casas, and McPherson in 1989 is meant for the patients who are dependent for feeding and it is found reliable in the children with neurologic deficits. It is a numerical rating scale developed to assess various components which includes physical/neurologic factors (posture, tone, reflexes, and motor control), oral-facial structure, oral-facial sensory inputs, oral-facial motor function, ventilation/phonation, and a functional feeding assessment. It assesses based on different kinds of feeding, i.e. spoon feeding, biting, chewing, cup drinking and straw drinking. This tool was found to be reliable based on the studies conducted by Judd, Kenny, Koheil, Miller, and Moran (1989).

Oral-motor Feeding Rating Scale (Jelm, 1990) is an assessment tool which provides a concise picture of feeding problem in children and adults (1 year to adulthood). It also provides guidelines regarding the management of it. It has six point rating scale from normal to abnormal which assesses feeding by breast, bottle, spoon, cup, biting, chewing, and straw drinking.

The Child Eating Behavior Inventory (CEBI) developed by Archer, Rosenbaum, and Streiner (1991) is to assess feeding problems and how the parent-child relationship is influenced. It is developed for children in the 2-12 years of age range and it is administered on the parents. It consists of 40 items and is rated on 5 point rating scale with responses: never, seldom, sometimes, often and always. A cutoff score of 16% is indicative of having an eating problem.

Exeter dysphagia assessment technique (EDAT) proposed by Selly, Flack, Ellis and Brooks (1990) and revised by Parrot, Selly, Flack, Ellis, Brooks, Lethbridge, Cole, and Tripp (1992) is a non-invasive way to measure swallowing function to distinguish dysphagia because of sensory nerve, motor nerve or functional involvement. It uses diverse specialized equipments to document oral, respiratory and swallowing features.

Clinical feeding evaluation of infants (Wolf & Glass, 1992) assesses feeding difficulties among infants fed by bottle or breast, also assesses difficulty which may be present while spoon feeding and cup drinking.

The Neonatal Oral Motor Assessment Scale (NOMAS) given by Palmer, Crawley, and Blanco (1993) is a checklist to evaluate the behaviors in categories of normal, disorganized and dysfunction of tongue and jaw movement in the age range of birth to 8 weeks. It was originally given by Braun and Palmer (1986) and revised by Case-Smith, Cooper, and Scala in 1989.

Behavioral pediatric feeding Assessment Scale developed by Crist, McDonnell, Beck, Gillespie, Barrett, and Matthews (1994) contains 25 items which assesses child's feeding behavior and 10 more items with which parent's feeling about dealing with feeding problems of the child can be assessed. Also, there is a 5 point rating scale where parents have to tell how much they agree or disagree with the statements provided. Therefore, higher the score more problematic feeding behavior is present. This tool is found to be valid and reliable for representing child's and parents mealtime behavior.

Schedule for Oral motor Assessment (SOMA) developed by Reilly, Skuse, Stevenson, and Mathisen (1995) is used to rate objectively oral-motor skills and recognize the areas of the dysfunction which might lead to feeding difficulties. It can be administered on children in the age range of 8-24 months. It covers 75-90 items which are scored pass or fail for each of the 6 food types administered. The items are divided into the categories of jaw, lip and tongue movements and reactivity, acceptance, initiation, food loss/ drooling, sequencing and swallowing. They assess based on the different kinds of food i.e., liquid (by breast/bottle and/ or spouted cup, regular cup and straw), spoon feeding of puree, semi-solid and solid, and finger feeding of biscuit and dried fruits.

Children's eating behavior Questionnaire developed by Wardle, Guthrie, Sanderson, and Rapoport (2001) is to assess a variety of aspect of the eating style based on eight dimensions i.e. responsiveness to food, enjoyment to food, satiety responsiveness, slowness in eating, fussiness, emotional overeating, emotional under eating, and desire for drinks.

Dysphagia Disorder Survey (DDS)- Pediatric developed by Sheppard (2002) is a screening instrument to assess feeding and swallowing function in children and adults with

developmental disabilities (3-78years). Calis, Veugelers, Sheppard, Tibboel, Evenhuis, and Penning (2008) used DDS on group of 166 children in the age range of 1-19 years with moderate to severe CP and intellectual disability to assess oral motor and swallowing function in them. They found 1% of the children had no dysphagia, 8% had mild, 76% had moderate to severe and 15% had profound dysphagia making a prevalence of dyphagia in 99% of the CP children.

Early feeding skills (EFS) given by Thoyre, Shaker, and Pridham (2004) is a checklist for assessing infant readiness for and tolerance of feeding and to profile the infants developmental stage according to feeding skills i.e. abilities to remain engaged in feeding, organized oral motor functioning, coordinate swallowing with breathing and maintain physiologic stability. There are many more feeding assessment tools which helps in assessing feeding difficulties in infants e.g. Infant Breastfeeding Assessment tool (IBFAT), the Mother Baby Assessment Tool (MBA), the LATCH assessment tool, Preterm Infant Breastfeeding Behavior Scale (PIBBS), Systematic Assessment of the Infant at Breast (SAIB) and many more.

As it is well studied that CP is frequently associated with feeding difficulties therefore it is very important to have assessment tools specific to feeding difficulties in children with cerebral palsy. In the Indian context, Rajshree and Manjula (1991) have developed an Assessment scale for the children with CP which assesses three skills i.e. speech, non-speech and feeding skills. The tool is compilation of two earlier studies conducted on normals by Kavitha (1989) and Jyothi (1990) on speech, non-speech and feeding skills respectively. It was administered on 32 children with CP (18 were spastic, 7 athetoids and 7 mixed) in the age range of 4-17 years. It was found that children with cerebral palsy performed poorer than the typically developing children. Also, the swallowing difficulties were found to be similar across the three groups i.e. spastic, athetoid and mixed.

In addition to this, there are several tools available to assess swallowing in adults such as Dysphagia goal handicap (Gustafsson & Tibbling, 1991); Burke Dysphagia screening Test (De Pppo, Holas, & Reding, 1994); MD Anderson Dysphagia Inventory (Chen, Frankowski, Bishop-Leone, Hebert, Leyk, Lewin, & Goepfert, 2001); Mann's assessment of swallowing ability (Mann, 2002); Swallowing ability and functional evaluation (Kipping & Ross Swain, 2003); SWAL-QOL-Patient self assessment scale (Mc Horney, Colleen, & Harris, 2006), SWAL-CARE-Patient self assessment scale (Mc Horney, Colleen, & Harris, 2006); Toronto bedside screening test (Matrino & Damant, 2007); Eating Assessment Tool-EAT-10 (Belafsky, Mouadeb, Rees, Pryor, Postma, Allen, & Leonard, 2008); and Dysphagia Handicap Index (Silbergleit, Schultz, Jacobson, Beardsley, & Johnson , 2012).

Assessing quality of life

The presence of the disorder itself can cause deterioration in the quality of life in some individuals. Quality of life (QOL) is defined as 'an overall assessment of well-being across various domains' (Bjornson & McLaughlin, 2001). It is a multidimensional construct including both health (i.e. physical, emotional, social) and non-health domains (i.e. finances, school, autonomy). Health-related quality of life (HRQOL) is a subdomain of the more global construct of QOL, including domains such as physical, mental and social well-being (Waters, Maher, Salmon, Reddihough, & Boyd, 2005). The measurement of HRQOL or quality of life can help identify individual priorities that are problematic, so that therapeutic objectives, programs and policies may be aligned with needs of patients and caregivers (Schneider, Gurucharri, Gutierrez, & Gaebler-Spira, 2001, von Steinbuechel, Richter, Morawetz, & Riemsma, 2005). This information might assist decision-making, and may be used in clinical practice to evaluate the patient's response to interventions that can guide on-going treatment or alteration in management

(Dijkers, 1999). Consideration of HRQOL is therefore crucial to designing and maintaining a system of patient-centered care (Berzon, 1998). Since the goal of most interventions for these children is to preserve or improve quality of life, these outcomes must be included in clinical trials of these interventions whenever possible.

However, it is challenging to measure HRQOL in children with severe developmental disabilities, especially the younger children. These children are often unable to communicate their perspective on quality of life. Under such circumstances, one is compelled to rely on the parents or caregivers to report their perception of their child's quality of life. Such reports will no longer truly be a measure of the child's HRQOL but a proxy that inevitably will be influenced by the parent's or caregiver's unique perceptions and attitudes, value judgments, as well as elements of their own quality of life. Nevertheless, such reports are the closest possible approximation of severely disabled children's HRQL and have generally proven to be reliable and valid (Sherifali & Pinelli, 2007; Varni, Limbers, & Burwinkle, 2007; Eiser & Jenney, 2007). This is consistent with real life practice, where health care providers ought to respond to the concerns of parents or caregivers and their perception of their children's needs to arrive at recommendations that address these priorities. Hence addressing these issues is valuable and beneficial to both the caregivers and their children.

Researchers have developed several health related quality of life questionnaires to assess the impact of CP. QOL instruments are used to evaluate the effectiveness of intervention for children with CP (Davis,Waters, Mackinnon, et al., 2006). All these questionnaires are disability specific, meant to assess the QOL in parents/caregivers of children with CP. Commonly used instruments include The Pediatric Outcomes Data Collection Instrument (Daltroy, Liang, Fossel, & Goldberg, 1998); The modified Caregiver Questionnaire (Schneider, Gurucharri, Gutierrez, &

Gaebler-Spira, 2001), which has only parent proxy version (for 5-18 years of age); The Lifestyle Assessment Questionnaire (Mackie, Jessen, & Jarvis, 2002), which has only parent proxy version for children; The Child Health Questionnaire (McCarthy, Silberstein, Atkins, Harryman, Sponseller, & Hadley-Miller, 2002), which consist of both parent proxy version (for 5-18 years of age) and child self reported version (for 10 and above); A European generic health related quality of life questionnaire-KIDSCREEN (Ravens-Sieberer, Gosch, Rajmil, et al., 2005), which has only child self reported version for the age range of 8-12 years; The Pediatric Quality of Life Inventory (Varni, Burwinkle, Berrin, et al., 2006), which has both parent proxy version and child self reported version (for 2-18 years of age); Child Health Index of Life with Disabilities-CPCHILD (Narayanan, Fehlings, Weir, Knight, Kiran, & Campbell, 2006), which is a parent reported questionnaire used for the children with CP in the age range 5-18 years; and The Cerebral Palsy Quality of Life Questionnaire for Children-CP QOL-Child (Davis,Waters, Mackinnon, et al., 2007), which consist of both parent proxy version (for 4-12 years of age) and child self reported version (for 9-12 years of age).

The caregiver Priorities and child health index of life with disabilities (CPCHILD) Questionnaire measures caregiver perspectives on the health status, comfort, well being, functional abilities and ease of care giving of children with severe developmental disabilities. The subsections include activities of daily living/ personal care (9 items), positioning, transferring & mobility (8 items), comfort & emotions (9 items), communication & social interaction (7 items), health (3 items) and overall quality of life (1 item). The scoring can be done on a 7 point rating scale where ‘0’ signifies ‘impossible’ and ‘6’ signifies ‘No problem at all’.

Davis et al. (2008) developed a CP Quality of Life –child which assesses aspects of life of parent and children from 4 years of age. It has two versions, viz., the parent proxy version which is for the children in the range of 4-12 years, consisting of 65 items and the child self-report version for the children in the age range of 9-12 years and it consisting of 53 items. It has subsections like participation and physical wellbeing, emotional wellbeing social esteem, access to services, pain and impact of disability and family health. But it moderately correlates with generic quality of life and health. For scoring, the test items are transformed to a scale with a possible range of 0-100 and the algebraic mean was calculated for each domain.

Further, there have been tools developed to study the quality of life in adults with dysphagia such as Dysphagia Goal Handicap (DGH, Gustaffson & Tibbling, 1991), Quality of life in Swallowing disorder-SWAL-QOL (McHorney etal., 2002), and the Dysphagia Handicap Index (Silbergleit, Jacobson, Beardsley, & Johnson, 2012). These are patient reported outcome tools which provide information regarding the patient's swallowing difficulty and the severity of it.

To sum, the review of the existing literature revealed that feeding, which is a crucial process required for growth and development of the child, is affected in children with CP. These deficits could arise because of the motor difficulties seen in these children following neurological impairment and vary according to the type and severity of CP. These feeding and or swallowing deficits could be in the oral, pharyngeal or esophageal region. This consequently leads to several other problems such as aspiration pneumonia, poor weight gain, malnutrition, etc in these children. It is possible that these feeding problems cause a negative impact on the life of children with CP.

Although several tools are available to assess the nature and extent of feeding problems and the impact of cerebral palsy on the quality of the life of the child, there are no questionnaires or assessment scales to assess specifically the impact of the feeding difficulties on the life of the child, especially in the Indian context. Further studies have been conducted to assess the impact of cerebral palsy itself on the life of the child and his/her parents/caregivers; however there are limited studies which investigate the impact of feeding problems on the child.

Thus a need was felt to develop a tool to assess the impact of feeding difficulties on the physical, functional and emotional aspects of the child. Keeping this in view, the present study was planned with the aim of developing a feeding handicap index that would measure the handicapping effect of feeding problems in children with CP.

CHAPTER-3

Method

The present study aimed at developing and standardizing a feeding handicap index that measures the handicapping effect of feeding problems in children with cerebral palsy in the age range of 2-10 years with regard to three domains viz. physical, functional and emotional. The study was undertaken in the following phases:

Phase I: Construction of the feeding handicap index

Phase II: Validation of the index by administering it on typically developing and children with cerebral palsy.

Phase III: Assessment of test-retest reliability.

Phase I: Construction of the feeding handicap index

As a part of construction, the following research steps were undertaken:

Step 1: Development of the feeding handicap index

This step involved the development of a preliminary version of the feeding handicap index which was in the form of a questionnaire to assess the perspectives of the parents/caregivers regarding the feeding difficulties faced by their children with cerebral palsy. This was prepared by collating information from the literature and from the complaints concerning feeding received from the clients registered in the Special clinic for motor speech disorders, Department of Clinical Services, All India Institute of Speech and Hearing, Mysore. The questions focused on the physical problems faced by the children during feeding and swallowing, i.e. problems related to oral, pharyngeal and esophageal phase of feeding and

swallowing. The questions also focused on the impact of these problems on the day to day functioning and emotional aspects of the child. The questions were grouped under three domains such as physical, functional and emotional. Below mentioned are a few sample questions that were included under these domains:

a) The physical discomfort faced by the child due to feeding problems, e.g., My child has difficulty in sucking from the feeding bottle ; My child is not able to eat independently with his fingers ; etc.,
b) The functional aspects i.e. the impact of the feeding problems on daily activities, e.g., I avoid giving solid food to my child because of feeding difficulty; I pour water/milk to ensure that the food is swallowed. etc. and
c) The emotional aspects which include the emotional problems of the child due to the feeding difficulties, e.g., My child feels embarrassed to eat food in social gathering ; My child feels upset that he can't eat food like the other children etc.

A rating scale to assess the feeding problems objectively was also prepared to rate the responses obtained from the parents in order to obtain an objective score. Each statement was accompanied with response choice of "never" (a score of zero), "sometimes" (a score of 1) or "always" (a score of 2). To rate the overall severity of the child's feeding and swallowing problem, a 7 point rating scale was also developed where '1' represented no difficulty at all; '4' represented somewhat problem is present; '7' represented the worse problem the child could have. This preliminary version of the tool developed had a total of 50 items with 18 in the physical domain, 20 in the functional domain and 12 in the emotional domain.

Step 2: Content validity check

The content validity of the questionnaire and the rating scale was assessed by obtaining the feedback from seven experienced speech-language pathologists, one nutritionist, one occupational therapist and one psychologist. The other team members were included since they too are involved in the rehabilitation of these children with feeding difficulties. They were asked to judge the appropriateness of the items included and the rating scale used. The feedback was collected using a 3 point rating scale ranging from the contents are not very valid (score 0) to all the contents are valid (score 2).

Initially, there were 50 items which were reduced to 38 after the content validation. The items in physical domain were increased from 18 to 21, in the functional domain it was reduced from 20 to 10 and in the emotional domain it was reduced from 12 to 5. The items which obtained higher scores by at least 60% of the professionals were retained in the questionnaire. The ambiguous items were deleted and if there were two items which implied the same meaning, e.g., My child feels upset that he can't eat food like the other children, my child does not enjoy eating), one of the items were retained and the other deleted. The content, sentence structure and the sequence of the items were modified as per suggestions given by the professionals.

Step 3: Pilot study

A pilot study was carried out in which this questionnaire was administered on ten parents/caregivers of children with cerebral palsy in the different age groups between 2-10 years with a history of feeding problems. Children with different types of cerebral palsy were included. The responses obtained were documented. In addition they were also questioned about any other additional difficulties they faced while feeding their children. At the completion of the test, the parents/caregivers were asked to rate the overall severity of their child's feeding and swallowing

problem on the 7 point rating scale. After the pilot study, it was found that there was a need for including examples under a few items in the questionnaire for better understanding of the questions by the parents/caregivers.

Step 4: Finalization of the feeding handicap index

The final version of the questionnaire was prepared after the content validation was carried out by the ten professionals for the preliminary version of the questionnaire. The final form of the tool had a total of 38 items with 21 in the physical domain, 10 in the functional domain and 5 in the emotional domain. These three domains were referred to as subscales. The final version of the feeding handicap index has been provided in the Appendix.

Phase II: Validation of the rating scale by administering it on typically developing children and children with cerebral palsy

The final version of the feeding handicap index was administered on the parents of 60 children with cerebral palsy and 60 typically developing children and in the age range of 2-10 years. The details of the participants have been provided below.

Participants

Sixty children with cerebral palsy (21 females and 39 males) in the age range of 2-10 years who reported to the Department of Clinical Services, All India Institute of Speech and Hearing, Mysore were considered for the study. They were diagnosed as 'Delayed speech and language with cerebral palsy' by a qualified team of professionals including speech-language pathologist, pediatrician, physiotherapist and a clinical psychologist. They constituted the clinical group. There were 20 children in the higher age group (6-10 years) and 40 in the lower age group (2-6 years). They were also grouped based on the type and topographical distribution

of cerebral palsy. There were 39 children with spastic type of cerebral palsy, 7 with dyskinetic type of CP (Athetosis, chorea, choreoatheoid, & dystonia) and rest 14 were other types of CP (Hypotonic, Ataxic & Mixed). There were 8 children with monoplegia, 2 with diplegia, 10 with paraplegia, 32 with quadriplegia, 6 with hemiplegia, 1 with triplegia and 1 with double hemiplegia. Some children with cerebral palsy also had associated problems such as seizure disorders (n=20), mental retardation (n=32) or hearing impairment (n=2). Their oro-motor abilities were assessed by administering the Checklist for Assessment of Oro-motor skills in Toddlers (Archana & Karanth, 2008). All the children included in the study were enrolled in an intervention program. All the participants belonged to the middle class socio-economic status which was ascertained using the NIMH socioeconomic status scale developed by Venkatesan (2009). The scale has sections such as occupation and education of the parents, annual family income, property, and per capita income to assess the socioeconomic status of the participants.

A group of sixty typically developing children (29 females and 31 males) matched for age and socioeconomic status were selected and they constituted the control group. There were 30 children in higher age group and 30 in the lower age group. The following criteria were adhered to while selecting the participants of the control group:

1. Participants should have had no history of neurological, oromotor, communicative, cognitive, or sensorimotor, and academic impairment. This was ensured using the 'WHO Ten-question disability screening checklist' (Singhi, Kumar, Malhi, & Kumar, 2007).
2. Participants should have had age adequate language abilities which were ascertained using Assessment Checklist for speech-language domain (Swapna, Jayaram, Prema, & Geetha 2010).

All ethical standards were met for participant selection and their participation. Prior to testing, a written consent was obtained from the parents of the participants after explaining the purpose of the study.

Procedure

The participants were selected based on the criteria mentioned above. The testing was carried out in a relatively noise free environment with minimum distractions. Each child was tested individually. A rapport was established with the mother/caregiver. The purpose of the administration was explained. The demographic data was obtained initially. The Com-DEALL oro-motor checklist was administered for the clinical group. The WHO Ten-question disability screening checklist and the Assessment Checklist for speech-language domain was administered on the typically developing children. The final version of the feeding handicap index was administered. The responses obtained from the parents/caregivers were documented based on the rating scale. They were also asked to rate the overall severity of the feeding problem based on the 7 point rating scale. In addition, the child was given different items to eat and drink (e.g., Biscuit, banana, water etc.) to permit a first hand observation of the feeding skills. The feeding problems faced by the child were noted. The time taken to administer the tool was approximately 45minutes. On the whole to administer all the necessary protocols, the time taken was approximately one and a half hours. Positive reinforcements like verbal and social reinforcements were provided to maintain the interest and motivation of the child throughout the test administration.

Phase III: Assessment of test-retest reliability

To assess the reliability of the final version of the questionnaire, this was administered again on ten of the participant sample selected randomly from the clinical group after 1 week of their initial responses. Cronbach's alpha test was administered to assess the test-retest reliability.

Analysis

The scores obtained from each participant in both the groups were totaled. A total score on the feeding handicap index and domain specific scores were obtained.

Statistical analysis

These scores were averaged across all the participants and fed to the computer for statistical analysis. SPSS version 20 software was used for the statistical analysis. Descriptive statistics was used to obtain mean, median and standard deviation of scores obtained on the feeding handicap index for both the groups. Chi square test was used measure to 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 was used to compare the control and the clinical group and to measure the influence of different independent variables. Spearman's correlation test was used to assess the correlation between scores obtained on the feeding handicap index and other independent variables. The results obtained have been presented and discussed in the next chapter.

CHAPTER-4

Results and Discussion

The present study aimed at developing a feeding handicap index for children with cerebral palsy and standardizing the same by establishing the content and clinical validity and test-retest reliability. The specific objectives of this study were to compare the performance of the children with cerebral palsy with that of the typically developing children on the feeding handicap index, to compare between the lower vs. higher age group of children, different types of cerebral palsy and different topographical distribution, to find whether a relationship existed between feeding problems and the oro-motor abilities, and to investigate the influence of mental retardation on feeding problems in children with cerebral palsy.

The feeding handicap index (FHI) was developed initially with a set of 50 items. The content validity was established following which the number of items reduced to 38. The final version of the feeding handicap index had a total of 38 items. The items focused on the physical, functional and emotional domains involved in feeding and were divided into three subscales. The three subscales were titled as Physical, Functional and Emotional and it had 21, 12 and 5 statements respectively. The possible range of total FHI score that can be obtained by a child varied from 0-76 and the possible range for the physical, functional and emotional subscales varied from 0-42, 0-24 and 0-10 respectively.

The clinical validity was assessed by administering the index on a total of 120 participants. Two groups of participants were considered. The clinical group consisted of 60 children with cerebral palsy and the control group consisted of 60 typically developing children in the age range of 2-10 years. The feeding handicap questionnaire was administered on these participants

and the responses obtained from the caregivers were scored on a 3 point rating scale where 'Never' signified no problem, 'Sometimes' signified problem is seen sometimes and 'Always' signified problem is seen always. The scores obtained from each participant were totaled to obtain the total FHI score and the scores were also obtained for the three different subscales. These scores were totaled for all the participants, tabulated and subjected to statistical analyses using SPSS software version 20. The following statistical procedures were carried out:

- Descriptive statistics to obtain mean, median and standard deviation for both the groups.
- Chi square test to measure the frequency and significance level of each item.
- Cronbach's alpha to determine the test-retest reliability.
- Kruskal-Wallis test and Mann Whitney U test was used to compare the control group and the clinical group and to measure the influence of different independent variables.
- Spearman' correlation test was used to assess the correlation between FHI and other independent variables.

The results obtained from all the above statistical measures have been presented and discussed under the following sections:

I. Clinical validity

- Comparison between the clinical and the control group
- Frequency of different responses on each item of the FHI in the clinical and the control group
- Relation between total FHI score, the scores on the three subscales and parent/caregiver reported severity of feeding problem in the clinical group

- Comparison between the lower (2-6 years) and the higher (6-10 years) age group of children in both the groups
- Relation between the total FHI score, the scores on the three subscales and the type of CP
- Relation between the total FHI score, the scores on the three subscales FHI and the topographical distribution of CP
- Relation between total FHI score and oro-motor abilities in the clinical group
- Relation between total FHI score, the scores on the three subscales and the degree of mental retardation

II. Test-retest reliability

Section I: Clinical validity

a) Comparison between the clinical and the control group

The clinical group (children with cerebral palsy) was compared with the control group (typically developing children) for the total FHI scores and FHI subscale (Physical, Functional & Emotional) scores obtained on the questionnaire. The mean and standard deviation obtained have been depicted in Table 4.1. On comparison, it was seen that the mean scores (Total FHI and FHI subscales) were higher for the clinical group than for the control group. To check whether a significant difference existed between the two groups, Mann-Whitney test was used. The results revealed that the clinical group had significantly higher scores than the control group. The /z/ values have been depicted in table 4.1. The mean of the total FHI scores and the scores obtained across the three subscales of the two groups has been depicted graphically in figure 4.1.

Table 4.1

Mean, standard deviation (SD) and /z/ values of both the groups for the total FHI scores and the scores across the three subscales

Subscales	**Clinical group**	**Control group**	**/z/ value**
Total	22.65±12.67	3.53±3.35	8.98*
Physical	15.91±8.79	1.68±2.20	8.79*
Functional	5.45±4.43	1.35±1.31	6.32*
Emotional	1.31±1.52	0.56±0.87	2.93*

Values are given as Mean±SD, * $p < 0.01$

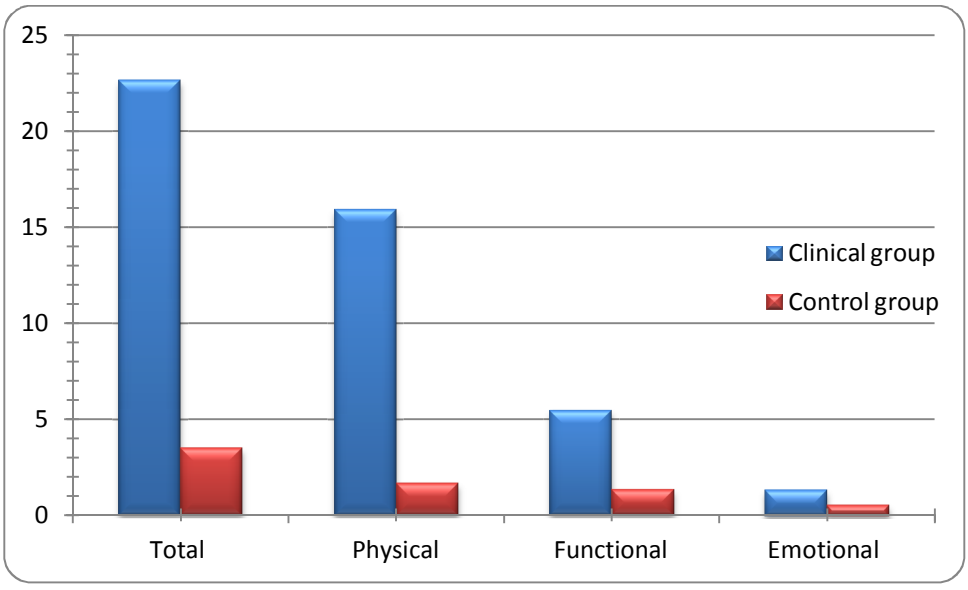

Figure 4.1. Mean FHI score and the scores across the three subscales of both the groups.

In the present study the mean of the total FHI scores and scores for each subscale was higher for the clinical group and there was a significant difference between the two groups. This results indicate that children with CP exhibited feeding problems. The feeding problems in children with CP could be attributed to inadequate sucking skills, inadequate biting and chewing, inadequate lip closure, restricted tongue movement, inadequate jaw movement and fine motor deficits (mainly in the upper limbs). Arvedson and Brodsky (2002) also reported that the feeding problems could be consequent to the abnormal oral muscle tone and strength and general body posture. Rogers et al., (1994) also attributed the feeding problems to restricted oro-motor abilities.

This result is in agreement with the studies done by Gisel and Patrick (1988); Reilly, Skuse, and Poblete (1996); Stallings et al., (1996); Trier and Thomas (1998) where they have found that feeding difficulties are seen in 40 to 90% of the children with cerebral palsy. Rajshree and Manjula (1991) have also found that children with CP performed poorer than typically developing children with regard to feeding skills. Gangil et al. (2001) have also found that feeding problems are frequently associated with children with CP and it is essential to assess the feeding problems and nutritional status at regular intervals of time. Sullivan et al. (2007) concluded from their study that feeding problem in children with neurological impairment is frequent and severe and parents should be concerned about it. Calis et al. (2008) found that 1% of the children had no dysphagia, 8% had mild, 76% had moderate to severe and 15% had profound dysphagia making a prevalence of dyphagia in 99% of the children with cerebral palsy. Similar results have also been obtained by Silbergleit, Jacobson, Beardsley, and Johnson (2012) who assessed the swallowing problem in adults using the Dysphagia handicap index. They found

that the dysphagia group had obtained significantly higher scores on all the subscales (Physical, Functional & Emotional) in comparison to the control group.

b) Frequency of different responses on each item of the FHI in the clinical and the control group

The responses obtained from the parents/caregivers under the three response categories viz. 'never', 'sometimes', and 'always' were totaled for different participants in both the groups for each item. The frequency of occurrence of the responses for each item for both the groups has been depicted in Table 4.2. To investigate whether significant differences, if any existed in the different aspects of feeding between both the groups for each item Chi-square test was used. The chi square values ranged between 0 to 82.94. The results of the test revealed that the items 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 16, 21, 23, 25, 26, 27, and 33 were highly significant at 0.001 level, the items 15, 22, 29, and 32 were significant at 0.01 level and the items 4, 28, 34, 36, and 38 were significant at 0.05 level. However, there was no significant difference in the items 17, 18, 19, 20, 24, 30, 31, 35 and 37 between both the groups. The table 4.2 depicts the chi square values obtained for each item.

Table 4.2

Frequency of responses for each item in both the groups and the results of chi square test.

Item no.	Clinical group (60)			Control group (60)			χ^2 (df=2)
	Never	Sometimes	Always	Never	Sometimes	Always	
1.	39	3	18	60	0	0	25.45***
2.	44	8	8	60	0	0	18.46***
3.	30	8	22	56	4	0	31.13***
4.	40	11	9	53	7	0	11.70*
5.	22	15	23	50	10	0	34.89***
6.	17	7	36	54	5	1	52.72***
7.	27	14	19	51	9	0	27.47***
8.	16	5	39	55	3	2	55.31***
9.	39	5	16	60	0	0	25.45***
10.	26	5	29	56	4	0	40.09***
11.	20	7	33	55	5	0	49.67***
12.	40	9	11	60	0	0	24.00***
13.	34	18	8	56	4	0	22.29***
14.	8	9	43	57	3	0	82.94***
15.	44	7	9	48	12	0	10.49**
16.	11	12	37	60	0	0	82.82***
17.	56	3	1	60	0	0	4.14
18.	48	10	2	51	9	0	2.14
19.	49	9	2	56	4	0	4.39
20.	37	21	2	45	15	0	3.78
21.	45	1	14	57	3	0	16.41***
22.	45	5	10	57	3	0	11.91**
23.	37	8	15	48	12	0	17.22***
24.	59	0	1	57	3	0	4.03
25.	40	5	15	60	0	0	24.00***
26.	33	12	15	45	15	0	17.18***
27.	30	9	21	41	19	0	26.28***
28.	45	9	6	55	5	0	8.14*
29.	49	4	7	60	0	0	12.11**
30.	60	0	0	60	0	0	-
31.	56	3	1	60	0	0	4.138
32.	25	11	24	41	11	8	11.88**
33.	47	3	10	60	0	0	14.58***
34.	40	14	6	45	15	0	6.33*
35.	56	2	2	60	0	0	4.14
36.	44	9	7	52	8	0	7.73*
37.	54	5	1	59	1	0	3.89
38.	48	6	6	58	2	0	8.94*

* $p < 0.05$, ** $p < 0.01$,*** $p < 0.001$

The parent/caregiver responses obtained from the clinical group also revealed that for item numbers 6, 8, 11, 14 and 16, 30-45 children with CP exhibited difficulties always and around 5-10 children with CP had these difficulty sometimes. These items mainly focused on the usage of spoon by the child, drinking using straw, usage of tongue to clear the food particles in the mouth and ability to rinse and spit. For item numbers, 1, 3, 5, 7, 9, 10, 21, 23, 25 and 32, around 15-25 children with CP had difficulties always and 2-10 children had them sometimes. These items were mainly about sucking, chewing, eating with fingers, drinking using glass/cup, inadequate weight gain, inadequate amount of eating, avoidance of solid food and longer feeding time. The item number 14 which dealt with the use of tongue to clear the food particles stuck in between the teeth or between the gums and the cheeks was found to be a critical question where more than 70% of the children with CP had difficulty. This indicated restricted tongue movement in most of the children. For the item number 30 which talks about pinching child's nose to make him/her swallow the food, 0% score was obtained indicating that none of the parent/caregiver used this strategy to feed the children. However few of the parents/caregivers of children with CP reported that they had previously used this strategy when their children were much younger to facilitate feeding.

Gangil, Patwari, Aneja, Ahuja and Anand (2001) also found that children with CP had feeding problems. The inability to self feed was found in 90% of the children with cerebral palsy, inadequate tongue lateralization in 84%, chewing problem in 81%, inability to take solid food in 33%, sucking problem in 23% and no closure of lips around spoon in 20%. Sjakti et al. (2008) found that 66% and 11% of children with cerebral palsy were undernourished and had severe malnutrition respectively. Sullivan et al. (2000) found that out of 377 children with neurological impairment 28% of them had reported with prolonged feeding time and 38% were underweight.

Diwan and Diwan (2013) found that in children with spastic quadriplegic type of CP (75.0%) had problems related to sucking and swallowing, inability to self-feed, prolonged feeding time, coughing and choking during feeding, vomiting, oral motor dysfunction and drooling.

For the item numbers 17, 18, 19, 24, 30, 31, 35, and 37, parents/caregivers of around 45-60 children with CP reported that their children never had these problems. These items mainly focused on the nasal regurgitation, vomiting, choking, usage of special utensils, and feelings of embarrassment or sadness due to the feeding problem. Sullivan et al. (2000) also found that 22% of children had vomiting problem, however they found that choking was seen in 56% of them. In addition they found that there was a significant correlation between the severity of the motor deficit and the stress perceived by the children during mealtime. In Gangil et al. (2001)'s study also, vomiting and nasal regurgitation was present in only 23% of the children with CP. However cough/choking during feeding was present in 62% of them. Wilson and Hustad (2009), Ghayas and Sulman (2013) and Diwan and Diwan (2013) also found that there was increased frequency of choking and coughing in children with cerebral palsy. The fact that cough was found frequently in most children with CP in the studies reported in the literature was not in agreement with the present study. The results of the present study revealed that vomiting and cough was present only in 3% of the children with CP. However, even in the present study during the course of data collection, it was seen that most parents/caregivers reported of coughing/choking when their children were younger than two years of age. Since in this study only the current feeding problems in children were focused, the answer to this question was in negative. However the fact that vomiting was found in a small percentage of children in most of the studies in literature are in consensus with the present study.

In the control group, the responses to almost all the items was 'never' which indicated that there was no major problems in feeding the children. However the responses to the item numbers 6, 8 and 32 were 'Always' for few of the parents/caregivers. The item number 6 and 8 dealt with the usage of spoon for eating and 1-2 parents/caregivers of the typically developing children had reported problems in these items. This was found only in the children in the lower age group (especially children at 2 years of age). 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. According to Arvedson & Brodsky (1993), self-feeding skills such as grasping the spoon, holding the cup with two hands, holding the bottle and taking 4-5 consecutive swallows start developing by the end of 1 year of age. However the spilling is greater during this period. However by the end of 2 years of age, skills for independent self feeding such as trying to eat with spoon without spilling, stabbing the food with fork etc. start refining and the spilling decreases. The results obtained for the control group in the present study are in agreement with study by Arvedson & Brodsky (1993).

c) Relation between total FHI score, the scores on the three subscales and parent/caregiver reported severity of feeding problem in the clinical group

The parent/caregivers of the children with CP also self rated the overall severity of the feeding problem at the end of the administration of the questionnaire. These severity ratings were divided into four groups i.e. 1= normal, 2 and 3= mild, 4 and 5= moderate and 6 and 7 = severe. Out of the 60 children with cerebral palsy, caregivers of 10 (16.6%) children reported of no feeding problem, 22 (36.6%) reported mild, 26 (43.3%) reported moderate and 2 (3.3%) reported of severe feeding problems. The total FHI score and score for each domain was calculated

separately for the four severity groups. Descriptive statistics was used to compute the mean and the standard deviation. FHI mean scores obtained was higher for the moderate group followed by severe, mild and normal groups. The score obtained for the severe group was lower than that of the moderate group probably because of the inadequate sample size comprising of only two children, which is not a good representation of the population. Table 4.3 depicts the mean, standard deviation and chi square values for the different severity groups for the total FHI score and the scores on the three subscales.

Table 4.3

Mean, standard deviation (SD) and chi-square values for the different severity groups for the total FHI score and the scores on the three subscales.

	Normal (n=10)	**Mild (n=22)**	**Moderate (n=26)**	**Severe (n=2)**	χ^2
Total FHI	12.1±7.4	17.3±7.0	30.1±13.2	23.0±8.4	23.1*
Physical	8.7±5.6	12.6±5.3	20.9±9.1	9.5±2.1	19.8*
Functional	2.1±2.3	3.9±3.0	7.6±4.8	3.0±1.4	19.3*
Emotional	1.3±1.3	0.8±0.9	1.5±1.8	3.0±1.4	3.8

Values are given as Mean±SD, *p < 0.001

The results of the Kruskal-Wallis test showed that the groups made based on parent/caregiver severity rating scale (Normal, mild, moderate, severe) differed significantly from the total FHI and FHI subscales (Physical and Functional). However, this significant

difference was not seen for Emotional subscale. This could be attributed to the fact that in the present study, a parent/caregiver reported severity rating was used; hence there was a possibility that they might not have been able to indicate the emotional aspects of their children appropriately in comparison to how a person can indicate the same on his/her own.

Spearman's correlation test showed there was a high correlation between FHI mean scores and caregiver severity rating scale (Spearman' correlation co-efficient=0.665). Silbergleit, Jacobson, Beardsley, and Johnson (2012) in their study on persons with adult dysphagia found moderate-high relationship between self-perceived dysphagia severity rating and Dysphagia handicap index scores and its subscales in adults.

d) Comparison between the lower (2-6 years) and the higher (6-10 years) age group of children in both the groups

The children in both the clinical and control group were divided into two age groups i.e., 2-6 years and 6-10 years to check if any differences in performance on the FHI existed since the participants were in the developmental period. The mean and standard deviation values for both the age groups for both the groups were computed using descriptive statistics and have been depicted in table 4.4. In the clinical group, higher mean scores were obtained by the lower age group for both the total FHI score and the subscale scores. Similar results were obtained for the control group too. Mann-Whitney test showed that there was a significant difference between the two age groups for the total FHI score and the scores on physical, functional and emotional subscales for the control group.

However, in the clinical group, the results of the Mann Whitney test showed that for the functional and emotional subscales there was no significant difference between two age groups,

although there was a significant difference with respect to the total FHI score and the score on the physical subscale. This could be attributed to the fact that all the children were enrolled into a training program and the significant difference in scores between the two age groups could be the result of the progress seen consequent to the training program. It also is due to the maturation that happens in children since they were in the developmental period. Although the mean scores obtained on the functional and the emotional scale reduced with increase in the age in the clinical group, this reduction was not significant. This indicated that the improvements seen in the physical abilities were not generalized completely to the other domains. These results point to the need for including the functional and the emotional aspects in the treatment protocol of these children. The /z/ values obtained for the two age groups in the clinical and the control groups have been shown in Table 4.4. The mean values of the lower and higher age group for both the groups have been depicted graphically in Figure 4.2.

Table 4.4

Mean, standard deviation (SD) and the /z/ values for the lower and higher age group for the clinical and the control group

Subscales	**Clinical group**			**Control group**		
	2-6 years	**6-10 years**	**/z/value**	**2-6 years**	**6-10 years**	**/z/ value**
Total	25.60±12.82	16.75±10.31	2.629*	4.63±3.35	2.43±3.13	3.044*
Physical	18.05±8.53	11.65±7.86	2.708*	2.23±2.62	1.13±2.62	2.152*
Functional	6.20±4.68	3.95±3.51	1.946	1.46±0.86	1.23±1.65	1.978*
Emotional	1.40±1.58	1.15±1.42	0.687	0.93±1.04	0.20±0.40	3.044*

Values are given as Mean±SD, * $p < 0.05$

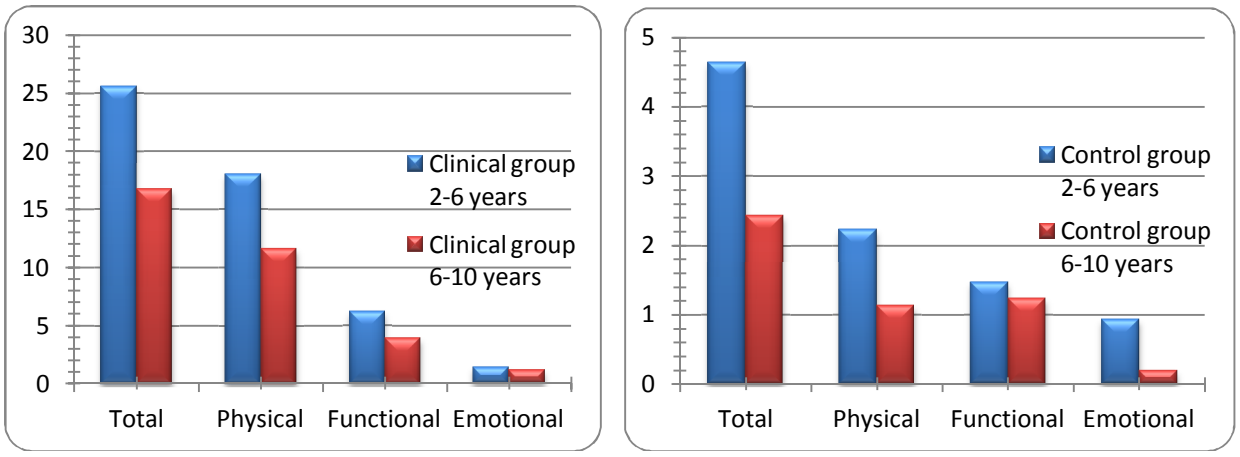

Figure 4.2. Age wise mean score comparison of the clinical and the Control group

As indicated earlier, there was a significant difference in the control group between the lower and the higher age group. This could be attributed to the following reasons. The maturation in mastication coordination in typically developing children is fully achieved by 6 years age (Vitti & Basamajian, 1975). Gisel and Patrick (1988) also reported that the time taken for chewing the solid food gets lesser as the child grows older. Further the refinement of independent self-feeding skills occurs only after 2 years of age (Pridham, 1990).

e) Relation between the total FHI score, the scores on the three subscales and the type of CP

The children with CP included in the clinical group had different types of CP and were grouped under three categories i.e. Spastic (39), Dyskinetic (n=7) [Athetosis, chorea, choreoatheoid, & dystonia] and others [Hypotonic (n=4), Ataxic (n=4) & Mixed (6)]. The mean scores obtained on the FHI, physical & emotional subscales were higher for the dyskinetic group compared to the other two categories. However, the score on the functional subscale was almost the same for spastic and dyskinetic but higher than the third group which comprised of children with other types of CP (Hypotonia, ataxia & mixed). The mean and standard deviation values

have been depicted in the Table 4.5. This indicates that greater number of feeding difficulties was associated with dyskinetic type of CP rather than spastic and other types. The mean scores of the different types of CP obtained on the FHI as a whole and on the three subscales have been depicted in Figure 3.

Table 4.5

Mean and standard deviation (SD) values for different types of CP on the total FHI and on the different subscales

Parameters	**Type of cerebral palsy**			
	Spastic (n=39)	**Dyskinetic (n=7)**	**Others (n=14)**	χ^2
Total FHI	24.3±13.28	28.8±13.2	14.9±6.31	7.504*
Physical	16.9±9.0	21.0±7.0	10.5±6.5	9.012*
Functional	6.1±4.7	6.0±4.9	3.3±2.2	3.670
Emotional	1.3±1.52	1.8±2.1	1.0±1.2	0.616

Values are given as Mean±SD, * $p < 0.05$

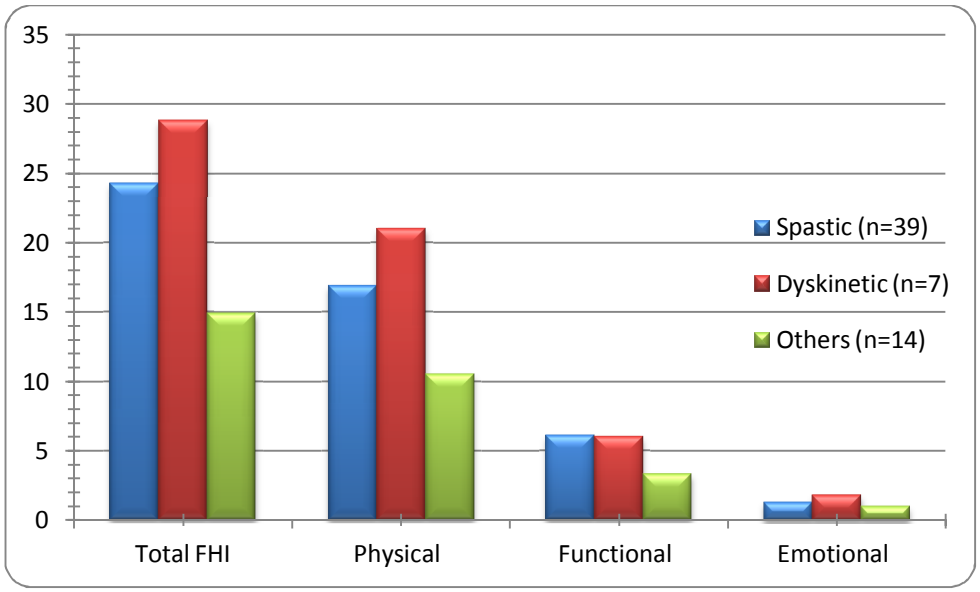

Figure 4.3. Mean score for different types of CP on the total FHI and on the different subscales

On administration of Kruskal wallis test on the three groups (Spastic, Dyskinetic & Others), a statistically significant difference was observed for the total FHI score and the physical subscale score. However, for functional (p=0.160) and emotional (p=0.735) subscales there was no significant difference between the groups. Mann whitney test was performed to see between which two groups the significant difference existed. The /z/ values have been depicted in Table 4.6. There was no significant difference between the spastic and the dyskinetic group for total FHI scores and the physical domain scores. However, a significant difference was observed between the spastic and other kinds of CP and dyskinetic vs. other kinds of CP. This result indicated that the both the spastics and dyskinetics exhibited greater problems related to feeding than the other types of CP. This could be attributed to the type of motor deficits seen in these varieties of children with cerebral palsy. Dyskinetics exhibit involuntary movements, in

addition to the abnormalities in the tone, whereas the spastics exhibit an abnormally high tone in the muscles.

Table 4.6

/z/ values across three categories of cerebral palsy

	Spastic vs. Dyskinetic		**Spastic vs. Other**		**Dyskinetic vs. Other**	
	Physical domain	**Total FHI**	**Physical domain**	**Total FHI**	**Physical domain**	**Total FHI**
/z/ value	1.44	0.93	2.40*	2.35*	2.54*	2.32*

* $p < 0.05$

The results of the present study are in consonance with the findings of Selly et al., (2001) and Arvedson and Brodsky (2002). Although Selly et al. (2001) reported that there was no significant relationship when looked at from a statistical point of view between feeding problems and the type of CP, they also reported that quadriplegic athetoid CP (dyskinetic type) had feeding problems to a greater extent. Arvedson and Brodsky (2002) reported that feeding problems in children with athetoid CP could be frequent because of the involuntary movements. The feeding problems in spastic cerebral palsy is generally linked to improper movements of tongue, such as forward sucking, or to difficulty in lifting the lip or using lateral movements. It could also be due to the stiffness of the muscles which could interfere with gathering the food and taking it to mouth in self feeding (Denhoff & Robinault, 1960).

The table 4.7 depicts the maximum and minimum values of mean at 95% confidence interval for FHI and the three FHI subscales across the different types of CP. These values can be used as a reference data to decide whether feeding problems exist across the different types of CP. Also, it contains the maximum and minimum score obtained on different subscales for different types of CP in the present study.

Table 4.7

Maximum and minimum mean values at 95% confidence interval for FHI and the three subscales across the different types of CP

	Type of CP	95% Confidence Interval for Mean		Minimum score obtained	Maximum score obtained
		Lower bound	Upper bound		
Total FHI	Spastic	20.0	28.6	5	55
	Dyskinetic	16.6	41.0	7	47
	Others	11.2	18.5	7	29
	Normal	2.6	4.4	0	5
Physical	Spastic	14.03	19.8	1	36
	Dyskinetic	14.4	27.5	7	27
	Others	6.7	14.2	1	25
	Normal	1.1	2.2	0	9
Functional	Spastic	4.5	7.6	0	19
	Dyskinetic	1.4	10.5	0	14
	Others	2.08	4.6	1	9
	Normal	1.01	1.6	0	5
Emotional	Spastic	0.81	1.8	0	5
	Dyskinetic	-0.09	3.8	0	6
	Others	0.37	1.7	0	4
	Normal	0.34	0.79	0	3

f) Relation between the total FHI score, the scores on the three subscales FHI and the topographical distribution of CP

The children with CP were divided into seven categories depending upon the topographical distribution i.e., according to the number and location of limbs which were involved. The categories included Monoplegia (n=9), Diplegia (n=2), Paraplegia (10), Quadriplegia (n=32), Hemiplegia (n=6), Triplegia (n=1) and Double hemiplegia (n=1). The mean score and standard deviation values obtained for the quadriplegic, hemiplegic, monoplegic, diplegic and paraplegic were 26.8±13.6, 19.5±14.0, 15.1±9.7, 1.5±2.1 and 1.1±1.2 respectively. There was only one child with triplegia and one with double hemiplegia and score obtained by them were 7 and 9 respectively. On comparison of the means, it was seen that the children with quadriplegia had the greatest problems related to feeding compared to the children who had other kinds of topographical distribution. This could be attributed to the fact that their upper limbs were involved along with their lower limbs and the upper limbs have a significant role in feeding. The children with paraplegia had the least problems related to feeding since only their lower limbs were involved.

This result is in consonance with the studies reported in the literature. Reilly et al., (1996) also found that individuals with spastic quadriplegia had the greatest motor difficulties and up to 85% of them had severe feeding difficulties. Sjakti et al. (2008) included 55 children with cerebral palsy in their study out of which 42 children (76%) had feeding problems. Among them 55% were spastic quadriplegic, 38% were spastic diplegic, 7% were spastic hemiplegic and 1 child was paraplegic hypotonic. Also, as reported in the study by Sullivan et al. (2000), children with quadriplegia and dyskinesia are likely to have swallowing and articulation problems. Venkateswaran and Shevell (2008) reported that children spastic quadriplegia required additional

support for feeding. Diwan and Diwan (2013) also have found that maximum feeding problems are seen in spastic quadriplegic type of CP followed by spastic diplegic. In the present study too, the results revealed that the quadriplegics obtained higher total FHI mean score than the other types.

g) Relation between total FHI score and oro-motor abilities in the clinical group

Com-DEALL Oro Motor Checklist (Archana, 2008) was administered to assess the oro-motor deficits present in the children with CP. The checklist consists of four domains i.e. Jaw movement, tongue movement, lip movement and speech and a total of 30 questions. Responses were rated on a three point rating scale where '0' signified absent, '1' signified only spontaneously present and '2' signified consistently present. A higher score on this checklist indicates better oro-motor skills. The scores for each child were obtained for each domain which was added up to obtain the total oro-motor scores. Oro-motor scores obtained for children with CP revealed that all the 60 children had oro-motor difficulties. The mean and standard deviation values were computed which has been depicted in Table 4.8. High mean values on the total Com DEALL oro-motor scores were obtained for the third group which comprised of children with hypotonia, ataxia & mixed CP, followed by spastic and then dyskinetic. Hence, least oro-motor difficulties were seen in the third group

Kruskal-Wallis Test indicated that there was no significant difference between the three groups on the total Com DEALL oro-motor scores. With regard to the individual jaw, lip, tongue movement and speech, a significant difference was found between the different types of CP (Spastic, Dyskinetic & Others) only on the jaw movement ($p=0.039$). Mann Whitney test indicated that there was a significant difference between spastic and others ($/z/= 2.38$, $/z/= 2.00$, $p=0.017$) and between dyskinetic and others ($p=0.045$) on the jaw movement. However there

was no significant difference between spastic and dyskinetic with regard to the jaw movement. This suggests that spastic and dyskinetic groups had the same amount of difficulty in jaw movement.

Spearman' correlation test was carried out to assess if there was a correlation between the total FHI score and the oro-motor score. The results indicated that there was a high correlation between FHI and Com-DEALL Oro Motor Checklist scores (Spearman's coefficient= -0.706). Higher scores on the Com-DEALL Oro Motor Checklist indicates better oro-motor skills while higher FHI score indicates poor feeding skills. Therefore, higher oro-motor scores obtained on the Com DEALL checklist and lower FHI scores indicates adequate feeding skills and vice versa.

Table 4.8

Mean, standard deviation (SD) and chi square values for FHI and Oro Motor Checklist for different types of CP

Parameters	**Type of cerebral palsy**			
	Spastic (n=39)	**Dyskinetic (n=7)**	**Others (n=14)**	χ^2
Total FHI	24.3±13.28	28.8±13.2	14.9±6.31	7.504*
Com-DEALL Scores	23.1±15.1	16.1±8.0	30.8±13.13	5.969
Jaw movement	6.3±3.0	6.2±2.3	8.4±1.6	6.488*
Tongue movement	7.2±6.7	4.1±2.5	10.4±6.9	4.081
Lip movement	7.8±5.1	4.5±1.9	9.2±4.7	3.722
Speech	1.7±2.9	1.1±3.0	2.6±4.2	2.162

Values are given as Mean±SD, *p< 0.05

The finding that all the 60 children included in the study had oro-motor deficits is in agreement with the studies reported in the literature. Reilly et al., (1996) observed that oro-motor dysfunction was seen in 90% of the individuals with cerebral palsy. Sjakti et al. (2008) in their study also observed that oro-motor dysfunction was the most frequent cause of feeding problems seen in their 56% of the patients. Oro-motor dysfunctions reported in the study are poor lip closure, perioral hyposensitivenss/ hypersensitiveness, tongue thrust, limited tongue movement, jaw instability and inadequate lip retraction. Clancy and Hustad (2011) also found that children

with CP with oro-motor involvement are more likely to have feeding difficulties. They found that children with mild-moderate oro-motor difficulties had issues like asymmetry of oro-facial structures during movement or at rest and drooling and children with severe oro-motor difficulties had issues like extremely limited volitional control of feeding musculature along with severe drooling. In present study too similar oro-motor difficulties were found in children with CP such as inadequate lip closure, restricted tongue movement and inadequate jaw movement.

h) Relation between total FHI score, the scores on the three subscales and the degree of mental retardation

Some of the children with CP had associated mental retardation. Based on the degree of retardation, the children with cerebral palsy were divided into 4 groups, where there were 28 (46.6%) children with CP with no intellectual retardation, 25 (41.6%) with mild retardation, 5 (8.3%) with moderate retardation and 2 (3.3%) with severe retardation. Table 4.9 depicts the mean and the standard deviation obtained for the FHI scores for each group. Mean scores for FHI were highest for the No retardation group followed by Severe, Mild and moderate groups. Kruskal Wallis test indicated that there was no significant difference across the groups (No retardation, Mild, moderate, severe retardation). This could be due of the fact that these children with CP without retardation were aware of their problems to a greater extent and could express them better compared to the other groups of children with retardation. There was also a possibility that in an individual with cerebral palsy there was no intellectual disability but the degree of severity of cerebral palsy could have been greater leading to greater motor, oro-motor and feeding deficits. Amongst the group of children with CP with retardation, the children with severe grade mental retardation exhibited the maximum feeding related problems. This could be due to the reduced sample size included in the group. Spearman's correlation test showed there

was no correlation between the degree of mental retardation and FHI total score (Spearman' correlation co efficient= -0.016).

Table 4.9

Mean FHI scores for the different groups divided based on the degree of mental retardation mental retardation

Mental retardation	**No (n=28)**	**Mild (n=25)**	**Moderate (n=5)**	**Severe (n=2)**
Total FHI	23.9±15.0	21.8±10.9	19.8±9.6	22.0±1.4

Values are given as Mean±SD

Section II: Test-retest reliability

The test-retest reliability was determined for 33% of the samples from both the groups using Cronbach's alpha. The alpha values for the total FHI scores and scores for FHI domains was found to be strong (Total FHI= 0.95, Physical= 0.95, Functional= 0.94, Emotional=0.94) which indicated significantly high test-retest reliability. Kappa Measures of coefficient for Parent reported severity was $p < 0.001$, $k=0.71$ which again indicated a good test-retest reliability.

In sum, the results of the present study indicated that the total FHI scores and scores for each subscale was higher for the clinical group in comparison to the control group and there was a significant difference between both the groups. This indicates a good clinical validity for the tool developed. The alpha values obtained were also high indicating a good reliability. There is a high correlation between total FHI scores and parent/caregiver reported severity rating scale.

Further, it was seen that for both the clinical and control group, higher mean scores were obtained for the lower age group than the higher age group for all the subscales. The total FHI scores varied significantly across the three types (Spastic, Dyskinetic & Others) of CP. The mean scores obtained for the total FHI, physical & emotional subscales were higher for the dyskinetic group compared to the other two categories. However, the score for the functional subscale was almost the same for spastic and dyskinetic but higher than the third group which comprised of children with other types of CP (Hypotonia & Ataxic). There was also a high correlation between FHI and Com-DEALL Oro Motor Checklist scores. Also, the FHI mean score obtained for quadriplegics were higher compared to the other categories (Monoplegic, Diplegic, Paraplegic, Hemiplegic, Triplegic, Double Hemiplegic). In addition it was also seen that there was no correlation between the total FHI score and the degree of mental retardation.

CHAPTER-5

Summary and Conclusions

Feeding problems are quite common in children with cerebral palsy and vary according to the type and severity of cerebral palsy. Several studies have been carried out to identify the nature and extent of feeding problems. It is possible that these problems in feeding faced by these children have a negative impact on the life of the child, which may in turn hinder the progress of the child during intervention. The feeding problems could affect the social and emotional life and he/she could perceive the feeding problems as a big handicap. Hence a need was felt to develop a questionnaire to assess the extent of impact of the feeding problem on a child with cerebral palsy in three domains, viz., physical, functional and emotional. Although there are assessment scales available to assess the nature and extent of feeding problems and the impact of cerebral palsy on the quality of the life of the child, there are no tools available to assess the extent of impact of the feeding problems on the life of children especially in the Indian context. Thus a need was felt to develop a feeding handicap index, that is easy to administer and less time consuming, to measure the impact of the feeding difficulties on the day to day activities and other socio-emotional aspects.

Therefore, the present study was undertaken with the aim of developing and standardizing a feeding handicap index that measures the handicapping effect of feeding problems in children with cerebral palsy in the age range of 2-10 years with regard to three domains viz. physical, functional and emotional. Initially, the preliminary version of a feeding handicap index was developed which was in the form of a questionnaire for the assessment of perspectives of the parents/caregivers regarding the feeding difficulties faced by their children

with cerebral palsy. This was prepared by collating information from the literature and from the complaints concerning feeding received from the clients. It had a 3 point rating scale to assess the feeding problems and to rate the responses obtained from the parents in order to obtain an objective score.

The content validity of the questionnaire and the rating scale was assessed by obtaining the feedback from seven experienced speech-language pathologists, one nutritionist, one occupational therapist and one psychologist. The feedback was collected using a 3 point rating scale ranging from the contents are not very valid (score 0) to all the contents are valid (score 2). Initially, there were 50 items which were reduced to 38 after the content validation. This was followed by a pilot study and it was found that there was a need for including examples in the few items for better understanding of the questions by the parents/caregivers. The final version of the questionnaire was prepared after the content validation.

The final form of the tool developed had a total of 38 items with 21 in the physical domain, 10 in the functional domain and 5 in the emotional domain. These domains were titled as subscales. The final version of the feeding handicap index was administered on the parents of 60 children with cerebral palsy and 60 typically developing children in the age range of 2-10 years. The children with cerebral palsy were grouped based on the type (Spastic, Dyskinetic and others) and topographical distribution (monoplegic, diplegic, paraplegic, quadriplegic, hemiplegic, triplegic and double hemiplegic). Their oro-motor abilities were assessed by administering the Checklist for Assessment of Oro-motor skills in Toddlers (Archana & Karanth, 2008).

The responses obtained from the parents/caregivers during the administration of the feeding handicap index (FHI) were documented based on the rating scale. They were also asked to rate the overall severity of the feeding problem based on the 7 point rating scale. In addition, the children were given different items to eat and drink (e.g., biscuit, banana, water etc.) to permit a firsthand observation of the feeding skills. The scores obtained from each participant were totaled to obtain the total FHI score and the scores were also obtained for the three different subscales. These scores were totaled for all the participants, tabulated and subjected to statistical analyses using SPSS software version 20.

The results of the present study indicated that the total FHI scores and scores for each subscale was higher for the clinical group in comparison to the control group and there was a significant difference between both the groups. This indicated a good clinical validity for the tool developed. The alpha values obtained were also high indicating a good reliability. There is a high correlation between total FHI scores and parent/caregiver reported severity rating scale. Therefore it can be concluded that the feeding handicap index is a valid and reliable tool for measuring handicapping effect of feeding problems in children with cerebral palsy. This tool is a parent proxy version since it assesses the parents' perspectives on the feeding problems and its impact on their child's life.

Further, it was seen that for both the clinical and control group, higher mean scores were obtained for the lower age group than the higher age group for all the subscales. The total FHI scores also varied significantly across the three types (Spastic, Dyskinetic & Others) of CP. The mean scores obtained for the total FHI, physical & emotional subscales were higher for the dyskinetic group compared to the other two categories. There was also a high correlation between FHI and Com-DEALL Oro Motor Checklist scores. Also, the FHI mean score obtained

for quadriplegics were higher compared to the other categories considered (Monoplegic, Diplegic, Paraplegic, Hemiplegic, Triplegic, Double Hemiplegic). In addition it was also seen that there was no correlation between the total FHI score and the degree of mental retardation.

Implications of the study

The Feeding handicap index that has been developed provides us with information on the parent perspective of the feeding problems present in a child with cerebral palsy. It helps in quantifying the feeding difficulties in children with cerebral palsy by providing a quantitative score called the feeding handicap index. This study also provided the feeding handicap index scores in the children with cerebral palsy and typically developing children. These indices can be used as reference data for comparison purposes. These quantitative scores obtained from the parents will strengthen the clinical findings made by speech-language pathologists and other relevant professionals regarding the feeding problems of the child. This will also help the speech-language pathologists in prioritizing the goals taken up during feeding therapy. The rating scale can also be used to monitor the progress achieved during feeding therapy by comparing the pre-therapy with the post-therapy scores.

Future directions

The test can be adapted to various Indian languages. The test can be administered on a larger population by controlling the severity of cerebral palsy. This feeding handicap index can be used to assess the feeding problems and its impact in children with other communication disorders such as cleft lip and palate, autism spectrum disorders, Down syndrome etc.

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Appendix

Demographic detail

Name:

Age:

Date of birth:

Language:

Type of Cerebral palsy: Spastic/ Dyskinetic/ Others (Please Specify)

Topographical distribution:

Monoplegia/ Diplegia/ Hemiplegia/ paraplegia / double hemiplegia/ tetraplegia/ quadriplegia/ pentaplegia

GMFCS:

ComDEALL Findings:

Duration of therapy:

Attending therapy: Physiotherapy/ Occupational therapy/ Speech and Language therapy

Educational background:

Socio-economic status: (NIMH Socio-economic status Scale)

Highest occupation	
Highest education	
Annual family income	
Property	
Per Capita Income	

Any other associated problems:

Medication:

Address & Phone No.:

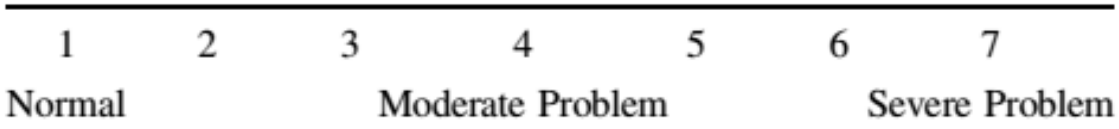
Feeding Handicap Index

Sl.No.	Domain	Statements	Never has this problem	Sometimes has this problem	Always has this problem	Remarks Please specify
1.	P	My child has difficulty in sucking from the feeding bottle	0	1	2	
2.	P	My child has difficulty in biting hard food (e.g., biscuit, wafer, cucumber etc.) and/or soft food (e.g. cake, bread, dairy milk, banana etc.)	0	1	2	
3.	P	My child has difficulty in chewing the hard food (e.g., chapatti, puri etc.) and/ or soft food (e.g., idli, banana, rice, sweets etc.)	0	1	2	
4.	P	My child has difficulty in swallowing solid/ semi-solid or mashed/ liquid food	0	1	2	
5.	P	My child is not able to eat independently with his fingers	0	1	2	
6.	P	My child is not able to scoop the food from the bowl/plate with a spoon	0	1	2	
7.	P	My child is not able to clear the food from the spoon when held near the lips	0	1	2	
8.	P	My child is not able to eat with a spoon independently	0	1	2	
9.	P	My child is not able to drink liquid from a glass/cup when held	0	1	2	
10.	P	My child is not able to drink independently	0	1	2	
11.	P	My child has a problem in drinking through a straw	0	1	2	
12.	P	My child drools while feeding	0	1	2	
13.	P	My child has difficulty in holding the solid/ liquid food in mouth (food/liquid leaks from the mouth) in upright position	0	1	2	

14.	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	
15.	P	My child keeps the food in the mouth without swallowing for a long time	0	1	2	
16.	P	My child cannot rinse the mouth and spit the water after eating	0	1	2	
17.	P	The food/liquid comes through the nose during swallowing	0	1	2	
18.	P	My child gags when solid/liquid food is given	0	1	2	
19.	P	My child vomits when solid/liquid food is given	0	1	2	
20.	P	My child chokes while feeding	0	1	2	
21.	P	My child is not able to gain weight and/or having nutritional deficiency due to feeding difficulty	0	1	2	
22.	F	My child requires smaller meals more often due to the feeding problem	0	1	2	
23.	F	My child eats less because of the feeding problem	0	1	2	
24.	F	My child needs special utensils and/or different way of feeding for drinking / eating (e.g., feeding tube, special feeding bottles etc.)	0	1	2	
25.	F	I avoid giving solid food to my child because of feeding difficulty.	0	1	2	
26.	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	
27.	F	My child strongly refuses certain food/liquid based on the taste or	0	1	2	

		temperature				
28.	F	I pour water/milk to ensure that the food is swallowed.	0	1	2	
29.	F	I push the food to back of the mouth of my child so that he/she can swallow it easily	0	1	2	
30.	F	I pinch my child's nose to make him swallow the food	0	1	2	
31.	F	I shake the child/close the lips/jaw for easy swallow	0	1	2	
32.	F	My child takes longer to be fed	0	1	2	
33.	F	My child need to be placed in a specific position during feeding (e.g. may be using special chair, bean bag etc.)	0	1	2	
34.	E	My child refuses to open his/her mouth while feeding	0	1	2	
35.	E	My child feels upset that he can't eat food like the other children	0	1	2	
36.	E	My child exhibit frustration or temper tantrums before/during feeding	0	1	2	
37.	E	My child feels embarrassed to eat food in social gathering	0	1	2	
38.	E	He doesn't like being dependent on the others for feeding	0	1	2	

P-Physical, F-Functional, E-Emotional



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