ASSESSMENT OF FEEDING AND SWALLOWING IN ADOLESCENTS WITH CEREBRAL PALSY

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Register No.: 15SLP005

A Dissertation Submitted in Part Fulfilment of Degree of Master of Science

(Speech-Language Pathology)

University of Mysore

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May, 2017

MYSURU

CERTIFICATE

This is to certify that this dissertation entitled ***"Assessment of Feeding and Swallowing in Adolescents with Cerebral Palsy"*** is a bonafide work submitted in part fulfilment for degree of Master of Science (Speech-Language Pathology) of the student Registration Number: 15SLP005. This has been carried out under the guidance of a faculty of this institute and has not been submitted earlier to any other University for the award of any other Diploma or Degree.

Mysuru
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CERTIFICATE

This is to certify that this dissertation entitled ***"Assessment of Feeding and Swallowing in Adolescents with Cerebral Palsy"*** has been prepared under my supervision and guidance. It is also been certified that this dissertation has not been submitted earlier to any other University for the award of any other Diploma or Degree.

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DECLARATION

This is to certify that this dissertation entitled ***"Assessment of Feeding and Swallowing in Adolescents with Cerebral Palsy"*** is the result of my own study under the guidance of Dr.Swapna.N, Reader of Speech Pathology, Department of Speech-Language Pathology, All India Institute of Speech and Hearing, Mysuru, and has not been submitted earlier to any other University for the award of any other Diploma or Degree.

Mysuru **Registration No. 15SLP005**

May, 2017

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ACKNOWLEDGEMENTS

Initially I would like to express my gratitude to ***Dr. S.R. Savithri ,*** Director AIISH for giving me an opportunity to carry out my dissertation.

Next I would like to extend my sincere gratitude to my beloved guide ***Dr.Swapna.N*** who was the pillar of the study. I whole heartedly thank you ma'am for your help, support, guidance, criticism, appreciation etc. You were always approachable. I had a great pleasure working under your guidance.

A special thanks to ***Mr. James.P*** (Director of Sneha Kirana Spastic Society of Mysore, Mysore), ***Ms. Sonia Jacob*** (Principal of Sneha Kirana Spastic Society of Mysore, Mysore), All the teachers of the Sneha Kirana Spastic Society of Mysore, Mysore), All the parents and participants from Sneha Kirana Spastic Society of Mysore, Mysore and other participants from AIISH, Mysore. Without your help I would not completed my data collection. I once again sincerely thank you all for your cooperation.

I thank all my family members especially my beloved ***Mom***, Sister ***Priya*** and Brother In-Law ***Sreenivas*** for all their encouragement, guidance, comfort and support. You all made me to complete this work. I thank you immensely.

I would like to thank ***Mr. Freddy Antony***, for helping and guiding me in all the ways possible.

I thank ***Dr.Vasanthalakshmi.M.S*** for guiding and helping in clearing all the statistical doubts. Thank you ma'am for your patience.

I thank ***all my classmates*** who helped me in any way for completing this work.

'Once again thank you all'

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CHAPTER I

INTRODUCTION

Cerebral Palsy (CP) is a disorder of motor impairment which can be expressed in terms of both global and physical symptoms (Krigger, 2006). It is an umbrella term which describes a non-progressive group of disorders which includes disorder of movement and posture, causing activity limitation due to disturbances of brain structures during foetal development or during prenatal, perinatal and postnatal periods up to two years of age (Pirila, van der Meere, Pentikainen, Ruusu-Niemi et al., 2007; Mus, 2010; Benfer, Weir, Bell, Ware, Davies, & Boyd, 2013). The site of lesion in the brain could be different leading to different types of CP which include Spasticity, Rigidity Atonic, Ataxia, Athetoid, Dystonia, Tremor, Ballismus, Chorea, and mixed forms (Shyamala, 1987; Morris, 2007). The motor manifestation and the overall severity of the condition can vary depending on the nature and extent of lesion in the brain.

The incidence of CP is estimated to be 2 to 2.5 in 1000 live births (Krigger, 2006; Pirila et al., 2007). Shahanawaz, Palekar, and Shah (2015) reported that in the Indian context, the incidence of CP is up to 2 to 2.5 cases per 1000 live births**,** making it the most common cause of disability according to Indian Academy of Cerebral Palsy (IACP).

CP is often accompanied by disturbances of sensation, cognition, communication, perception, behaviour and seizure disorder (Mus, 2010). Some of the associated problems include impaired oral motor functions, drooling, speech and language deficits, communication difficulties, feeding difficulties, hearing and vision abnormalities, mental retardation, osteopenia, osteoporosis, fractures, pain, and

gastrointestinal abnormalities (Krigger, 2006).

One of the problems commonly seen in children with CP is feeding and or swallowing difficulties, which could lead to aspiration during oral feeding, pulmonary consequences (infections, pneumonia etc), poor nutrition/hydration status and long and stressful meal times. Field, Garland and Williams (2003) reported that the feeding problems are the adverse effect of medical conditions, congenital problems and developmental issues and it is characterized by food refusal to consume all or most of the food presented to the individual, refusal to eat food textures that are developmentally appropriate (selectivity by texture), eating narrow range of food that was nutritionally inappropriate (selectivity by type), problems with chewing, tongue movement, lip closure or other oromotor areas (oral motor delays) and problems with swallowing (dysphagia).

CP is the common neurological impairment which leads to feeding difficulties right from birth (Cooper, Peter & Stein, 2013). In infants, feeding is mainly carried out through sucking and 57% of children with CP were reported to have sucking problems, 38% had swallowing problems () within 12 months of life and 80% of the infants were fed nonorally atleast once (Reilly, Skuse, & Poblete, 1996). A review study Aggarwal, Chadha, and Pathak (2015) revealed that the prevalence of feeding problems in individuals with CP can vary between 30% to 100%.

Children with CP may have difficulty in all phases of swallowing or any of the phases of swallowing such as oral, pharyngeal and esophageal (Arvedson, 2013) which is a major health problem. The common type of dysphagia in children with CP is oropharyngeal dysphagia (OPD) which is reported to be present in 90% of children and which is a major risk factor for survival in these children (Benfer, Weir, & Boyd,

2012; Benfer et al., 2013). Oropharyngeal dysphagia is also prevalent even in children with mild CP (Arvedson, 2013). The types of problems that are seen in children with CP in the oral and pharyngeal phase includes reduced lip closure, poor tongue function, tongue thrust, exaggerated bite reflex, tactile hypersensitivity, delayed swallow initiation, and reduced pharyngeal motility. Impaired oral sensorimotor function will lead to drooling that in turn results in impaired hydration (Arvedson, 2013). According to Calis, Veugelers, Sheppard, Tibboel, Evenhuis, and Penning (2008), the various causes for dysphagia can be oromotor dysfunction, abnormal neurological maturation, oral and sensory impairment, or esophageal motility disorders, and may worsen due to concurrent gastro-esophageal reflux disease (GERD).

The nature and severity of the swallowing problems vary widely with respect to the type of CP, gross and fine motor impairment, oromotor skills, severity of drooling, history of seizures, episodes of pneumonia, age, cognitive/ communication deficits of an individual etc. (e.g., intelligent quotient, severity of speech impairment) (Mus, 2010; Cohen & Manor, 2011; Benfer et al., 2012; Benfer et al., 2013). Children with generalized severe motor impairment (for e.g., spastic quadriplegia) are likely to experience greater swallowing deficits than those with diplegia (Mus, 2010; Benfer, Weir, & Boyd, 2012; Benfer et al., 2013).

Several studies have been carried out to examine feeding problems in children with CP. A longitudinal study by Clancy and Hustad (2012) examined differences in feeding among children with CP who varied in the severity of their oral motor involvement and severity of motor deficits. Twenty-three children with the age range of 4 and 7 years participated in the study. The data was collected from parent questionnaires at 6 month intervals over 30 months. Results indicated that children

with CP with severe oral-motor involvement had marked and pervasive feeding difficulties which showed some fluctuation with time, but generally were stable. Children with CP with no oral motor involvement and those who had mild-moderate involvement also exhibited little to no change over time and had fewer problems when compared to the severe group.

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 to elicit a detailed feeding history and assess the feeding habits. 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, and cry/strong extensor thrust during feeding.

Shabnam and Swapna (2016) investigated the feeding and oro-motor skills on 60 children with cerebral palsy (CP) in the age range of 2-10 years. To assess the feeding and oro-motor skills, the physical domain of Feeding Handicap Index (FHI) (Shabnam, 2014) and the Com-DEALL oro-motor assessment checklist (Archana & Karanth, 2008) was used. The results indicated that feeding and oro-motor problems were present in children with CP and they found strong correlation between physical domain of FHI and the oro-motor scores obtained on the Com-DEALL checklist. Further, the correlation was much stronger for the dyskinetic, rather than the other types of CP. It was also seen that the feeding issues were greatest in quadriplegics.

CP is a lifelong disability and hence when these children enter into the adolescent/adulthood period, the feeding/swallowing difficulties may persist. According to Donkervoort, Wiegerink, Van Meeteren, Stam, and Roebroeck (2009), adolescence is a developmental phase between childhood and adulthood. It is a period where in there are changes in several aspects such as biological, social, and emotional. In this period, adolescents consolidate their identity, they want to be independent from their parents, establish relationships with adults outside the family setup, and they find a vocation. But for young people with disabilities like CP, the transition period is reported to be very difficult as they encounter problems due to their impairments. The extra health maintenance skills that are required by them, lack of experience in activities and participation, isolation made by the society, or factors related to environmental, family, and personal factors could have a negative impact on them.

In adolescence, the time of transition is important, especially for individuals with CP, because many are thought to experience a decline in physical function during adolescence and early adulthood (Livingston, Rosenbaum, Russell, & Palisano, 2007). Some impairment may lead to secondary problems such as contractures, joint dislocation or chest infections. Adolescents with CP have a range of type and severity of impairments; in addition to problems with movement or posture, they usually have one or more additional impairments of vision, hearing, intellect, communication or behaviour. Growth and puberty will also interact with impairments; for example incontinence, previously tolerated, may adversely affect body image and emerging sexuality (Colver, & Dickinson, 2010).

Colver and Dickinson (2010) explained that the adjustments during the transition period are always challenging and often difficult, especially for disabled adolescents. Participation in any physical ability is influenced by age and gross motor

function in adolescents with CP. As age increases in adolescents with CP, they show a decrease in physical abilities. Moreover, adolescents with more severe motor problems are participating less in physical activity than adolescents with less severe motor problems (Claassen, Gorter, Stewart, Verschuren, Galuppi, &Shimmell, 2011). Parents and caregivers also have a difficult time as their role in the young person's life and their relationship with their children changes (Björquist, 2013).

Rapp and Torres (2000) described the changes that are present in different aspects in adolescence and adults with CP such as change in the neurological system, neuromuscular system, maturity in reproductive sexuality due to growth of the genital organs which reflect the hormonal changes, changes in the nutrition and diet, i.e., low caloric intake, especially in adolescents which result in poor growth and decreased muscle mass at maturity. Another very common major problem which is reported to be present during the adolescent period is anorexia which is a eating disorder which further leads to secondary complications such as cardiac disorders, affected growth, osteoporosis, structural and functional changes (Katzman, 2005; Cooper & Stein, 2006).

Eating and swallowing impairments may develop or worsen with age. The changes in eating and swallowing can happen rapidly, which indicates that adults, caregivers, and professionals should monitor and track for early symptoms of eating difficulties in prior (Haak, Lenski, Hidecker, Li, &Paneth, 2009).

Nystrand, Beckung, Dickinson, and Colver (2014) investigated the stability of impairments between childhood and adolescence period in CP population. The aim of the study was to investigate the factors that influence the participation and quality of life in children and adolescents with CP. 818 children in the age range of 8 to 12 years

were randomly selected for the study, among them, 594 subjects (73%) were followed up at the age of 13 to 17 years. The results revealed that there was stability between childhood and adolescence period for domains such as fine motor function, seizures, vision and feeding. As per the results obtained with detailed observation and parental report, among 594 participants, 429 participants had 'no feeding problem', 131 participants could 'feed orally with difficulty' and 34 participants could partially feed or had no oral feeding during childhood period. Similarly during adolescence period, 448 participants had 'no feeding problem', 99 were fed orally and 44 were partially fed or not fed orally.

Calis, Veugelers, Sheppard, Tibboel, Evenhuis, and Penning (2008) assessed the severity of dysphagia in 166 children with severe generalized CP and intellectual impairments in the age range of 2years 1month to 19years 1month. They exhibited varying levels of gross motor ability which was evaluated through the Gross Motor Function Classification System (GMFCS, Palisano, Rosenbaum, Walter, Russell, Wood, Galuppi, 1997). Along with feeding observation, parental reports on feeding problems were taken. This study reported the presence of prevalence of dysphagia in 99% of subjects (1% of subjects showed no significant dysphagia, 8% had mild dysphagia, 76% had moderate to severe degree of dysphagia, and 15% had profound dysphagia, receiving nil by mouth) which correlated with motor impairment. The parental report of their child enjoying mealtime and mealtime duration did not significantly correlate with the severity of dysphagia.

Studies have also focused on the quality of life and self-esteem abilities in adolescents with CP. A review study of quality of life in adolescents showed that they had poor quality of life when compared to typical individuals due to the gross motor impairment, physical limitation, health issues, parental stress, pain, contractures etc.

(Livingston, Rosenbaum, Russell, & Palisano, 2007; Colver, Rapp, Eisemann, Ehlinger, Thyen et al., 2015). Even though these studies have included feeding/swallowing among the factors in assessing the quality of life, a detailed description of the type of feeding problems and their impact on quality of life has not been explained.

Some studies have been carried out in the adult population with CP. Balandin and Morgan (1997) studied 279 adults with CP above 30 years of age and found that out of them, 10% of them (28) had swallowing difficulties. A study by Balandin, Hemsley, Hanley and Sheppard (2009) investigated the changes in the swallowing capabilities of adults with CP (30-69 years of age) as they aged. In-depth interviews about their experiences of changes in their swallowing and related management of their mealtimes were assessed. The changes found were increased coughing and choking, digestive or gastro-oesophageal symptoms, diet modification, loss of independence with psychosocial consequences. It was concluded adults with CP experienced gradual changes in their swallowing and mealtime capabilities from as early as 30 years of age.

Need for the study

A systematic review of the literature revealed some understanding of feeding issues related to children, adolescents and adults with CP. Most of the studies related to feeding and CP have been carried out in the population of children. A few studies have been done in the adult population with CP which indicates that they do have feeding and/or swallowing problems. Very few studies explain the feeding and or swallowing problems faced by the adolescent population. Some of the studies carried out in the west have included the children and adolescents with CP and considered them as a whole group during analysis. It is possible that through such analysis, the

feeding problems that could be specifically seen in the adolescent population be under identified. The few studies which have been done in the adolescent population, primarily concentrate on other aspects such as physical activity, pain, contractures and quality of life. However the domain of feeding and swallowing has been less well investigated even though feeding adequately is important for the survival and health of the person. Moreover the literature review suggests that many confounding factors could influence feeding abilities and the patterns can change from childhood to adolescence. Further, it is possible that feeding may not be affected in these individuals which need to be investigated.

There is a need to understand the feeding patterns in adolescents with CP, so that adequate guidelines/therapy can be provided to overcome the problems, if any, that the individuals are facing. These problems in feeding faced by the adolescents with CP, if left untreated, certainly could have a negative impact on their life, as well as on the life of his/her parents/caregivers. The assessment of feeding and or swallowing skills will provide valuable input to the speech-language clinician during the treatment of feeding problems in these individuals. The clinician will be aware of the extent of the feeding problems in greater detail. This would help the speech-language clinician in prioritizing the goals during therapy depending on which aspect needs immediate attention. The information will also help in counselling the caregivers with respect to the feeding issues. Keeping this in view, a need was felt to assess the feeding problems in adolescents with CP.

Aim of the study: The aim of this study was to investigate the feeding and swallowing problems, if any, in adolescents with CP in the age group of 13-17.11 years. The specific objectives of the study were

- To compare the feeding and/or swallowing abilities between the adolescents with CP whose parents/caregivers report/or are aware of the feeding problems (known feeding problem group) and those whose parents/caregivers report of no feeding problems (unknown feeding problem group).
- To assess the overall gross motor functional severity
- To assess the level of oromotorsensory functioning
- To investigate the oral functioning during feeding
- To investigate the feeding problems (physical domain) and their impact on functional and emotional domains and the parent rating of the overall severity of dysphagia.
- To assess the overall severity of dysphagia
- To investigate the nature of relationship between
    - Severity of dysphagia and overall gross motor functional severity
    - Severity of dysphagia and level of oromotorsensory functioning
    - Severity of dysphagia and oral functioning during feeding
    - Severity of dysphagia and physical, functional and emotional domains of feeding
    - Severity of dysphagia and parent rating of the overall severity of dysphagia

CHAPTER II

REVIEW OF LITERATURE

Breathing and eating are the two most important and basic biological functions which are very essential for survival of any living being. Breathing is reflexive but on the other hand eating is a complex process which is partly reflexive and partly controlled voluntarily by the person with the working of around 30 nerves and muscles (Matsuo & Palmer, 2008).Eating can be described as a series of coordinated activities such as eating food that has been presented to the person, then bringing the food towards the mouth and consuming the food in culturally appropriate and socially acceptable ways, cutting or breaking food into pieces with the mouth, opening bottles and cans, using eating various implements, having meals, feasting or dining (W.H.O., 2011). Normal swallowing requires precise integration of breathing, eating and speaking (Arvedson & Brodsky, 2002).

During the developmental period of a child, feeding and eating serve a range of functions such as biological, psychological and social functions. The biological function is in terms of providing the adequate nutrition, the psychological issues revolve around how the impaired feeding affects the health and mental status of the child and social issues address the social interactions with the family members and significant others during mealtimes (Cooper & Stein, 2006). In addition, feeding process provides large sensory and motor stimulation; it creates a bond between the mother and the child and helps in oro-motor development (Kummer, 2008). The oral cavity, pharynx and oesophagus are the major structures which play a role in feeding and swallowing.

Feeding abilities progresses as the infant grows. The development of feeding skill is an extremely complex process and it is influenced by anatomical/biological factors, neurophysiological factors, environmental factors, social and cultural factors. Most children complete the necessary developmental sequence required for normal feeding process within the first two years of their life (Arvedson, 1993). To develop normal feeding abilities, proper functioning of central nervous system, appropriate and adequate muscle tone, functionally appropriate oral and sensory motor systems and good health are prerequisites.

When the food is taken into the mouth, the consumed food is passed from the oral cavity to abdomen along with airway protection to avoid food from reaching the respiratory system of the person. As described before eating and drinking are complex sensorimotor activities that can be described in various stages/phases such as ***oral preparatory phase, oral phase, pharyngeal, and esophageal phases*** of swallowing**,** according to the location of the bolus (Dodds, Stewart, & Logemann, 1990; Logemann, 1998; Arvedson, 2008; Benfer, Weir, Bell, Ware, Davies, & Boyd, 2012; Benfer, 2015). The movement of the food from the oral cavity to the oropharynx differs depending on the type of food that is consumed in terms of whether the food is solid or liquid, the texture of the food, the temperature of the food etc. The various stages of swallowing have been described below (Dodds, Stewart, &Logemann, 1990; Logemann, 1998; Arvedson, 2008; Benfer, Weir, Bell, Ware, Davies, & Boyd, 2012; Benfer, 2015):

Oral preparatory phase

The oral preparatory phase is a voluntary stage which includes the mastication stage where in the hard food is converted into a soft bolus form by mixing the food with saliva. The formed bolus is then reorganized in terms of size,

shape, and position on the tongue which is then ready for swallowing. When the food or fluid is taken into the mouth, the oral-preparatory phase is initiated and involves several tasks which are necessary information for a good bolus formation such as sucking, biting, munching and chewing etc. The various types of food and various fluids are made to stay in the oral cavity and it is surrounded by the upper dental arch along with the complete seal of the lips since the lip closure prevents the spillage of bolus or liquid from the mouth. The posterior leakage of the fluid bolus is prevented with the help of contact that occurs between the soft palate and tongue, but this does not occur or the structures do not maintain the same during the processing of the solid bolus. It mainly involves five neuromotor behaviors:

- At first the lips close in order to keep the food in the anterior portion of the mouth.
- Followed by this, there is a tension created in the buccal and labial muscles to close of the lateral and anterior sulci further preventing any fall of food in the sulci.
- Jaw is moved in rotatory /circular motion to crush the food.
- A rolling lateral motion of the tongue occurs in order to pick up food from the teeth, then mix it with saliva and roll it back onto the teeth.
- The soft palate is pulled in forward direction to seal the food in the oral cavity posteriorly and it widens the nasal airway too.

At the end of this phase, the food is formed into a single mass of bolus by the tongue action. The tongue then shapes itself around the bolus. The tongue sides are elevated and a groove is formed to hold the bolus.

When defining the swallow stages for solid foods, Matsuo and Palmer (2008) advocate the use of the *Process Model of Feeding*. Here the authors describe that

there is an overlap between the different stages of swallowing. The Process Model divides the oral-preparatory phase into two stages such as *Transport* and *Food processing stage.* In *Transport Stage*, the food is ingested and it is moved onto the lateral occlusal surfaces of the teeth and in the *second stage,* the consistency required for swallowing is prepared. This stage is also referred to as oral propulsive phase i.e. the backward propulsion of the bolus.

Oral phase

This phase is also a voluntary phase. Oral phase begins when the tongue propels the bolus posteriorly in an upward and backward rolling motion. The oral (propulsive) phase involves pushing of the bolus backward by the tongue and posteriorly it has contact with the hard palate to initiate the pharyngeal stage of swallowing (Averdson & Brodsky, 2002; Matsuo & Palmer, 2008). Here, to prevent the nasopharyngeal reflux, the nasopharynx is sealed off at the time of swallowing. Depending on the individual's age, textures of the food, and the utensils, the duration and movements necessary for this phase differs. The tongue squeezes the food along the palate until the bolus reaches the anterior faucial pillars. At this point of time the swallow reflex gets triggered. The approximate duration of this phase is around 1second (Logemann, 1998).

Pharyngeal phase

The pharyngeal phase of the swallow explains the way in which the food or fluid boluses pass through the pharynx region. During initiation of the pharyngeal phase, the soft palate is elevated to close off the nasopharynx region in order to prevent the nasal regurgitation. The base of the tongue gets retracted and it propels the bolus posteriorly against the pharyngeal walls. Later the pharyngeal constrictor

muscles are contracted to squeeze the bolus in the downward direction. For airway protection during bolus passage the following actions occur.

- Respiration /breathing stops for moment (a period referred to as deglutition apnoea)
- Both the true and the false vocal folds close completely in order to prevent the food spillage of food into the trachea
- The arytenoids bend forward in order to meet the base of the epiglottis
- Under the base of the tongue, the larynx is elevated or lifted and the epiglottis inverts to seal the laryngeal vestibule.
- When the relaxation of the cricopharyngeous muscle occurs, the upper oesophageal sphincter is opened and the bolus descends down.

Esophageal phase

Once the bolus enters the cricopharyngeus muscle at the base of the pharynx, it is esopharyngeal stage. The esophageal phase is the final phase of the swallow, which begins as the bolus moves through the upper esophageal sphincter, to be transported via automatic peristaltic wave like motion to the stomach. The first wave starts from the upper esophageal sphincter to lower esophageal sphincter and the second wave starts at the mid portion of the esophagus and goes till the stomach level. When the bolus enters the esophagus, it is beyond the clinicians' control and no exercise program will be beneficial for esophageal swallowing disorders. Stevenson and Allaire (1991) explained the major elements of feeding process as follows:

- The complete process of normal feeding and swallowing should include appropriate structural integrity i.e. feeding function is mainly affected by the

anatomic/biological structures which are associated with growth of an individual.

- During the infancy stage, feeding process is reflexive and it is under the control of brainstem which does not require any input from suprabulbar structure. As feeding development progresses, the basic brainstem-mediated response comes under voluntary control.
- The infant swallow does not require a voluntary control of oral-preparatory and oral phase but in adults, the swallow is said to be mature which occurs with a voluntary control over oral-preparatory phase and oral phase, and involuntary control over pharyngeal and esophageal phases.
- The feeding and swallowing process involves neurophysiologic control which includes close integration of sensory and motor functions which are essential in the development of normal feeding skills i.e. it includes sensory afferent nerve fibers, motor efferent fibers, paired brainstem swallowing centers, and suprabulbar neural input.
- Even though the feeding development process requires an integration of various structures and neurologic maturation, it is also influenced by other factors such as the oral sensation, fine and gross motor development and the learnt experience while feeding.
- The basic physiologic complexity of feeding is compounded by individual temperament, interpersonal relationships, environmental influences, and culture.
- The main aim of the feeding is to acquire sufficient nutrients for age adequate growth and development.

- During swallowing, a reflexive airway protection occurs, the stages of airway protection include opposition of the epiglottis and aryepiglottic folds followed by the closure of both false and true vocal folds.

Development of feeding skills

Feeding skills in children has a series of important changes through their developmental phase i.e. from infancy to childhood years. In the initial stages during infancy period the feeding skill include the suckle ability, later the oropharyngeal skill improves and transitional feeding occurs between 4 and 36 months (Arvedson & Brodsky, 1993). The range of food textures which can be eaten by the children safely and efficiently undergoes changes and gradually gets expanded as the age progress. The table 2.1 below depicts the systems and domains involved in the development of feeding.

Table 2.1:

Systems and domains involved in the development of feeding. (Source: Arvedson & Brodsky, 1993; Stevenson & Allaire, 1991)

Systems	Required for
Oromotor function	Sucking, munching, chewing, and movement of the bolus; also needed for speech
Respiratory system	Maintaining normal oxygen exchange, coordinating suck and swallow, coughing to protect airways
Cardiovascular system	Maintaining normal blood pressure and oxygenation of the tissues

Pharyngeal coordination	Coordinating swallowing and breathing, safely transporting the bolus to the esophagus
Gastrointestinal system	Esophageal transporting of the bolus to the stomach and lowering esophageal sphincter to avoid reflux. Gastric emptying to the duodenum and transporting throughout the bowel
Gross motor domain	Maintaining head in midline and upright position, sitting stability on the chair
Fine motor domain	Finger feeding, using a spoon, holding a cup
Expressive language domain	Asking for more or saying no during feeding
Nonverbal Communication	Pointing for food, opening mouth to receive food, gesturing, playing
Receptive language domain	Comprehension of the meaning of words, "food, bottle", understanding of commands
Hypothalamus	Controlling hunger and satiety
Cognitive domain	Recognizing foods by color, appearance, taste and so on; learning the associations related to feeding; learning to self-serve food
Social domain	Giving positive feedback to the caregiver, eye contact
Caregiver (Socio economics)	Providing appropriate amount and type of food
Care giver (Emotional)	Funnelling positive emotional support of a child during the learning process, setting rules and limits

Suckling and sucking skills develop first. When an infant is in prone or supine position, physiological flexion is seen. Hence both suckling and sucking skills are addressed as flexor skills. Among suckling and sucking, suckling is the first pattern of development which occurs prior to sucking around 2nd and 3rd trimester of birth period. Suckling includes back and forth movements of the tongue. Later at around 6 months of age sucking pattern develops in infant. During sucking the body of the tongue lifts and lowers with the activity of all intrinsic muscles of the tongue and as a consequence the jaw also makes small vertical movements. The approximation of lips also occurs and finally the negative pressure is built up in the oral cavity. All these movements together help an infant to pull the liquid or solid inside the mouth (Arvedson & Brodsky, 1993). During breast feeding, the tip of the tongue is placed towards the back of the lip and above the lower gum and other remaining parts of the tongue surrounds the areola of breast to be pressed against the alveolar ridge of an infant. The tongue approximation towards the cheek keeps in the milk in the tongues' groove. The suck swallow pattern occurs at the time of breast feeding once per second till the infant is feeding.

Next is the ***transition phase feeding*** which occurs during 4 to 6 months of age wherein an infant is ready to consume varied type of texture of food along with some anatomical changes in the body and central nervous system control. In this phase there is a growth in the upper aerodigestive tract, there is an increase in intraoral space as the mandible grows downward and forward. Also the oral cavity elongates, larynx and hyoid bone moves downwards and the sucking pads (a lobulated mass of fat that occupies the space between the masseter muscle and the external surface of the buccinators muscle) are gradually observed. Eruption of teeth is the most noticeable change during this period. Mandibular teeth are erupted before the eruption of

maxillary teeth. Around 6 to 24 months of age, the deciduous teeth erupt and molars erupt around 16 to 20 months of age. During this stage the biting and chewing process is referred to ‘Munching’. Since the oral cavity size increases due to all the above changes, the tongue and the buccal wall play a major role in manipulating the food.

Carruth and Skinner (2002) explained that at around 18 to 24 months of age, children can typically chew and swallow firm chewable foods, and can eat food which consists of dual textures such as juicy fruits. Initially the pattern of chewing will be simple and later as the complexity of the chewing pattern improves they can chew food with hard textures, as in when the pattern of chewing improves from a rhythmic phasic bite reflex in infancy period to more graduating chewing patterns with vertical movements, and finally they will acquire multi-plane rotary chewing by around 24 to 36 months of age. The type of utensils children use during feeding also progress through these early years, and influence how independently, efficiently and safely children manage drinking and eating. Many children may continue to use cups with lids until 20 months, before regularly drinking from an open cup between 24 to 36 months. The following table 2 depicts how the food type/textures, adaptive /social skill, and positioning during feeding changes as the age progresses.

Table 2.2:

Normal feeding milestones from 0 weeks to 24 months (Source: Cooper & Stein, 2006)

Age	Food type/texture	Oral skills	Adaptive/social skills	Positioning
0 to 12 weeks	Breast or bottle Liquid feeding	*Reflexes:* Rooting, lip closure /opening, lateral movements of the tongue, biting, gag reflex, Babinski sign are present. *Functional:* Rhythmic sucking or suck swallow present, loses some liquid, rarely drools	Begins hand to mouth; increasing control of behavioural state & alertness, responsiveness, smile.	Supine with head slightly elevated or prone, or at an angle less than 45 degrees or side lying
12 to 20 weeks	May begin cereals or strained purees	*Reflexes*: as above *Functional:* Primitive suckle or swallow response present. Intermittent gagging or choking occurs. Pre chewing movements such as	Prolonged alertness and face to face play &intersubjectivity distinction; conditioned reactions	Semisolids fed in a supported position reclining at an angle of 45 to 90 degrees

		lateral movements, symmetrical bilateral depression of tongue are present		
20 to 28 weeks	Strained/ pureed foods mashed in cracker/rusks; teething biscuits introduced	*Reflexes:* As above. Generally are more subtle involving fewer movements. *Functional*: Chewing pattern with lip closure; starts swallowing higher textured foods, jaw more stabilised; moves lip in eating	Recognises spoon, opens and positions mouth for spoon insertion, transfers objects, drops objects; readiness to hold digestive biscuits etc.; Consolidation self/ other distinction	Approximately 90 degree sitting position, external support in high chair /baby chair
8 to 10 months	Junior foods: mashed, cooked and canned food. Introduction of liquid from cups	Closes mouth on cup rim, bites on objects; holds crackers between the gums & breaks off, still problem while drinking from cup, moves food with tongue (centre to	Finger feeds crackers/rusks; accepts one sip at a time from cup, holds a bottle, emerging specific emotions expressed.	Sitting infant /high chair , no additional side supports

		side movements – blows raspberries)		
10 to 12 months	Mashed to coarsely chopped table foods, finely chopped meats/ desired fruits.	Controlled sustained bite on biscuits, uses tongue (elevation while swallowing). No /little loss of food during swallowing, lateral movements of the tongue is present. Beginning of rotary chewing. Swallowing follows sucking with no pause. Some choking may occur	Finger feeds small pieces, begins to grasp spoon and stirs & lifts food with spoon, accept 4-5 continuous sips, picks up small objects, starts coordinated placing of objects on the table	Sitting in high or infant chair
12 to 18 months	Coarsely chopped foods, raw fruits & vegetables	Rotary chewing licks all of lower lip with tongue, little loss of food or saliva during chewing; decreasing drooling, spits food.	Grasps spoon; attempts to take to mouth; drinks from beaker independently and cup with assistance; decrease in	Infant /high chair; clip on chair on the table, seating on infant table in chair with side and back rest, feet

			mouthing objects. Starting to drink from straw	reaching the floor
18 to 24 months	Regular table foods; some chopped fine meats	Mature rotary chewing; controlled sustained biting (Grades jaw opening to bite food of different thickness)	Self-feeding; drinks from cup and places on table, weaning of bottle completely, unscrews lids, sustained attention is present.	Infant chair / own table /booster seat

The above milestones describe the feeding development in normal children, however the children with various disorders of central nervous system such as microcephaly, megalencephaly, hydrocephaly, anencephaly etc. fail to attain or complete the milestones of feeding due to their disability (Arvedson, 2002; Verity & Firth, 2003). Even a small injury to the developing brain can have a magnified negative effect on the rest of the sequence of the developing brain. About 25% of such children are reported to present with some form of feeding disorder, which increases to 80% in developmentally delayed children.

Feeding disorder is a broader term comprising of wide range of problems in eating activities. These difficulties may or may not be reflected or associated with impairment in swallowing food and liquid. Food refusal, inappropriate and disruptive mealtime behavior, food preferences are very rigid, poor growth than required, and failure to learn and master the feeding skills by self that are appropriate for

developmental levels are the characteristics of feeding disorders (Logemann, 1998; Averdson, 2008). Problems in the oral, pharyngeal and /or esophageal phase of swallowing can be described as dysphagia /swallowing disorder. It might result from anatomical and functional abnormalities in the oral cavity, pharynx, larynx and esophagus.

Among the central nervous system disorder/abnormalities, cerebral palsy takes the first place in the list of disorders which has a wide range of feeding and eating difficulties. Benfer (2015) describes that each of the levels of feeding development are greatly challenging for a child with cerebral palsy in terms of the complex textures of food, volumes of intake, use of different utensils, disturbance in mealtime, additional requirements during feeding and most importantly the child's oral sensorimotor skill or abilities, swallow-respiratory capacities and their cognitive abilities.

Cerebral palsy

Cerebral palsy (CP) is the most common physical disability of nervous system in early childhood. This condition was first described by Dr. William Little in 1861 and later the term was coined as 'cerebral palsy' by Phelps (Rosenbaum et al., 2007; Shimony, Lawrence, Neil, & Inder, 2008; Berker & Yalcin, 2010; Stamer, 2015). It is defined as an umbrella term which comprises of group of non-progressive (the primary lesion), but often changing, motor disabilities/syndromes which are consequences of lesions or anomalies of the brain structures arising in the early stages of its development. The presentation of this condition varies as the age of the child progresses (Sankar & Mundkur, 2005). CP is primarily a disorder of movement and posture (motor dysfunction), which includes disturbances in various domains such as sensation, perception, communication, cognition, behavioural issues, swallowing and

feeding difficulties which causes activity limitation of the individuals. CP presents with multiple handicaps such as difficulty in leading day to day activities, mobility, independent living etc. Since the severity of the condition varies across individuals, the abilities and participation level changes in everyday routine activities (Rosenbaum, Paneth, Goldstien et al., 2007).

Incidence, prevalence and etiology of CP

The worldwide prevalence of CP is approximately 2–2.5 per 1,000 live births (Sankar & Mundkur, 2005). World health organization (WHO) estimates that around 10% of the global population has some form of disability, among which India has around 3.8% of disability. In the Indian scenario, nearly 15-20 % of the total physically handicapped children suffer from CP and the estimated incidence of CP is found to be of 3/1000 live births (Vyas, Kori, Rajagopala, & Patel, 2013).Pohl and Cantrell (2006) reported the incidence as 4 per 1000 live births.

The direct causes of CP are often unidentified. However various risk factors have been identified that can lead to CP which could be categorized in different ways (Cruickshank, 1955; Minear, 1956; Denhoff & Robinault, 1960; Shyamala, 1987) based on the period during which the injury occurs. The risk factors in the prenatal period include heredity factors, infections (rubella, toxoplasmosis), anoxia, cerebral haemorrhage, metabolic disturbances (diabetes or hyperthyroidism, high blood pressure, high blood sugar levels), poor nutrition of the mother, mental retardation or seizures, trauma/fall of the mother causing brain injury, incompetent cervix (premature dilation) leading to premature delivery, bleeding in the third month of pregnancy, infection (TORCH), severe toxemia, exposure or consumption of toxic/poisonous substances such as using drug, alcohol or tobacco, trauma, multiple pregnancies and abortions, over aging of the parents, and placental insufficiency in

the womb. The risk factors in the perinatal period comprise of breech deliveries with delay, trauma, and haemorrhage, maternal anoxia, hypotension of mother, premature delivery (gestation of less than 37 weeks), low birth weight of <1.5 kg, difficult labour and increased time for delivery, vaginal bleeding at the time before the delivery, rupture of the amniotic membranes for more than 24 hours which leads to infection of the foetus (meningitis, encephalitis, brain abcess), umbilical cord around the neck of the foetus, vacuum delivery, Rh or A130 blood type incompatibility between mother and infant, delayed birth cry, asphyxia (reduced oxygen supply to the brain), severely depressed fetal heart rate during delivery indicating fetal distress, and a low score in the APGAR scale. The factors which leads to CP in the postnatal period include trauma, infections to the brain such as meningitis, encephalitis etc., seizures, hypoxia, hyperbilirubinemia, syphilis and other infections, trauma, interventricularhemorrhage (I. V. H.) leading to bleeding into the interior spaces of the brain or into the brain tissue, periventricular leukomalacia **(**damage to the brain tissue located around the ventricles.)

Further several investigators such as Erasmus, van Hulst, Rotteveel, Willemsen, and Jongerius (2012), Pirila et al., (2007); Mus (2010); Benfer, Weir, Bell, Ware, Davies, and Boyd, (2013) described that among various factors, up to 80% of cases with CP arise due to antenatal factors such as birth asphyxia which contributes to approximately 10% of them. Acquired cases in the postnatal period are usually related to central nervous system infection, trauma, stroke, severe hypoxic events, genetic disorders and acquired insults follow a pattern of selective vulnerability during early brain development of an infant.

Clinical manifestation of CP

The clinical manifestation of CP can be grouped under three heads as primary impairments, secondary impairments and tertiary impairments. Primary impairments include problem in the muscle tone, balancing ability, strength and selectivity of an individual which are manifested due the direct damage related to the central nervous system. Secondary impairments include muscle contractures and deformities which develop over a period of time as a consequence of primary problems and musculoskeletal growth. Tertiary impairments are adaptive mechanisms which an individual with CP develops to cope up with the primary and secondary impairments (Berker & Yalçın, 2010).

Primary impairments: The following signs and symptoms can be noticed as a part of their primary impairments:

- Delayed head control, rolling over, reaching with one hand, sitting without support, crawling, or walking milestones
- Persistence of "primitive" reflexes which are supposed to be disappearing at 3-6 months of age
- Development of handedness before 18 months of age which indicates weakness or abnormal muscle tone on one side; which is one of the early sign of CP.
- Abnormal tone in the muscles. The muscles may be very stiff in case of spastic or unusually relaxed and "floppy" in case of flaccid. Limbs may be held or positioned in unusual or awkward positions.
- Presence of abnormal involuntary movements such as jerky or abrupt, or slow and writhing movements which are uncontrollable or they are purposeless movements.

- Presence of weakness of muscle.
- Issues with balance and coordination.
- Delayed speech and language milestones and presence of unintelligible speech due to poor coordination between the different subsystems of speech such as respiratory, laryngeal, velopharyngeal and articulatory system.

Secondary impairments

These secondary impairments manifest in response to the primary impairments. Children with CP exhibit the following secondary impairments:

- Skeletal deformities: Individuals with CP have many problems with respect to the skeletal structure. They have shortened limbs on the affected side of the body. If they are not corrected through surgery or a device, it can lead to further damage to the pelvic bones and leads to contractures and scoliosis (curvature of the spine).
- Joint contractures: Since individuals with CP have unequal pressures on the joints exerted by muscles with tone or strength, they exhibit severe stiffening of the joints.

Tertiary impairments: These are the results of the coping strategies that children with CP use to adapt to the primary and secondary impairments which they already have. It includes problems such as deformities of the musculoskeletal system that tend to become fixed with time. For example, if a child has gastrocnemius spasticity as a primary impairment, the child develops ankle plantar flexion contracture as a secondary impairment and knee hyperextension in stance as a tertiary impairment.

Types of CP

The site of lesion in the brain could be different in children and consequently different types of CP can result which include Spasticity, Rigidity Atonic, Ataxia, Athetoid, Dystonia, Tremor, Ballismus, Chorea, and mixed forms(Shyamala, 1987; Morris, 2007). Though there are several types of CP, the most common are spastic, dyskinetic, ataxic and mixed variety, the description of which is provided below. The motor manifestation can vary depending on extent and site of lesion and can involve one or more limbs. Consequently based on the topographic distribution, CP can also be divided into Paraplegia, Diplegia, Quadriplegia, Hemiplegia, Triplegia, Monoplegia, Double hemiplegia (Cruickshank, 1955; Denhoff & Robinault, 1960; Sankar & Mundkur, 2005; Berker &Yalcin, 2010).

Spasticity: In this condition, there is an increase in stretch reflex (hyperactive stretch reflex which is particularly seen in the antigravity muscle) and increase in the tone of the muscle. Spasticity is defined as an increase in the physiological resistance of muscle to passive motion. It is a condition caused due to upper motor neuron syndrome and is characterized by various features such as hyperreflexia, clonus, extensor plantar responses and persistence of primitive reflexes and poorly coordinated movements. Spastic CP is the most common type of CP all over the world. Approximately 70% to 80% of children with CP are spastic. When a movement is initiated, resistance to movement by antagonists which are normally inhibited, increases enormously in spastic cases and involuntary muscular spasms are created due to which the limbs become stiff, rigid, and resistant to flexing or relaxing. In supine position they exhibit strong extensor spasticity and in prone position they show flexor spasticity (Bobath & Bobath, 1954). Depending upon the severity of spasticity, the motoric symptoms exhibited by these children vary. A severe spastic

child will have dysrhythmic, jerky, scissored gait, but in mild cases, the symptoms such as strabismus, drooling, hyperactivity and distractibility only can be seen.

Dyskinetic: Reflexive tone may vary; it can be either hypo/hypertonic with involuntary muscle resistance which is not velocity dependent. With voluntary efforts, there is an increase in the involuntary, recurring and uncontrolled movements. Dyskinetic CP includes *Dystonia, Athetosis and Chorea.*

Dystonia: The suspected lesion for this type of CP is in the extrapyramidal system. Dytsonia considered as an extreme form of athetosis. The child will have involuntary movements which are characterized in the regions such as 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.

Athetosis: Here the individuals exhibit involuntary and purposeless movements which are characterized by varying degrees of tension. It is chiefly characterized 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**.** Reflexes in this type of CP are exaggerated and primitive. Voluntary movements can occur but with initial delay before the movement. The involuntary movements can be of two types: tremor or rotary and it can occur with or without the tension Tone may either hypo or hypertonic. Involuntary movements disappear during sleep. In some children due to the inability to bear their weight, dance like movements are also seen (athetoid dance). Paralysis of gaze movements may occur and restrict the movements of eyes upward and sometimes their ability to close eyes is impaired. The dyskinetic characteristics change over a period of time. A child with athetoid CP exhibits

problem while tying the shoes, buttoning the shirt, cutting with scissors, and doing other fine motor tasks.

Chorea: The lesion for this type of CP is in the extrapyramidal system. The involuntary movements seen can be described as quasi purposive movements 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, and the head may turn in the same direction. The tone can fluctuate between hyper and hypotone.

Ataxia: In ataxic type of CP, there is fixation of the head, trunk, shoulder and pelvic girdles. The prominent features include lack of equilibrium and incoordination in voluntary muscle activity, shakiness, poor balance and an unsteady broad based gait. Though the muscles are normal, sometimes they may have muscular weakness (Hypotonia is usual). Voluntary movements are present but they are clumsy and uncoordinated. The child overreaches or underreaches the object (dysmetria).Reaching for objects can initiate an "intention tremor" in these children. The tremor may worsen as the child tries to get closer to the object. In these children the suspected lesion is in the cerebellum and/or to the pathways which conjoin it with cerebral cortex and brainstem. 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. Tremors also occur when the child attempts actions requiring specific muscle control, such as writing.

Mixed: Some individuals with CP exhibit combinations of neuromuscular characteristics. The overall appearance of the person can be determined by the type of neuromuscular characteristics that 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. This type of CP is the consequence of injury to both the extrapyramidal and pyramidal areas of the brain.

The condition of CP can be also classified according to the distribution of the disorder in the body i.e. topographical classification as follows:

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. In this condition, the arms are involved to a greater extent compared to the legs. It is usually seen in spastic type of CP and occasionally in athetoid CP. A delay in walking or an early hand preference may be the first noticeable sign of mild hemiplegia. Twenty percent of children with spastic CP have hemiplegia. A focal traumatic, vascular, or infectious lesion is the cause in many cases (Berker & Yalcin, 2010).

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

Quadriplegia (Tetraplegia): Thirty percent of children with spastic CP have quadriplegia (Berker & Yalcin, 2010). 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.

Diplegia: 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. Fifty per cent of children with spastic CP have diplegia (Berker &Yalcin, 2010). Motor involvement in diplegia is often about the same on both sides of the body. Strabismus (crossed eyes) is commonly seen in this type. Also sensory, perceptual, and learning problems are observed. 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).

Triplegia: Three extremities are affected in this type of CP. More often both legs and one arm are involved. It is usually seen in spastic CP.

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

Double Hemiplegia: Here the arms are more involved than the legs. Most of the time, this condition occurs with spasticity. Quadriplegics whose one side is more involved than the other side can also be described as double hemiplegics rather than quadriplegics.

Associated conditions/problems in children with CP

There can be are various associated impairments along with the primary impairments in individuals with CP. Odding, Roebroeck, and Stam (2006) reported that that 25-80% of the children with CP have additional impairments. The manifestation of these impairments depends on the severity of the condition. The associated problems which can be noticed in CP are as follows:

- ***Mental retardation***: Cognitive impairment is present in two thirds of persons with cerebral palsy. Neurosis and psychosis can also co-occur (Krigger, 2006; Odding et al., 2006). It is more common in spastic type when compared to other types of CP. Among the spastic type of CP, those with spastic quadriplegia tend to have mental retardation more often than spastic diplegics or hemiplegics (Sharma, Sharma, & Kabra, 1999).
- ***Seizures:*** One half of children with CP demonstrate seizure activity (Krigger, 2006). Odding et al., 2006 report that around 20-40% of the population with CP exhibit seizures and it is most common among the hemi and tetraplegics). 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. A study by Ashwal, Russman, and Blasco (2004) revealed that epilepsy was seen in almost 28-35% of hemiplegics, 19-36% of tetraplegics, 14% of diplegics, 13-16% of ataxics and 8-13% of dyskinetics.
- ***Vision problems:*** Schenk-Rootlieb, Nieuwenhuizen, and van der Graaf (1992) reported that around 70% of the children with CP have low visual acuity. Commonly reported problem is strabismus and hemianopia in spastic CP (Krigger, 2006). The other problems include nystagmus, refractive error,

amblyopia, optic atrophy, cortical visual impairments, blur red vision, hemianopia etc. Visual defects occur in 25 to 39% of adults with CP (Krigger, 2006).

- ***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) reported that in most of the hemiplegics there are bilateral sensory deficits such as stereognosis, proprioception, and impaired sensation for pain, touch and temperature.

- ***Dental problems***: Children with CP 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***: It is caused due to delayed gastric emptying, abnormal autonomic control of gastrointestinal mobility, immobilization, inadequate oral intake, and prolonged colonic transit which finally leads to vomiting, constipation, or bowel obstruction (krigger, 2006).

- ***Bowel and/or bladder control problems:*** These are caused by impaired control of bladder muscles (krigger, 2006). The common problems include bed-wetting, uncontrolled urination during physical activities, or slow leaking of urine throughout the day.

- ***Sleep impairment:*** Newman, O'Regan and Hensey (2006) reported that individuals with CP have difficulty in initiating and maintaining sleep, sleep wake-transition and sleep related breathing disorders. They found that the active epilepsy was associated with the presence of a sleep disorder. Disorders

of initiation and maintenance of sleep were more frequent in children with spastic quadriplegia than those with dyskinetic CP.

- ***Behaviour problems***: Problems such as increased irritability or hyperactivity could be seen in some children (Shyamala, 1987). 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.

- ***Emotional disturbances:*** There can be withdrawal and insecurity feeling in these children. Frustration is one of the most common problems which can be noticed. Emotional problems can also be due to the inability to communicate.

Feeding and swallowing problems in children with CP

In addition to the above mentioned associated problems, ***feeding and swallowing problems*** are also present in children with CP which can be noticed right after their birth. Swallowing is a very complex function that requires precise interaction of many groups of muscles. Individuals with CP who are unable to control these muscles will have problems in different eating processes such as sucking, biting, chewing, and drinking. They also have food/fluid loss during feeding, drooling and sequencing and rhythmicity difficulties (Aggarwal, Chadha, & Pathak, 2015). They are at risk for aspiration which can cause dangerous consequences such as pneumonia and even death.

Feeding difficulties leads to failure in the growth and deficits in the nutrition. Hence it plays a major role as a prognostic indicator for survival of an individual (Adams, 2009). Children with CP manifest difficulties with ingesting food as well as an inability to consume enough calories to meet the demands of growth. Severe feeding problems are already apparent in infancy period as reported by Reilly, Skuse, and Poblete (1996).

Prevalence of feeding problems in children with CP

Calis, Veugelers, Sheppard, Tibboel, Evenhuis, and Penning (2008) reported prevalence of dysphagia in around 99%of individuals with CP. Sjakti, Syarif, and Wahyuni (2008)reported that the prevalence of feeding difficulties in CP varies between 30 to 60%.Dahlseng, Finbråten, Júlíusson, Skranes, Andersen, and Vik (2012) estimated the prevalence of feeding and nutritional problems in children with CP in Norway. The children who were born between 1996 to 2003 (mean age 6 years 7 months) were included in the study. The measures of both weight and height were available for all children and the body mass index (BMI) (kg ⁄m2) was calculated in order to assess the nutritional status of children. Among the total individuals, around 132 children (21%) were completely dependent on assistance from others during feeding. The prevalence of gastrostomy tube feeding was 14%. Higher weight and BMI was significantly associated with longer duration of gastrostomy tube feeding but not with height. They found that only 63% of the children were having normal BMI. Thus they concluded that the feeding problems found in children with CP have an association with poor linear growth. Benfer et al., (2013) described that the most noticed type of dysphagia in CP was oropharyngeal dysphagia (OPD) which was estimated to be present around 19 to 99 % of the cases.

A review study was conducted by Aggarwal, Chadha, and Pathak (2015). The aim of this study was to review the studies conducted among children with CP to understand the feeding impairments and the consequence of the same. The prevalence of feeding problems in CP population as reported by different researchers cited in this study has been provided in the table 2.3 below.

Table 2.3:

Prevalence of feeding problems

S.No.	Study	Locale	Sample size	Description of sample	Prevalence of feeding problems
1.	Dahl et al. (1996)	Sweden, Retrospective study	35 (2-15 years)	Included only moderate to severe CP	60%
2.	Sullivan et al.(2000)	US	271 (4-13 years)	All types of CP included	34%
3.	Gangil et al. (2001a)	India, Hospital based study	100 (1-9 years)	Included mostly severe cases of CP	70%
4.	Sjakti et al. (2008)	Indonesia, Hospital based study	55 (1-10 years)	Included mostly SQCP	76%
5.	Dahlseng et al. (2012)	Norway	661 (mean age: 6 years 7 months)	All types of CP included	30%
7.	Walker et al. (2012)	Australia	73 (1-5 years)	Mostly SQCP	76%
8.	Ghayas (2013)	Pakistan	122 (3-15 years)	Included only moderate to severe CP	100%

Causes of feeding problems in children with CP

Feeding problems are frequently present in individuals with CP as stated earlier. These problems are due to the neurological dysfunction or brain injury itself (Love &Webb, 1992).Mastication and deglutition are relatively complex motor behaviors in the repertoire of infant motor activity, and therefore they are highly sensitive to neurologic dysfunctions. The other causes for the manifestation of feeding or swallowing problems in children with CP include persistence of the primitive reflexes (Ottenbacher, Bundy, & Short, 1983), abnormal oral muscle tone and strength, misalignment of trunk/head, hyperextension of head, pelvic instability, general body posture (Arvedson & Brodsky, 2002) and incoordination in the oropharyngeal structures (Gantasala, Sullivan, & Thomas, 2013; Sullivan, 2013).Lack of tongue lateralization, hypertonic tongue, instability of the lower jaw, restricted temporo-mandibular joint movements and phasic biting are also causes for feeding impairments (Rogers, Arvedson, Buck, Smart, & Msall, 1994; Gangil, Patwari, Aneja, Ahuja, & Anand, 2001).

The other 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.

According to Redstone and West (2004), children with CP and other neurodisabilities often exhibit decreased postural control which in turn affects the feeding/swallowing of an individual. They described that the pelvic stability, trunk control, head control, jaw stability, tongue control and lip control are very essential

for feeding. In CP, both the alignment and stability of the oral structures for feeding/swallowing were affected due to the abnormal muscle tone and movement patterns. Hence they recommended that the most basic, essential, and effective treatment for children with neurogenic disorders who have feeding/swallowing problems was to establish a better/optimum position of the head/trunk and the oral area. Oral control may influence the stability and movement of the oral structures which is essential for efficient feeding. The strength of this study is that the authors have explained how the positioning, jaw control, lip control etc. should be worked upon along with images/pictures representing the same and they also provide checklist to identify the faults in different sections. Hence it can be used as a guide for the parents and clinicians.

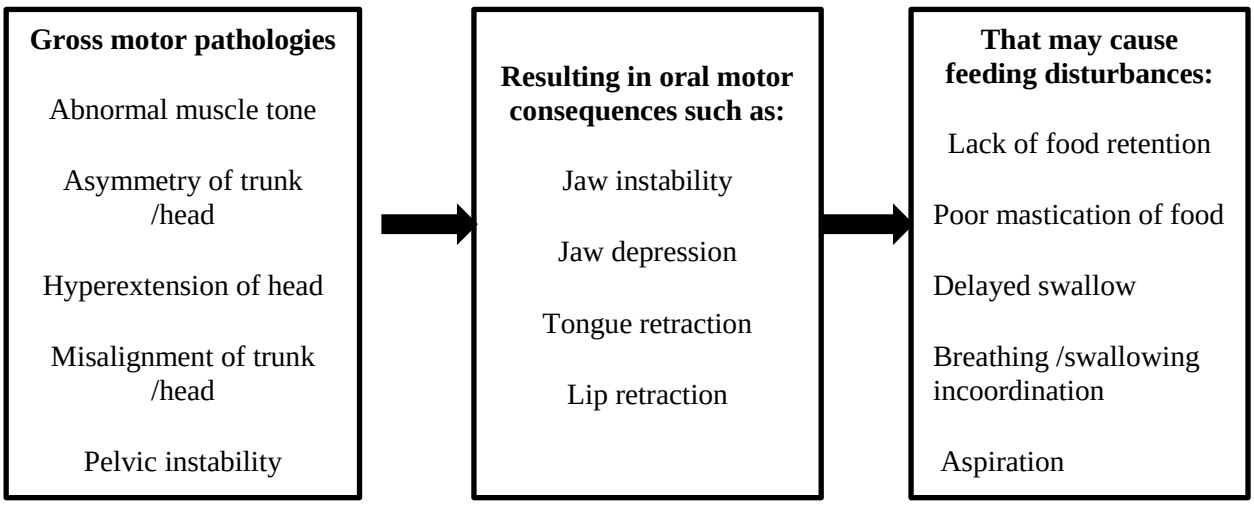


Figure 1.1: Causes and consequences of feeding disturbances in children with CP.

Aggarwal, Chadha, and Pathak (2015) reported tongue thrust, limited tongue movement, choking, persistent bite reflex, jaw instability, inefficient chewing, drinking difficulties, poor respiratory coordination, poor gag reflex, lip retraction,

primitive chewing reflex, perioral hyposensitiveness/ hypersensitiveness as the major causes for feeding impairments in individuals with cerebral palsy.

Nature of feeding difficulties in infants and children with CP

Children with CP may have difficulty in all phases of swallowing or any of the phases of swallowing such as oral, pharyngeal and esophageal (Reily, Wisbeach, & Carr, 2000; Pohl & Cantrell, 2006) which is a major health problem. The common type of dysphagia in children with CP is Oropharyngeal dysphagia (OPD) which is reported to be present in 90% of children and is a major risk factor for survival in these children (Benfer, Weir, & Boyd, 2012; Benfer et al., 2013). Oropharyngeal dysphagia is also prevalent even in children with mild CP (Arvedson, 2013). The types of problems that are seen in children with CP in the oral and pharyngeal phase includes reduced lip closure, discoordinated tongue movement patterns, poor tongue function, tongue thrust, exaggerated bite reflex, tactile hypersensitivity, 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, delayed swallow initiation, 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, reduced pharyngeal motility and poorly coordinated ventilatory cycle and swallowing. Impaired oral sensorimotor function will lead to drooling that in turn results in impaired hydration (Arvedson, 2013). Sullivan (2013) reported reduction in the rate of feeding, prolonged feeding times, excessive spillage of food and difficulty in having a safe swallow in children with CP.

The common esophageal phase problems include vomiting, esophageal dysmotility, delayed gastric emptying, Gastroesophageal reflux disease (GERD), aspiration of gastroesophageal reflux andoesophagitis (Reily, Wisbeach, & Carr, 2000; Pohl & Cantrell, 2006).GERD is one of the serious problems which can be present in 70-75% of children with CP. CP children with GERD present with various feeding problems. They can have recurrent vomiting and chest infections, reactive airway disease such as nocturnal asthma, choking attacks, anaemia and wheezing which leads to poor growth and nutrition (Gangil, Patwari, Bajaj, Kashyap, &Anand, 2001). Arvedson (2013) described the possible problems which can lead to oropharyngeal dysphagi in various stages of swallowing. The same has been depicted in the table 2.4.

Table 2.4:

Oropharyngeal dysphagia: Processes and problems by phase of swallowing (Source: Arvedson, 2013)

Phase of Swallowing	**Processes in brief**	**Possible problems (not intended to be all inclusive list)**
Bolus Formation	Getting food into mouth, manipulating via lip closure, jaw stability, tongue action, getting ready to propel food or liquid over tongue posteriorly	Loss of food from mouth; material in anterior or lateral sulcus; limited or immature chewing; limited tongue action
Oral transit	Moving material through oral cavity (mouth) into pharynx	Initial tongue motion is forward resulting in spillage from the

	(throat)	mouth; delayed initiation of posterior tongue propulsion
Pharyngeal phase initiation	Involving critical timing of tongue propulsion and closure of Airway	Material in valleculae more than 1 s and/or into pyriform sinuses before swallow initiation; material on tonsil tissue or posterior pharyngeal wall (PPW)
Pharyngeal Phase	Involving active coordinated strong muscle function of tongue base, pharyngeal constrictors, and PPW, to move material through pharynx into upper esophagus sphincter (UES)	Reduced airway closure resulting in aspiration, especially with thin liquid; residue in pharynx with reduced muscle strength, usually thick food; pharyngonasal backflow; reduced UES opening
Upper esophageal phase	Opening of UES by anterior & superior movement of hyolaryngeal complex; peristaltic action to move bolus on down through esophagus	Reduced UES opening; reduced duration of UES opening; cricopharyngeal bar (refers to the radiographic appearance of a prominent cricopharyngeus muscle contour on barium swallow) that may or may not inhibit bolus transit; peristaltic action moves bolus on down through esophagus

The nature of feeding problem can also vary with respect to the type of CP and their characteristics. In individuals with spastic type of CP, gathering the food and taking it to mouth in self-feeding is a tough task due to the presence of stiffened muscles. Occasionally there can be paralyses of facial structures which can be noticed at the time of birth leading to feeding problems (Denhoff & Robinault, 1960). In children with hypertonicity, extensor pattern of head, trunk, and limb leads to limited oral and thoracic movement which in turn affects the feeding process (Ottenbacher et al., 1983). Athetoid CP most commonly exhibits 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 presence of involuntary movements seen in athetoid CP often interferes with feeding (Arvedson & Brodsky, 2002).

The nature and severity of the swallowing problems can also vary widely with respect to the gross and fine motor impairment, oromotor skills, severity of drooling, history of seizures, episodes of pneumonia, age, cognitive/ communication deficits of an individual etc. (e.g., intelligent quotient, severity of speech impairment) (Mus, 2010; Cohen & Manor, 2011; Benfer et al., 2012; Benfer et al., 2013). Children with generalized severe motor impairment (for e.g., spastic quadriplegia) are likely to experience greater swallowing deficits than those with diplegia (Mus, 2010; Benfer, Weir, & Boyd, 2012; Benfer et al., 2013).

Several studies have been carried out to identify the nature of feeding problems in children with CP. Reilly, Skuse, and Poblete (1996) conducted a population survey which included both interview and home observational measures. 49 children in the age group of 12 to 72 months who had spastic, mixed and other

types of CP were considered. Within the first 12 months of life, sucking (57%) and swallowing (38%) impairments were present. More than one third of the children had severe oromotor dysfunction. The types of problems were difficulty in drinking liquids, consuming spooned purees, difficulty in eating both solid and semisolid food, frequent coughing and choking, regurgitation and vomiting and chest infections. One in three children were at risk of chronic undernourishment and they also found that the mothers reported longer duration of feeding time in contrary to brief period of feeding as observed. This study assessed only the oral stage of feeding and did not include the other stages of swallowing. But this is one of the earliest study which reported that feeding problems existed in individuals with CP and also described the type of feeding difficulties present among them.

Gangil, Patwari, Aneja, Ahuja, and Anand (2001) conducted a prospective hospital based interventional study. Hundred children (76 boys and 24 girls) in the age range of 1-9 years with CP were recruited for the study. Parental perception of feeding was assessed. Oral motor dysfunction was found in all the subjects. The mean duration of the feeding time was calculated to be around 31.5 minutes. Scores on feeding skills were very poor for spastic quadriplegic CP and hypotonic patients. Most of the children with oral motor dysfunction were on liquid or semisolid diet. Individuals with associated seizure condition exhibited more feeding problems when compared to otherwise. Also most of the parents had less awareness regarding their childrens' feeding ability and they underestimated the nutritional status too. Along with the direct observation of feeding skills, this study focussed on the parent perception of feeding difficulties. Further this study has also explained how the feeding skills can be affected if CP is associated with other co morbid conditions such as seizures.

The early feeding problems in CP were investigated using a longitudinal study by Motion, Northstone, Emond, Stucke, and Golding (2002). Children residing in Avon health authority area, born between 1st April 1991 and 31st December 1992 were recruited for the study. They investigated the feeding problems at 4 weeks and 6 months of age in 33 children. It was also checked whether early feeding problems in the participants had an impact on the functional and growth outcomes at age 8 years of age. Weak sucking at 4 weeks of age was reported in 11 of 23 children with CP. Feeding difficulties at 4 weeks of age were significantly associated with the functional impairment at 4 years of age. Same children were underweight and had speech and swallowing difficulties at 8 years of age. Hence this study reported the presence of early, persistent, and severe feeding problems in children with CP which may reflect poor growth, however this may not be true always in all conditions. The studies which were conducted later suggested that, even though the feeding issues were present early in life, if the same were treated early, they may exhibit better feeding skills than those who were not treated.

Sjakti, Syarif, and Wahyuni (2008) conducted a cross sectional study to determine the prevalence of feeding difficulties and malnutrition in children with CP. They were subjected to both nutritional and feeding difficulties assessment. Fifty five spastic (quadriplegic, diplegic, hemiplegic, paraplegic, hypotonic, dyskinetic, and mixed) children with CP in the age range of 13 months to 9 years were considered for the study. Around 76% of the subjects had malnutrition and most of them were spastic quadriplegic cerebral palsy (SQCP) and 38% were spastic diplegic. Oromotor difficulties (OMD's) such as sucking and swallowing difficulties, drooling, poor lip closure, limited tongue movement, tongue thrust, choking, poor gag reflex, and

primitive chewing reflex were noticed. 38% of parents whose children had feeding issues were not aware of the feeding difficulties present.

Wilson and Hustad (2009) investigated the early feeding problems in CP children with the help of parental reports by including the parents of children with and without oromotor involvement in the age range of 11-58 months. Along with the clinical evaluation of oral-motor involvement of each child, parent's questionnaires regarding their child's current and past feeding abilities were considered. Results indicated that CP children with oral-motor involvement had significantly more impairment in self-feeding abilities and increased frequency of coughing and choking. Also they were introduced to solid food at a later age when compared to children with no oral-motor involvement. Both the groups of children exhibited similar history of feeding difficulties such as of tube feeding, bottle feeding, difficulty with solid foods, use of adaptive equipment, duration of mealtimes, and presence of choking, coughing, and gagging.

A longitudinal study by Clancy and Hustad (2012) examined differences in feeding among children with CP who varied in the severity of their oral motor involvement and severity of motor deficits. Twenty-three children in the age range of 4 and 7 years participated in the study. The data was collected from parent questionnaires at 6 month intervals over 30 months. Results indicated that children with CP with severe oral-motor involvement had marked and pervasive feeding difficulties which showed some fluctuation with time, but generally were stable. Children with CP with no oral motor involvement and those who had mild-moderate involvement also exhibited little to no change over time and had fewer problems when compared to the severe group.

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. 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, and cry/strong extensor thrust during feeding.

Shabnam and Swapna (2016) investigated the feeding and oro-motor skills on 60 children with cerebral palsy (CP) in the age range of 2-10 years. To assess the feeding and oro-motor skills, the physical domain of Feeding Handicap Index (FHI) (Shabnam, 2014) and the Com-DEALL oro-motor assessment checklist (Archana & Karanth, 2008) was used. The results indicated that feeding and oro-motor problems were present in children with CP and they found strong correlation between physical domain of FHI and the oro-motor scores obtained on the Com-DEALL checklist. Further, the correlation was much stronger for the dyskinetic, rather than the other types of CP. It was also seen that the feeding issues were greatest in quadriplegics.

Relationship between the oropharyngeal dysphagia and gross motor functional skills

Mus (2010) investigated the relationship between, type of CP,age, GMFCS level, IQ and feeding problems with known swallowingdisorder and unknown swallowing disorder group using Dysphagia Disorder Screening and Dysphagia Management Staging Scale (Sheppard, 2002) in40 and 21 subjects each in the respective groups in the age range of 3 and 15 years of age. Both the groups consisted

of spastic quadriplegia, hemiplegia, ataxia and unclassifiable CP. However the Known feeding problem group had dyskinetic CP. For all the subjects, the levels of Gross Motor Function Classification System (GMFCS) and the IQ level were assessed. There were significant differences between the spastic and dyskinetic CP. The average scores for known dysphagia group were significantly higher compared to unknown dysphagia group and also there was significant correlation between the severities of dysphagia, GMFCS level and IQ, but no effect of age was noticed.

Kim, Han, Song, Oh, and Chung (2013) studied the characteristics of dysphagia in 29 children older than 1 year and younger than 18 years with CP in relation to the gross motor functioning abilities. To assess the feeding issues, video fluoroscopic swallow study was performed and along with a questionnaire for assessing the oromotor difficulties during feeding was used. The Gross motor function level was classified using Gross Motor Function Classification System Expanded and Revised (Palisano et al., 1997). Results revealed that nearly all the children in the moderate (GMFCS E&R level III) and severe group (GMFCS E&R level IV or V) exhibited impairments in oral preparatory, oral, and pharyngeal phases of swallowing. It was found that severe GMFCS level group had inadequate bolus formation and more than 90% of the children had residue in the valleculae in the moderate or severe groups. Also during the oral phase in moderate GMFCS level group, residue in the oral cavity and piecemeal deglutition around 71.4% and in severe group it was found around 83.3%. Except residue in the valleculae, all swallowing abnormalities were more commonly noted as in when the severity increased. The results of this study indicated that the severity of dysphagia is closely related to gross motor functioning ability in individual's children with CP and the authors claimed that children who are

classified as GMFCS E&R level III, IV, or V are at considerable risk for having dysphagia.

Weir et al., (2013) conducted a prospective, longitudinal, representative cohort study to understand the association between the parent-reported ability to eat different type of food textures of their young children with CP and the gross motor functional abilities of each individual in the age range of 1 year to 3 years. The Gross motor functioning ability was assessed using the Gross Motor Function Classification System (GMFCS). The subjects had GMFCS level from 1 to 5. Parent-reported eating ability was assessed using Paediatric evaluation of disability inventory. The results of the study suggested that the ability to consume to eat all textures of table foods decreased significantly as GMFCS level increased. GMFCS levels IV and V had decreased capability to eat pureed/blended and ground/lumpy foods when compared with GMFCS I.

Benfer,Weir, Bell, Ware, Davies and Boyd (2014) conducted a cross-sectional population-based cohort study in preschool children with CP to understand the patterns of oral phase oropharyngeal dysphagia (OPD) who had spasticity, dyskinesia, ataxia and hypotonia, and its association with mealtime duration, frequency and efficiency using Dyspahgia Disorders Survey (Sheppard 2003), Schedule for Oral Motor Impairment (Reilly, Skuse, &Wolke, 2000), Pre-Speech Assessment Scale (Morris, 1982) and parent-report. A total of 130 children diagnosed with CP and 40 children with typical development in the age range of 18–36 months were recruited for the study. Children with CP had various GMFCS level (GMFCS I = 57, II = 15, III = 23, IV = 12, V = 23). Results reported that around 93.8% of children had oral phase impairments during eating or drinking. OPD was prevalent across all levels of

gross motor function. As the GMFCS level increased, there was an increase in the severity of OPD. When compared to children with GMFCS level I (who were ambulant), children with GMFCS level V (who were nonambulant) had significantly increased OPD. The authors propose that the OPD can be present even in (GMFCS I-II) and GMFCS level was the only risk factor which was consistently associated with OPD.

A review study was conducted by Aggarwal, Chadha, and Pathak (2015). The aim of this study was to review the studies conducted among children with CP to understand the feeding impairments and the consequence of the same in growth and nutritional status of the child. The review suggested that the feeding problems were very common among CP children. The common feeding problems noticed were inefficient chewing, sucking and swallowing, inability to self-feed on their own, frequent coughing and choking during feeding along with vomiting and drooling. Factors such as oral motor dysfunction, severity of gross motor impairment (GMFCS), speech and communication disorders, type of CP, postural problems and age were significantly contributing to the prevalence of feeding issues. This study emphasized that these impairments had a negative impact on the child's growth, nutritional status and quality of life and hence required treatment at the earliest.

Transition from childhood to adolescence and feeding problems in the adolescent period

In children with CP, deaths are never common, but in the recent years, the death rate of CP has become very rare, unless the child is very severely and multiply disabled. Hence, most of the children with CP will survive into adulthood. Also Oskoui (2012) reported that almost 90% of individuals with CP live beyond their eighteenth birthday of life.

Even though the survival rate of CP is increasing, the details of the changes in several domains of the disorder is not well understood as the individual moves through adolescence, young adulthood, middle age, and old age period of life. Hence Haak, Lenski, Hidecker, Li, and Paneth (2009) proposed that there is a need to understand the same. Adults with CP require ongoing health services to continue to monitor for needs that were present in childhood. Since the feeding difficulties, gastroesophagal reflux, constipation, seizures, progressive scoliosis, contractures and dislocations secondary to unremitting spasticity continue to be present, they are very important medical issues to address in the later years of life (Oskoui, 2012).

Haak, Lenski, Hidecker, Li, and Paneth (2009) conducted a review study and described the various changes that occur as the child with CP continues to grow into adolescent and adult period. Most of the studies in the review reported that the children with CP live into adolescence, adult and even geriatric phases of life. The possible changes that were reported in several studies were as follows.

Changes in motor function: The possible causes of decreased function and mobility mentioned in the literature were changes in the muscle flexibility, reduction in the strength and endurance, increase in spasticity, arthritis, frequent falls and fractures, pain and fatigue. Presence of weight bearing difficulties, increased / decreased walking ability over time, inadequate nutrition, and other causes were considered potential risks for the early development of osteoporosis in these individuals.

Communication functioning: Individuals with CP have impairments in speech, language, and hearing which persist into adulthood. The speech of the adolescent or adult with CP is described as dysarthric speech which affects the different subsystems of speech such as respiration, phonation, resonance and articulation.

Eating and swallowing: Individuals with CP have trouble with one or more of the motor actions of swallowing (phases of swallow), which makes getting adequate nutrition and hydration difficult. The eating and swallowing impairments may develop or worsen as the age progress in CP individuals.

Quality of life in adults with CP: Quality of life (QoL) and health-related quality of life (HRQoL) among children and adolescents with CP are often assessed but the same is not done with adult population. QoL and HRQoL or health status in several studies on children and adolescents with CP has focused on domains such as emotional reactions, energy, pain, physical mobility, vitality, general and mental health, physical and social functioning, and emotional and physical roles. Few studies have even included mobility, self-care, anxiety and depression, and usual activities. Even though eating and swallowing behaviour is important for QOL, it has not been included.

A few studies have investigated the feeding problems in the adolescent and children with CP. Gisel, Alphonce, and Ramsay (2000) studied the functional feeding and oral praxis skills in twenty seven CP individuals with mild eating impairment and age matched control subjects in the age range of 4.0 to 16.0 years. The tests included are oral praxis tests (Oral facial motor function and Oral praxis test) and two standard ingestive skills tests such as Gisel video assessment (Gisel, 1988) and Functional feeding assessment (Gisel, 1994). Significantly lower scores were obtained for children with CP on both oral praxis tests compared to controls (p<0.001). Items which required repetition or smooth sequencing, lead to more difficulty in children with CP. In the ingestive skill tests, children with CP exhibited longer time for chewing a hard solid food texture than controls and also they had poor functional feeding skills such as in spoon feeding, biting, chewing, cup drinking, straw drinking

etc. than the control subjects. Hence the authors suggested that the assessment of oral praxis is very important and deficits in feeding may be due to consequence of the inefficient oro-facial motor function skills.

Troughton and Hill (2001) investigated the prevalence of under nutrition in individuals with CP and the relationship with their feeding abilities. Ninety individuals in the age range of 2.6 to 18.7 years (mean 10.8 years) from special schools were considered for the study. The diagnosis of under nutrition was made when the weight was <2nd centile (which indicated that only 2% of the children weighed less and 98% of children weighed more than the actual weight of the target population), a triceps or subscapular skinfold measurement was <3rd centile, and mid-arm circumference <5th centile. Similarly the feeding competence of each was scored by using the Multidisciplinary Feeding Profile by Kenny and colleagues (1989). Among the total subjects, 46% of the subjects had undernourishment and poor feeding ability and it was significantly correlated with weight, triceps or subscapsular skinfold measurement. Mean feeding competence score (mentioned in the brackets) varied with respect to the type of CP such as Diplegia (96), hemiplegia (92), dyskinesia (83) and quadriplegia (46). Quadriplegics had significantly lower scores compared to others. This study suggested that regular anthropometric measurement must be a routine part of clinical assessment since it has a correlation with feeding skills.

Fung et al., (2002) studied the parent-reported feeding dysfunction in children with CP and also their association with health and nutritional status. A total of 230 children within the age group of 9.7 ± 4.6 years with moderate to severe degree of CP and with the GMFCS level 3 to 5 were considered for the study. Anthropometry measurement was also done for all cases. Results indicated that poor health and

nutritional status was associated with the severity of feeding dysfunction. Subjects who were tube fed were taller and had greater body fat stores than orally fed subjects with similar motor impairment. Subjects with only mild feeding dysfunction had reduced triceps in comparison with no feeding problems group. For children with moderate to severe CP, feeding dysfunction was a common problem associated with poor health and nutritional status. This study reported that even children with mild feeding dysfunction may be a risk for poor nutritional status.

Calis, Veugelers, Sheppard, Tibboel, Evenhuis, and Penning (2008) assessed the severity of dysphagia in 166 individuals with severe generalized CP and intellectual impairments in the age range of 2years 1month to 19years 1month using Dysphagia Disorder Survey (DDS, Sheppard 2002). The participants exhibited varying levels of gross motor functioning ability. Along with feeding observation, parental reports on feeding problems were taken. This study reported the presence of 99% prevalence of dysphagia (1% of subjects showed no significant dysphagia, 8% had mild dysphagia, 76% had moderate to severe degree of dysphagia, and 15% had profound dysphagia, receiving nil by mouth) which was correlated with motor impairment of each individual and DDS part 1 items which included diet restrictions, feeding dependence, use of adaptive utensils, postural stability, and the use of feeding and swallowing strategies. Only the postural alignment did not have significant correlation with the severity of dysphagia. The questionnaire on parents' experience of problems faced during feeding, parents' opinion of their child enjoying mealtime, and mealtime duration did not significantly correlate with the severity of dysphagia. In this the study the results for both children and adolescent population could have been explained separately in great detail but however the groups are combined and the results not discussed separately.

Nystrand, Beckung, Dickinson, and Colver (2014) investigated the stability of impairments between childhood and adolescence period in CP population. The aim of the study was to investigate the factors that influence the participation and quality of life in children and adolescents with CP using SPARCLE 1 and SPARCLE 2 (Colver, 2006; Colver & Dickinson, 2010). 818 children in the age range of 8 to 12 years were randomly selected for the study; among them, 594 subjects (73%) were followed up at the age of 13 to 17 years (344 males, 250 females; median age 10y 4mo). The information collected were related to gross motor function (GMFCS), hand function (Bimanual Fine Motor Function [BFMF]), seizures, communication, feeding, cognitive level, vision, and hearing. Results stated that there was stability between childhood and adolescence period for domains such as fine motor function, seizures, vision and feeding. As per the results obtained with detailed observation and parental report, among 594 participants, 429 participants had 'no feeding problem', 131 participants could 'feed orally with difficulty' and 34 participants could partially feed or had no oral feeding during childhood period (in SPARCLE 1). Similarly during adolescence period, 448 participants had 'no feeding problem', 99 were fed orally and 44 were partially fed or not fed orally. It was concluded that motor function (GMFCS level greater than level 2 to 4) and additional impairments were generally stable between the period of childhood and adolescence. The authors' claimed that the feeding function was stabilized about 86%. But few studies describe that as the age progress; the feeding functioning may improve or become worse.

There are few studies which describe the presence of feeding problems in adult population too. Balandin, Hemsley, Hanley and Sheppard (2009) investigated the changes in the swallowing capabilities of adults with CP in the age range of 30-69 years of age as they aged. In method, in-depth interviews about their experiences of

changes in their swallowing and clinical evaluation of dysphagia were done using Dysphagia Disorders Survey and the Dysphagia Management Staging Scale (Sheppard, 2002). The changes found were increased coughing and choking, lack of control over food choice and self-feeding, digestive or gastro-oesophageal symptoms, diet modification, loss of independence, reduced social interactions during meal time with psychosocial consequences. The participants described wide range of feelings due to their eating impairments such as anger, frustration at the loss of preferred foods, fear of coughing or choking, fear of future deterioration in mealtime abilities. The authors of this study concluded that the adults with CP experienced gradual changes in their swallowing and mealtime capabilities from as early as 30 years of age.

To sum, a systematic review of the literature suggests the presence of feeding and swallowing impairments in individuals with CP from birth to adult period. The studies have used various protocols varying from simple parental reports to anthropometric measurements along with meal time observations to investigate the feeding problems. The studies try to find the causes for the same and try to correlate feeding abilities with different variables such as type of CP, oromotor dysfunction, GMFCS levels, treatment provided early or not, quality of life etc. But most of the studies are review based or cross sectional studies which have included participants in a wide age range. Even though the studies have included the adolescent population, the results for this group have not been separately analyzed. According to the literature the period of adolescence is very crucial wherein the individual undergoes lot of changes in various domains such as physical, emotional changes etc. Since the rate of survival in CP individuals is increasing, the professionals should monitor the changes that occur and provide the appropriate remedy for the same. Like any other

functioning, feeding and swallowing may also have an impact as the age increases. But the knowledge regarding the same is limited which will inturn have an impact on the delivery of rehabilitation services. Hence there was a need felt to carry out a study to understand the feeding and swallowing issues in adolescents with cerebral palsy. Keeping this in view, the present study was taken up.

CHAPTER III

METHOD

The present study aimed at investigating the feeding and swallowing problems in adolescents with Cerebral Palsy (CP) in the age group of 13-17.11 years.

Participants: Fifteen participants in the age range of 13 to 17.11 years with the diagnosis of CP made by a qualified team of professionals including speech-language pathologist, paediatrician, physiotherapist and a clinical psychologist were selected for the study. They were recruited from a special school (Spastic society for cerebral palsy, Mysore), and from the Department of clinical services housed at the All India institute of Speech and hearing, Mysuru. All the participants had attended an intervention program inclusive of speech, language and physiotherapy for a duration ranging from 6 months to 6-7 years. Except three, the rest of participants were enrolled in a special school for more than 9- 10 years.

All the participants had intellectual disability (ID) as an associated problem. They had ID of varying severity ranging from mild to severe (4 individuals had mild ID, 6 had moderate ID and 5 had severe ID). The participant group also comprised of individuals with different types of CP (12 participants had spastic type of CP; rest of the 3 participants had athetoid, mixed and ataxic (1 in each type of CP). The topographic distribution of affected limbs varied among the participants. Three participants had triplegic distribution of CP, 2 participants were hemiplegic, 2 participants were diplegic and 8 were having quadriplegic distribution of CP. Among 15 participants, 5 participants had a history of epilepsy and 3 participants were under medication for the same. The details of the participants have been described below in the table 3.1.

Table 3.1:

Details of participants

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

The adolescents diagnosed with a progressive or neurodegenerative lesion or those with some genetic syndromes were excluded. In addition, children with associated visual or hearing impairment were also excluded from the group.

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. Participants belonging to low, middle and high socio-economic statuses were included which was ascertained using the NIMH socioeconomic status scale developed by Venkatesan (2011). The scale has sections such as occupation and education of the parents, annual family income, property, and percapita income to assess the socioeconomic status of the participants. The socioeconomic status (SES) of the participants has been depicted in the table 3.1.Three participants belonged to 'SES 1', 3 participants belonged to 'SES 2', 6 participants belonged to 'SES 3', 1 participant belonged to 'SES 4' and 2 participants belonged to 'SES 5'. SES 5 indicated upper SES and SES1 indicated lower SES.

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 participant was tested individually. The participant was made to be seated comfortably and before carrying out the actual feeding assessment. A rapport was established with the parent/caregiver. The purpose of the administration was explained. The demographic data was obtained. The NIMH socioeconomic status was administered. The type of CP and the degree of intellectual deficit, if any and other associated problems was also noted. The parents/caregivers were interviewed initially (questioned regarding whether the adolescent has a feeding problem or not) to group them into 'known feeding problem' group and 'unknown feeding problem group' as this was one of the objective of the study.

Participants were assessed using GMFCS (Gross motor functional classification system- Expanded and Revised scale by Palisano et al., 2008) to check

the level of gross motor impairment to classify them according to different levels from level 1 to 5 (level 1 indicated lesser extent of impairment and 5 indicated greater extent of impairment). A copy of the scale has been provided in the Appendix I.

The participants were assessed for their oral motor and sensory skills using the protocol developed by Rupela (2008). Oral motor assessment protocol has 4 sections for assessing the motor and sensory behaviors. This includes the Posture (11 items, soring '1'- Yes and '0'- No), oral structures at rest (8 items, scoring pattern - 2 for 'a', 1 for 'b' and '0' for 'c'), function of the oral mechanism for speech (6 items, scoring pattern 1 for 'adequate' and 0 for 'inadequate) and oral sensory behavior (19 items, 4 point rating scale where in 0 indicated Never, 1 indicated 'Occasionally', 2 indicated 'Frequent' , 3 indicated 'Always', 0 indicated 'Not applicable'). A copy of the protocol has been provided in the Appendix II.

After performing the oral motor and sensory skills assessment, the feeding assessment was carried out. Feeding Handicap Index (FHI, Shabnam, 2014) was used to assess the feeding and /or swallowing difficulties, if any. FHI has 38 questions related to physical, emotional and functional aspects and it uses a 3 point rating scale (0, 1 & 2) where '0' indicated 'Never has this problem', '1' indicated 'Sometimes has this problem' and '3' indicated 'Always has this problem'. It also gives the overall severity of the problem as assessed by the parents on a 1- 7 rating scale where '1' indicates normal and '7' indicates severe problem. The previous feeding history and the difficulties, if any, faced during the childhood period, was also elicited from the parent/caregiver to acquire an understanding of whether the participant had some feeding and/or swallowing problems during childhood. A copy of the tool has been provided in the Appendix III.

Parental judgment of eating skills may be unreliable (Malavika, 2014). Hence in addition to the information obtained from the above questionnaires, information regarding the feeding and/or swallowing was obtained by asking the client to consume some food. The boluses were offered in the following order: solid food (biscuit) and then thin liquid (water) and semisolid (jelly). The usage of spoon during feeding was also assessed when they were eating (rice) with their own spoons**.** The adolescent was seated in his/her usual feeding position. As this assessment only concerns an observation of the natural feeding position, there were no risks involved. When participants fed on their own or with the help of parent/ caretaker, detailed observation was made and the session was video recorded.

The Behavioral assessment scale of oral functions in feeding (BASOFF, Stratton, 1981) was used to assess the oral function during feeding. This scale has sections like jaw closure, lip closure over spoon, tongue control, lip closure while swallowing, spillage, chewing (tongue /jaw control), sipping liquid, swallowing liquid and solid. It basically assesses how the structures coordinate while feeding. The scoring is based on a 4 point rating scale i.e. is from '0' to '5' where in '0' to 3 indicated passive movements, '4' indicated functional movements and '5' indicated Normal. A copy of the scale has been provided in the Appendix IV.

The severity of dysphagia was graded using Dysphagia outcome and severity Scale (DOSS, O'Neil, Purdy, Falk,& Gallo, (1999). This scale has 7 levels to describe characteristics of dysphagia where in level 7 indicated normal in all situations, level 6 – within functional limits, level 5- mild dysphagia, level 4 – mild to moderate

dysphagia, level 3- Moderate dysphagia, level 2- moderately severe, and level 1 – indicated severe dysphagia. A copy of the scale has been provided in the Appendix V.

Since the participants were adolescents and could manage on their own during school time, the parents were not available in the special school. Hence the assessment for the participants from the special school (for 10 participants) was done both in school and home setup. For them the assessment of feeding was carried out at school and the parental interview was conducted at home. For the rest of the participants, both assessment of feeding and the parental interview was carried out at their respective homes. The total time taken was around 1 to 1 hour 15 minutes per participant. After completing the test, the participants were provided with tangible reinforcement.

Scoring: Since the scoring pattern was not uniform for all the questionnaires chosen for the study, the categories of scoring for a few questionnaires were changed without disturbing the structure of the questionnaire. In the scoring pattern of protocol by Rupela (2008), section 'A' was changed to '1' – No and, '0'- Yes except for 2a. In section 'B' the scoring was changed as '0' for a, '1' for b and '2' for c. In section 'C' the scoring pattern was changed as '0' for adequate, '1' for inadequate. Similarly the scoring pattern was changed for the Behavioral assessment scale of oral functions in feeding (BASOFF, Stratton, 1981) as '5' indicating severe problem and '0' indicating normal movements. In Dysphagia outcome and severity Scale (DOSS, O'Neil, Purdy, Falk, & Gallo, (1999)too, the levels were graded as 1 – indicated normal in all situations, level 2– within functional limits, level 3- mild dysphagia, level 4 – mild to moderate dysphagia, level 5 - Moderate dysphagia, level 6- moderately severe dysphagia, level 7 – indicated severe dysphagia.

Pilot study: Before conducting the study, a pilot study on two individuals with CP was carried out. All the protocols were administered on the selected individuals to check the feasibility and time required for the complete assessment.

Test retest reliability: To assess the test retest reliability, the protocols were administered again on 40% of subjects (4 participants) of the total population who were selected randomly after one week of the initial data collection.

Analysis: The scores obtained from each participant with respect to each protocol were totalled and for protocols. Since the number of questions was not uniform across for protocols such as Feeding Handicap Index, Behavioral assessment scale of oral functions in feeding, oromotor and orosensory protocols, along with scores, the percentages were also calculated. These scores were averaged across all the participants and fed to the computer for statistical analysis.

Statistical analysis: SPSS version 21.0 software was used for the statistical analysis. For reliability checking, due to small size the severity matching was performed using Cronbach's Alpha instead of Kappa. Descriptive statistics was done to obtain mean, median and standard deviation for both the groups. Spearman correlation was done to find the significant correlation between the severity of dysphagia with severity of motor impairment, oromotor and orosensory functioning, oral function during feeding and the physical, functional and emotional domains of FHI. The correlation was done for the whole group and not across groups due to the small sample size. The results obtained have been presented and discussed in the next chapter.

CHAPTER IV

RESULTS AND DISCUSSION

The main aim of this study was to investigate the feeding and swallowing problems, if any, in adolescents with cerebral palsy (CP) in the age group of 13-17.11 years. The specific objectives of the study were to compare the feeding and/or swallowing abilities between the known feeding problem group and unknown feeding problem group, to assess the overall gross motor functional severity, level of oromotorsensory functioning, oral functioning during feeding and the overall severity of dysphagia, to investigate the nature of relationship between the severity of dysphagia and overall gross motor functioning, level of oromotorsensory functioning, oral functioning during feeding and the scores obtained on the Feeding Handicap Index (FHI).

The total number of participants was15. Among 15, 12 participants had spastic type of CP; the rest of them had other types of CP. All the participants had Intellectual disability (ID) of varying severities ranging from mild to severe; four individuals had mild ID, 6 had moderate ID and 5 had severe ID.

The scores obtained from all participants with respect to different protocols were totalled and averaged across all the participants and fed to the computer for statistical analysis using SPSS (version 20). The appropriate statistical measures carried out were listed as follows:

- For checking the test-retest reliability, Cronbach's Alpha was used.
- Descriptive statistics was done to obtain mean, median and standard deviation.

- Spearman correlation was done to find the significant correlation among the following:
    i. Severity of dysphagia and overall gross motor functional severity.
    ii. Severity of dysphagia and level of oromotorsensory functioning.
    iii. Severity of dysphagia and oral functioning during feeding.
    iv. Severity of dysphagia and the scores obtained on FHI.
    v. Severity of dysphagia with past (childhood) and present scores (adolescence) of FHI.
    vi. Severity of dysphagia with parent severity rating of FHI.
- Normality was checked for FHI data. Since only for physical and functional domains of FHI the normality was present, paired‘t’ test was done to find the significant difference between the past and the present data. For functional domain of FHI, the Wilcoxon test was administered was done to find the significant difference between the past and the present data.
- Kruskal-Wallis test was used to compare the feeding performance of participants with varying degrees of intellectual disability.
- Pairwise comparison of intellectual disability groups was done using Mann Whitney’s U- test.

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

I. Test-retest reliability :

Test retest reliability was computed for 40% of the total sample. The results indicated that Cronbach’s alpha for the physical, functional, emotional domain of FHI was 0.98, 0.95 and 0.85 respectively. The Cronbach’s alpha for the oromotor functioning was 0.99, orosensory functioning was 0.96; oral functioning during

feeding was 0.98 and for the overall severity of dysphagia was 0.99. Hence the 'α' varied between 0.85 and 0.90. This indicated that there was high test-retest reliability.

II. Comparison between known vs. unknown feeding problem group:

In order to fulfill the first objective, the parents were asked whether their children had feeding problems or not, even before the administration of all the feeding/swallowing related protocols. To this most of the parents reported 'yes', that is, they were aware that their wards had feeding or swallowing issues. However, two parents reported that their wards did not have feeding or swallowing problems. Since all the parents, except two reported that their wards had feeding problems, the participants could not be classified into two groups (known vs. unknown feeding problem group), to check for any statistically significant group differences in feeding or swallowing abilities.

Sjakti, Syarif, and Wahyuni (2008) reported in children with CP that 38% of parents whose children had feeding issues were not aware of the feeding difficulties present.Gangil, Patwari, Aneja, Ahuja, and Anand, (2001) reported that most of the parents of children with CP had less awareness regarding their children's feeding ability and they underestimated the nutritional status too. Aggarwal, Chadha, and Pathak (2015) reported through a review study in children with CP that the parents were largely unaware and did not appreciate the feeding problems to the extent that they should be, due to the deep psychological problems regarding their child's disability.

However, in the current study, most of the parents were aware of their wards' feeding difficulties. This could be because in this study, adolescents with CP were included as participants. They all had undergone intervention ranging from 6 months to more than 6-7 years. It is possible that during this period, the speech-language

pathologist handling the child could have pointed out to the feeding difficultiespresent in the children and provided feeding intervention. It is also possible that parents themselves would have noticed the feeding problems faced, since they hadbeen with their wards for a longer period of time (older children) compared to participants, especially children, considered in other studies. Moreover, the adolescents themselves would have expressed verbally or nonverbally to the parents that they had difficulties with certain feeding related issues.

III. Correlation between the severity of dysphagia and overall gross motor functioning ability

The severity of dysphagia was graded using Dysphagia Outcome and Severity Scale (DOSS; O'Neil, Purdy, Falk,& Gallo, 1999). This scale has seven levels to describe characteristics of dysphagia where in level 7 indicated normal in all situations, level 6 indicated within functional limits, level 5 indicated mild dysphagia, level 4 indicated mild to moderate dysphagia, level 3 indicated moderate dysphagia, level 2 indicated moderately severe dysphagia and level 1 indicated severe dysphagia. However, since across tools, the scoring was not uniform and for easy comparison across tools, the scoring criteria was modified as follows: the levels were graded as1 – indicated normal in all situations, level 2– within functional limits, level 3- mild dysphagia, level 4 – mild to moderate dysphagia, level 5 - Moderate dysphagia, level6- moderately severe, level 7 – indicated severe dysphagia.

Descriptive statistics was done to find the mean, median and standard deviation. The mean value for the score obtained on DOSS was 2.86, median was 3.0 and standard deviation was 1.24. The overall DOSS severity rating varied from 1 to 5 for the participants. Among the participants, 13.3 % had severe dysphagia, 33% had

moderately severe dysphagia, 26.6 % had moderate dysphagia',13.3 % had mild to moderate dysphagia and 13.3% were within functional limits. These results indicated that majority of the participants had moderately severe dysphagia.

Participants were assessed using gross motor functional classification system-Expanded and Revised scale (GMFCS; Palisano et al., 2008) to check the level of gross motor impairment to classify them according to different levels from level 1 to 5 (Level 1 Indicated lesser extent of impairment and level 5 indicated greater extent of impairment).

Descriptive statistics was done to find the mean, median and standard deviation. The mean value obtained for GMFCS level was 3.20, median was 4.0 and standard deviation was 1.20.The overall GMFCS score revealed that the gross motor functioning skills of the participantsvaried from level 1 to level 5. One participant had *GMFCS level 1*, 4 participants had *GMFCS level 2*, 8 participants had *GMFCS level 4*, and 2 participants had *GMFCS level 5*. The results indicated that majority of the participants had level 4 of gross motor functioning which reflected gross motor impairment towards the greater side.

To find the relation between overall severity of dysphagia and overall gross motor functioning ability, Spearman's correlation was carried out and. The result indicated that correlation coefficient was 0.29, with p value equal to 0.29. This indicated thatthere was no significant correlation between the two.

Most of the studies conducted in the past revealed that there was a significant correlation betweenseverity of dysphagia and gross motor functioning ability in individuals with CP (Calis, Veugelers, Sheppard, Tibboel, Evenhuis, & Penning,

2008; Mus, 2010; Kim, Han, Song, Oh,& Chung, 2013; Weir et al., 2013; Benfer, Weir, Bell, Ware, Davies &Boyd, 2014; Aggarwal, Chadha, &Pathak,2015).

Weir et al., (2013) reported that in children with CP, the ability to consume all textures of table foods decreased significantly as GMFCS level increased. They reported that the participants in the GMFCS levels IV and V had decreased capability to eat pureed/blended and ground/lumpy foods when compared with GMFCS I. Benfer, Weir, Bell, Ware, Davies, and Boyd (2014) reported that when the GMFCS level of children with CP increased, there was an increase seen in the severity of oropharyngeal dysphagia. Children with GMFCS level V who were nonambulant had significantly increased oropharyngeal dysphagia. Calis, Veugelers, Sheppard, Tibboel, Evenhuis, and Penning (2008) reported that GMFCS level significantly correlated with the severity of dysphagia in a combined group of children and adolescents with CP.

A study conducted by Kim, Han, Song, Oh and Chung (2013) revealed that nearly all the children and adolescents with CP in the moderate (GMFCS E&R level III) and severe group (GMFCS E&R level IV or V)exhibited impairments in oral preparatory, oral and pharyngeal phases of swallowing. It was found that severe GMFCS level group had inadequate bolus formation and more than 90% of the children had residue in the valleculae in the moderate or severe groups. Also during the oral phase, in the moderate GMFCS level group, residue in the oral cavity and piecemeal deglutition was seen in around 71.4% and in severe group, it was seen in around 83.3%. Hence the studies in the past revealed that as the severity of the gross motor functioning ability increased, the severity of the dysphagia increased. Benfer et al., (2014) reported that reported that around 93.8% of children with CP had oral

phase impairments during eating or drinking and oropharyngeal dysphagia was prevalent across all levels of gross motor function.

However in the current study there was no significant correlation found between the overall severity of dysphagia and gross motor functioning level. This could be attributed to the effect of intervention that the participants had undergone. Further the degree of feeding problems in the participants in the current study was lesser when compared to gross motor functioning ability. A few studies do report that as age increased in adolescents with CP, they showed a decrease in physical abilities(Livingston, Rosenbaum, Russell, &Palisano, 2007; Haak et al., 2009; Colver and Dickinson 2010).Nystrand, Beckung, Dickinson, and Colver (2014) also reported that the stability of motor functioning may or may not occur during adolescent period in the CP population.

IV. Correlation between the overall severity of dysphagia and level of oromotor and orosensory functioning

To assess the oromotorsensory functioning, the protocol by Rupela (2008) was used. The oromotor section was assessed by the clinician through a thorough observation of the participant and asking the participant to carry out various oromotor tasks. The orosensory section was assessed through a parental interview. A high score indicated severe impairment in oromotor and orosensory functioning. The scoring criteria was modified here too to suit the study.

The oromotor score for the participants ranged from 8 to 29 and orosensory scores ranged from 9 to 30. All the participants had both oromotor and orosensory deficits. The participants obtained a high score which indicated that they had greater degree of both oromotor and orosensory impairments. In oromotor section, 1

participant had a score of less than 10, 7 participants had a score of 10 to 15 and 7 participants had a score of 20 to 29.In orosensory section, 2 participants had a score of 9, 7 participants had a score of 10 to 20 and 6 participants had a score of 21 to 30.

Descriptive statistics was done to find the mean, median and standard deviation. This revealed that the mean percentage for oromotor functioning was 49.7, median was 46.87 and the standard deviation was23.89and the mean percentage for orosensory functioning section was 33.84, median was31.57 and the standard deviation was 13.44.

The relation between severity of dysphagia and oromotor and orosensory functioning was asessed using Spearman's correlation. The results suggested that correlation coefficient was 0.79 and $P<0.03*$for oromotor functioning and correlation coefficent was 0.86, $P<0.00**$ for orosensory functioning which indicated that there was significant positivehigh correlation between severity of dysphagia and oromotor and orosensory functioning

This finding is in agreement with most of the studies conducted in the literature.Gisel and Alphonce (1995) reported that children with severe oral motor involvement take 2-12 times longer to manipulate and swallow a standard amount of pureed type of food and they take 1- 15 times longer to chew and swallow solid food thanthe typically developing children.A population survey conducted by Reilly, Skuse, and Poblete (1996) in children with CP in the age group of 12 to 72 months revealed that more than one third of the children had severe oromotor dysfunction which lead to various problems such as difficulty in sucking, drinking liquids, consuming spooned purees, difficulty in eating both solid and semisolid food, frequent coughing and choking, regurgitation and vomiting and chest infections, swallowing impairments and finally leading to undernourishment in children.

Arvedson and Broadsky (2008) also reported in children that the feeding problems could be consequent to abnormal oral muscle tone.

According to Calis, Veugelers, Sheppard, Tibboel, Evenhuis, and Penning (2008), one of the causes for dysphagia is the oromotor dysfunction in individuals with CP. The nature and severity of the swallowing problems can vary widely with respect to the oromotor skills (Mus, 2010; Cohen & Manor, 2011; Benfer et al., 2012; Benfer et al., 2013). Sjakti, Syarif, and Wahyuni (2008) reported oromotor difficulties such as sucking and swallowing difficulties, drooling, poor lip closure, limited tongue movement, tongue thrust, choking, poor gag reflex, and primitive chewing reflex in children with CP in the age range of 13 months to 9 years which lead to feeding and swallowing impairments.Gangil, Patwari, Aneja, Ahuja, and Anand (2001) also found that most of the children with oromotor dysfunction were on liquid or semisolid diet.

Wilson and Hustad (2009) reported that individuals with CP with oral-motor involvement had significantly more impairment in self-feeding abilities and exhibited increased frequency of coughing and choking. Also they were introduced to solid food at a later age when compared to children with no oral-motor involvement. Clancy and Hustad (2012) reported that CP children with no oral motor involvement and those who had mild-moderate involvement also exhibited little to no change over time and had fewer problems when compared to the severe group.

Diwan and Diwan (2013) also reported that in children with CP, oral motor dysfunctions had an impact on feeding and swallowing abilities in spastic quadriplegic type of CP. A recent review study Aggarwal, Chadha, and Pathak (2015) also found different types of oromotor dysfunctions in children with CP which had an impact on feeding and swallowing abilities such as difficulty in sucking and swallowing, drooling, poor lip closure and perioral hyposensitiveness/

hypersensitiveness. The features of less prevalent oromotor dysfunctions include tongue thrust, limited tongue movement, choking, persistent bite reflex, jaw instability, poor respiratory coordination, poor gag reflex, lip retraction and primitive chewing reflex. The presence of oromotor dysfunctions has been significantly associated with more difficulty in self-feeding, increased chances of coughing and choking and late introduction of solid food. Shabnam and Swapna (2016) reported that as the oromotor functioning abilities reduced, the feeding impairments increased through the correlation obtained between the physical domain of Feeding handicap index and the oromotor scores.

Arvedson (2008) reported the different types of oral sensory impairments in children which can affect the feeding abilities such as lack of taste, differentiation of liquids in bottle despite intact sucking, efficiency with liquids better than with solid foods, sorting out food of different textures, e.g., fruit piece in yoghurt. Also there can be food held under tongue or in cheek to avoid swallowing, vomiting - certain textures, gagging noted when food approaches/ touches lip or tongue or gagging prominent with solids; normal swallow with liquid, no mouthing of toys, toleration of one's own fingers in mouth, but not others and refusal of tooth brushing.

V. Correlation between between the overall severity of dysphagia and oral functioning during feeding

The Behavioural assessment scale of oral functions in feeding (BASOFF, Stratton, 1981) was used to assess the oral function during feeding. This scale includes several sections like jaw closure, lip closure over spoon, tongue control, lip closure while swallowing, spillage, chewing (tongue /jaw control), sipping liquid and swallowing liquid and solid. It basically assesses how the structures coordinate while

feeding. The scoring criteria was adapted to suit the current study and to be in line with the scoring criteria of other protocols.

A score of ‘0’ to ‘3’ indicated functional to normal movements, ‘4’ and ‘5’ indicated passive movements. The total scores of the participants ranged from 12 to 47. Two participants had a score of less than 15,5 participants score ranged between 15 to 20, 6 participants scores ranged between 21 to 30 and 3 participants score ranged between 31 to 45.This indicated that majority of the participants had impaired oral functioning. Descriptive statistics was done to find the mean, median and standard deviation for the scores obtained on the protocol. It was found thatmean percentage for oral functioning during feeding was 37.34, median was 36.76 and the standard deviation was 15.28.

It was found that the participants had problems in jaw, tongue and lip movements during feeding. They had difficulty in drinking and sipping liquid, consuming solid food along with presence of cough. The frequently observed problems in most of the participants were initial jaw thrust while encountering a utensil, poor lip closure over the spoon, difficulty in chewing and swallowing, poor sipping skill, excess food and liquid loss (more than 10%) and presence of cough.

To find the relation between severity of dysphagia and oral functioning during feeding, Spearman correlation was carried out. The results revealed a correlation coefficient of 0.96 with $P<0.00^{**}$(significant at 2 tailed)which indicateda significantly high correlation between severity of dysphagia and oral functioning during feeding.

The result obtained from the current study is in consonance with other studies carried out in the past. Reilly, Skuse, and Poblete (1996) revealed that children with CP had severe oromotor dysfunction which lead to various dysfunctions in sucking,

drinking liquids, consuming spooned purees, difficulty in eating both solid and semisolid food, frequent coughing and choking, regurgitation and vomiting. Gisel, Alphonce and Ramsay (2000); Redstone and West (2004) who reported that trunk control, head control, jaw stability, tongue and lip control are very essential for feeding in children with CP. Gisel, Alphonce, and Ramsay (2000) described that the spoon feeding abilities, biting, cup drinking, and swallowing differed in individuals with CP years of age significantly from the control group. They had considered individuals in the age range of 4.0 to 16.0 years. Clinical observations of the feeding skills by authors suggested that these differences were related more to the quality of movements of each oral structure such as lip, tongue and jaw. Also the CP children were found eating clumsily with spillage (food loss) and had less refined table manners than typical controls.

Gangil, Patwari, Aneja, Ahuja, and Anand, (2001) reported 10% of the children with CP had a hypertonic tongue, 4% of them had choking and coughing, 10% had restricted temporomandibular joint (affecting the jaw movements), 5% had no closure of lips around the spoon. Yilmaz, Basar, and Gisel (2004) reported that CP individuals in the age range of 4 to 25 years (Children to adults) had difficulties in spoon feeding, biting, chewing, cup drinking, straw drinking, swallowing and clearing. A recent study by Aggarwal,Chadha, and Pathak (2015)also reported that tongue thrust, limited tongue movement, choking, persistent bite reflex, jaw instability, inefficient chewing, drinking difficulties, poor respiratory coordination, poor gag reflex, lip retraction and primitive chewing reflex can be seen in children with CP.

VI. Correlation between the severity of dysphagia and scores obtained on Feeding handicap index (FHI)

To understand more about the feeding impairment and its impact on functional and emotional domains, Feeding handicap index (FHI, Shabnam & Swapna, 2016) was administered by asking the questions present in the FHI to the parents of the participants. They were asked to describe the feeding problems that were present in the past and those that were present currently. FHI has 38 questions related to physical, emotional and functional aspects and it uses a 3 point rating scale (0, 1 & 2) where '0' indicates 'Never has this problem', '1' indicates 'Sometimes has this problem' and '3' indicates 'Always has this problem'. It also gives the overall severity of the problem as assessed by the parents on a 1- 7 rating scale where '1' indicates normal and '7' indicates severe problem.

Administration of FHI revealed that almost all the parents were aware of the feeding issues of their children in various domains such as physical, functional and even in emotional domains. Also the parents reported that their children exhibited more problems in physical domain when compared to functional domains and least problems in emotional domains. The total scores of FHI ranged from 10 to 52.

With respect to the parental rating of overall severity of dysphagia on the FHI, 1 parent had reported a severity of '2', 3 parents reported severity of '3', 8 parents reported severity of '4', 2 parents reported severity of '5' and 1 parent reported the severity of '6'. It can be inferred that majority of the parents reported that their wards had moderate to severe level of feeding problem.

Descriptive statistics was done to find the mean, median and standard deviation. The mean, median and the standard deviation obtained has been depicted in the table 4.1 below.

Table 4.1:

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

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

The mean percentage of physical domain was 47.92 which was greater than the mean percentage of functional domain and emotional domain which was 24.38 and 12.66 respectively. This indicated that the individuals exhibited more feeding problems in the physical domain in comparison with the functional and emotional domain. Spearman's correlation was used to find the relationship between the overall severity of dysphagia with each domain of FHI, total score of FHI and parent severity rating of FHI. The correlation coefficient and the p values have been depicted in the table 4.2 below.

Table 4.2:

Results of spearman's correlation between the severity of dysphagia and physical, functional and emotional domain of FHI

FHI Domains	Correlation coefficient	p value
Physical	0.88	0.00**
Functional	0.67	0.00**
Emotional	-0.27	0.32
Total FHI scores	0.83	0.00**
Parent severity rating	0.71	0.03*

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

The results revealed a strong correlation for physical domain and a moderate correlation for functional domain with overall severity of dysphagia. However there was no significant correlation found for emotional domain of FHI. The total score of FHI and the parent rating of FHI severity was also correlated with the overall severity of dysphagia. The results of the spearman correlation also revealed that there was a significantly high positive correlation between the FHI total scores and severity of dysphagia and between the parent rating of FHI severity and severity of dysphagia.

Most of the parents reported that their wards had problems in areas such as inability to chew efficiently, use fingers for eating (need help), difficulty in using spoon appropriately, and difficulties in drinking through straw. Choking and food spillage was also reported. This is in agreement with the other studies in the literature. Gangil, Patwari, Aneja, Ahuja, and Anand (2001) reported that 11% of the children with CP exhibited chewing problems, 16% had difficulty in self-feeding, 19% had

swallowing problem and 4% of them had coughing and choking problem in children with CP. Troughton and Hill (2001) reported that 46% of the subjects with CP had undernourishment and poor feeding ability and it was significantly correlated with weight, triceps or subscapsular skinfold measurement. Also Aggarwal, Chadha, and Pathak (2015) reported the presence of difficulty in chewing and presence of frequent choking in children with CP. Gisel, Alphonce, and Ramsay (2000) and Yilmaz, Basar and Gisel (2004) described that the spoon feeding abilities, biting, chewing, cup drinking, straw drinking and swallowing abilities in children, adolescents and adults with CP differed significantly from the control group. Wilson and Hustad (2009) reported that the children with and without oral motor impairments had feeding difficulties such as tube feeding, bottle feeding, difficulty with solid foods, use of adaptive equipment, duration of mealtimes, and presence of choking, coughing, and gagging. Diwan and Diwan (2013)also reported sucking and swallowing problems, 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, and cry/strong extensor thrust during feeding in children with CP. Benfer et al., (2014) reported that around 93.8% of children with CP had oral phase impairments during eating or drinking.

Palisano et al., (1997) and Calis et al., (2008) reported that parental report of their child enjoying mealtime and mealtime duration did not significantly correlate with the severity of dysphagia. Personal opinion, motivation, observation skills, and/or mood of the parents affect the rating of severity of feeding (Wilson, & Hustad, 2009). However, in the current study, there was a significant correlation between the overall

severity of dysphagia and the parent rating of FHI severity. This could probably be due to the increased awareness in the parents regarding their wards' feeding abilities.

Gangil, Patwari, Aneja, Ahuja, and Anand (2001) reported that parents of 90% of children were conscious regarding the feeding problems of their children. Parents of 10% of children did not perceive feeding as a significant problem. Parents of 17% of children perceived nutritional status of their children as bad, 34% as satisfactory and of 49% children as unsatisfactory.

Shabnam (2014) administered the Feeding handicap Index and obtained the parent rating of their childrens' feeding abilities on a severity rating scale. The results indicated that caregivers of 10 children reported of no feeding problem, 22 reported mild, 26 reported moderate and 2 reported of severe feeding problems. In the current study, however all the parents except two reported that their wards' had feeding and swallowing problems. One parent rated as '2', 3 parents rated as '3', 8 parents rated as'4', 2 parents rated as '5' and 1 parent rated as '6' (severe feeding problem) for their wards' feeding and swallowing impairment. This indicated that majority of them reported a moderate level of feeding impairment which is in consensus with the findings of the study by Shabnam (2014).

VII. Comparison of the feeding and/or swallowing problems across childhood and the adolescent period on FHI

As highlighted in the previous section, an attempt was also made to compare the feeding problems faced by the participants in the past and the problems faced by them currently while administering the FHI index The mean, median and standard deviation of FHI data was calculated using descriptive statistics and have been depicted in the table 4.3 below.

Table 4.3:

Mean percentage, median and standard deviation (SD) of past (Childhood) and present (adolescent) scores of FHI

Domains	Mean	Median	SD
P1	66.01	66.66	18.17
P2	47.92	47.61	22.80
F1	36.65	41.60	15.27
F2	24.38	25.00	12.80
E1	17.33	10.00	18.30
E2	12.66	10.00	11.62

(Note: Physical past – P1 , Physical present – P2 , Functional past – F1 , Functional Present – F2 , Emotional past –E1 , Emotional present – E2)

When the means of the percentages were obtained (past and present) on all the three domains were compared, it was seen that on all the domains, the adolescents had greater extent of feeding problems in the past compared to the present. Normality was checked for FHI data using Shapiro wilk's test of normality. Since normality was present only for physical and functional domains of FHI, paired't' test was done to find the significant difference between the past and the present data. For emotional domain of FHI, since normality was not present, nonparametric test was administered (Wilcoxon signed rank test). The results obtained are shown in table 4.4.

Table 4.4:

Results of paired t test (t and p value) for comparison of feeding problems in the past (during childhood) and present (during adolescence)

Pairs		't' value	p value
Pair 1	P1 - P2	5.45	0.00**
Pair 2	F1 - F2	6.99	0.00**

*Note: ** indicates 'p' significant at <0.01, P1- Past score on physical domain, P2- Present score on physical domain, F1- Past score on functional domain, Present score on functional score*

The results of the paired t test revealed that there was a significant difference between the past and present scores of both physical and functional domain i.e. $p<0.05$.

Parents reported more problems in feeding and swallowing during their wards' childhood period when compared to the present condition of adolescence. This may be attributed to the longer duration of intervention received by the adolescents following which the problems could have reduced in intensity. Motion et al., (2002) reported that the early feeding problems during infancy can be reflected during childhood period as well. Similarly in the current study all the participants exhibited feeding difficulty as they had during their childhood period but with less intensity and frequency.

The results of the Wilcoxon signed rank test to check for any significant difference in feeding problems seen in the past and in the present on the emotional domain revealed the /Z/ value to be 1.60 and 'p' value to be 0.10. This indicated that

there was no significant difference between the past and the present percentages of emotional domain of FHI. This indicted that the adolescents did not develop emotional problems. This again could be attributed to the effect of intervention.

VIII. Comparison of feeding and /or swallowing problems across different degrees of intellectual disability

All the 15 participants had intellectual disability (ID) of various severities ranging from mild to severe. 4 individuals had mild ID, 6 had moderate ID and 5 hadsevere ID.

Table 4.5:

Mean, median and Standard deviation (SD) of all three ID groups across all the protocols.

Domains	Severity of ID	Mean	Median	SD
GMFCS	Mild	2.25	2.00	1.25
	Moderate	4.00	4.00	1.09
	Severe	3.20	4.00	1.09
	Total	3.26	4.00	1.27
OMPER	Mild	36.71	37.49	9.32
	Moderate	37.37	38.75	21.44
	Severe	74.99	75.00	12.69
	Total	49.74	46.87	23.89
OSPER	Mild	33.79	36.89	13.41
	Moderate	29.65	25.90	12.85
	Severe	38.91	45.60	15.25
	Total	33.84	31.57	13.44
BASOFFPER	Mild	29.76	30.14	7.35
	Moderate	37.00	34.55	17.00

	Severe	43.81	44.11	17.47
	Total	37.34	36.76	15.28
PHYPER	Mild	43.45	35.71	22.36
	Moderate	46.81	41.65	27.59
	Severe	52.85	54.76	20.99
	Total	47.92	47.61	22.80
FUNPER	Mild	16.66	16.66	7.60
	Moderate	30.40	29.16	13.22
	Severe	23.33	29.16	14.00
	Total	24.38	25.00	12.80
EMOTPER	Mild	17.50	15.00	17.07
	Moderate	15.00	10.00	8.36
	Severe	6.00	0.00	8.94
	Total	12.66	10.00	11.62
FHI Total	Mild	24.00	19.00	12.11
	Moderate	28.50	26.50	14.32
	Severe	28.40	30.00	11.67
	Total	27.26	23.00	12.15
FHIPRAT	Mild	3.75	3.50	0.95
	Moderate	4.00	4.00	0.63
	Severe	4.00	4.00	1.41
	Total	3.93	4.00	0.96
DOSS	Mild	2.50	2.50	0.57
	Moderate	2.66	2.50	1.36
	Severe	3.40	4.00	1.51
	Total	2.86	3.00	1.24

Note: (GMFCS- Gross motor functioning level scale, OMPER- Oromotor percentage, OSPER- Orosensory percentage, BASOFFPER- Behavioral assessment of oral functioning during feeding percentage, PHYPER- Physical domain percentage of FHI, FUNPER- Functional domain percentage of FHI, EMOTPER- Emotional domain percentage of FHI, FHI total – Total scores of FHI, FHIPRAT- Parent rating of FHI severity & DOSS- DOSS- Dysphagia outcome and severity Scale)

Kruskal-Wallis test was used to compare different intellectual disability groups as a whole across different parameters and the results are tabulated as follow.

Table 4.6:

Results of Kruskal-Wallis test across different intellectual disability groups on various protocols

Domains	χ^2	**'p' value**
GMFCS	4.67	0.09
OM	7.72	0.02*
OS	1.02	0.59
BASOFF	2.36	0.30
DOSS	1.61	0.44
PHYS	0.52	0.77
FUN	2.71	0.25
EMOT	2.77	0.24
FHI total	0.62	0.73

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

(Note: PHYS–*physical domain, FUN- Functional domain, EMOT- Emotional domain, total score of FHI , OM – oromotor , OS – Orosensory, BASOFF- Behavioral Assessment Scale of Oral Functions in Feeding, DOSS- Dysphagia outcome and severity Scale& GMFCS- Gross motor functioning level scale)*

The results of the Kruskal Wallis test indicated that there was a significant difference only on oromotor functioning where the $p<0.05$. Pairwise comparison was done to find the significant difference between the mild and moderate group, mild and

severe group and moderate and severe group using Mann Whitney's U- test, specifically for oromotor functioning. The results of the Kruskal Wallis test has been depicted in the table 4.7.

Table 4.7:

/Z/ and 'p' values for pair wise comparison of different intellectual disability groups

Groups with ID	**/Z/value**	**'p' value**
Mild - Moderate	1.18	0.23
Mild- Severe	2.46	0.01*
Moderate - Severe	2.01	0.04*

*Note: * indicates 'p' significant at <0.05, ID: Intellectual disability*

The results revealed that there was a significant difference between the mild and severe group and moderate and the severe group. However, there was no significant difference between the moderate and severe groups. This could be attributed to the fact that the overall severity of feeding problems in the moderate and severe groups was almost similar in nature.

Aggarwal, Chadha, and Pathak (2015) reported that mental retardation is also a one of the factor for causing dysphagia in children with CP. In the current study mild group of intellectual disability individuals exhibited less severity of dysphagia when compared to group with greater degree of severity of intellectual disability. The results obtained are in consonance with the literature. Calis et al., (2008) and Mus (2010) reported the relationship between the severity of dysphagia and intelligent quotient in children and adolescents with CP. The results of both the studies indicated

that there was a significant correlation between the two i.e. as the severity of intellectual disability increased; there was an increase in the severity of dysphagia.

In sum, the overall results of the current study revealed that there was a significant correlation between the overall severity of dysphagia with oromotor functioning, orosensory functioning, oral functioning during feeding, scores obtained on the feeding handicap index and parents' rating of severity obtained from the feeding handicap index. There was a significant difference between the feeding problems experienced in the past (childhood period) and feeding problems present currently (adolescence period) based on the scores of FHI. Further, there was a significant difference between the participants with mild ID and severe ID and the participants with moderate and severe ID.

CHAPTER V

SUMMARY AND CONCLUSIONS

Cerebral palsy (CP) is a lifelong disability. In the recent years, the death rate of CP has considerably reduced. The literature suggests that the individuals with CP can live beyond their childhood period and move into young adulthood, middle age, and old age period of life. Feeding and swallowing problems in CP are one of the common associated problems which can be noticed right from the birth. To understand their feeding and swallowing impairments, studies have been carried out in the infants and children with CP. To obtain a holistic picture of the feeding and/or swallowing problems faced by them, it is important to consider the adolescent and the adult group of CP population and study the feeding and or swallowing problems seen in them. However, only a few studies have been done in the adolescent and adult population with CP. These studies indicated that they do have feeding and/or swallowing problems. Most of these studies have included both children and adolescents with CP and considered them as a whole group during analysis and the results of the feeding problems have not been discussed separately with respect to the feeding problems. Since the feeding and swallowing problems in adolescents with CP were less well studied, especially in the Indian context, the current study was planned to fill up the existing gap in the literature.

Hence, the present study was undertaken with the aim of investigating the feeding and swallowing problems, if any, in adolescents with CP in the age group of 13-17.11 years. The specific objectives of the study were to compare the feeding and/or swallowing abilities between the adolescents with CP whose parents/caregivers reported that they were aware of the feeding problems of their wards (known feeding

problem group) and those whose parents/caregivers did not report of or were not aware of their wards' feeding problems (unknown feeding problem group), to assess the overall gross motor functional severity, oromotorsensory functioning, oral functioning during feeding and the overall severity of dysphagia, to assess the feeding problems in the physical domain and to study its impact on the functional and emotional domain using Feeding Handicap Index (FHI, Shabnam, 2014), to investigate the nature of relationship between the severity of dysphagia and overall gross motor functional severity, severity of dysphagia and level of oromotorsensory functioning, severity of dysphagia and oral functioning during feeding, to assess the relationship between the overall severity of dysphagia and the FHI score and overall severity of dysphagia and parent severity rating of FHI.

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. In all the participants included in the study, the type of CP, presence of associated problems, their socioeconomic status and other demographic details was noted. The participants' gross motor functioning ability was assessed using GMFCS (Gross motor functional classification system- Expanded and Revised scale by Palisano et al., 2008). To assess the oromotorsensory functioning, the protocol by Rupela (2008) was used. The Behavioural assessment scale of oral functions in feeding (BASOFF, Stratton, 1981) was used to assess the oral function ability of the participants during feeding. To elicit the information about the problems in the physical domain of feeding and its impact on functional and emotional domains of feeding, the Feeding Handicap Index (FHI, Shabnam, 2014) was used as mentioned earlier. Finally the overall severity of dysphagia was graded using Dysphagia outcome and severity Scale (DOSS, O'Neil, Purdy, Falk & Gallo, 1999). The information

obtained from the protocols was supplemented though a video recording of actual feeding by the participants using two different bolus consistencies.

After completing the analysis, appropriate statistical measures were carried out using SPSS version 21. For checking the test-retest reliability, Cronbach's Alpha was used. Descriptive statistics was done to obtain mean, median and standard deviation. Spearman correlation was done to find the correlation between the severity of dysphagia and overall gross motor functional, level of oromotorsensory functioning, oral functioning during feeding, the scores obtained on Feeding handicap index and parent severity rating of Feeding handicap index.

The results of the study indicated that almost all the parents were aware regarding their wards' feeding and swallowing impairments. Similar to children with CP, adolescents with CP also continued to manifest feeding and swallowing difficulties. The common feeding problems found in adolescents with CP in the current study were drooling, poor lip closure, limited tongue movement, jaw movements, choking, and poor gag reflex. They had difficulty in drinking and sipping liquid and consuming solid food. The frequently observed problems in most of the participants were initial jaw thrust while encountering a utensil, poor lip closure over the spoon, chewing not functional for swallowing, excess food and liquid loss (more than 10%) and presence of cough. However the intensity and frequency of the feeding and swallowing problems found in the adolescents were less when compared to their childhood period, probably due to the intervention that they had undergone during their childhood period. This was found when a significant difference was obtained on FHI between their childhood and adolescent period. This was found using paired 't' test (physical and functional domain) and Wilcoxon test (emotional domain).

The severity of dysphagia correlated significantly with oromotor and orosensory abilities, oral functioning during feeding, FHI scores and parent rating of severity obtained from the FHI. However there was no significant correlation between the overall severity of dysphagia and gross motor functioning ability.

In addition, it was found that as the intellectual disability increased, there was an increase in the severity of the feeding problem. The comparison across different groups with intellectual disability was possible as there were 4 children with mild, 6 children with moderate and 5 children with severe intellectual disability. Kruskal Wallis test was done to compare the feeding performance between these groups with different intellectual disability. There was also a significant difference obtained between the mild and moderate group and between the moderate and severe group.

Hence it can be concluded that as the children with CP continue to grow older, the feeding and swallowing impairments persist. The oromotor and orosensory problems could have an impact on the feeding and swallowing problems. However with intensive intervention by a multidisciplinary team focussing on different skills such as motor, speech-language and feeding can help in reducing the intensity and extent of feeding problems.

Implications of study

The current study provides an insight into the feeding and/or swallowing and oromotorsensory problems seen in adolescents with CP. This study delineates the relationship between feeding and/or swallowing abilities and oromotorsensory abilities and gross motor skill attainment in children with CP. Greater understanding of these relationships assists the speech-language clinicians in selecting and framing appropriate treatment targets during the intervention. This study also helps speech-

language clinicians during the counselling of the parents/caregivers of cases with adolescents with CP who have inadequate feeding skills. Since the adolescent population turn out to be the adults in future, if feeding and/or swallowing problems are identified and treated early in this population, the quality of life of adolescents with CP might increase. This might reduce the burden on the caretakers /parents and avoiding parental stress too.

Limitations

Since all the participants had attended an intervention program for a duration ranging from 6 months to more than 6-7 years, the actual feeding problems in adolescents if left untreated could not be studied. The study setup was not uniform across the participants which could have influenced the results of the study.

Future directions

- The study was conducted in a small population and to generalize the results obtained from the current study, similar studies have to be carried out with a larger sample in the same age group.
- Future studies can also include a control group in order to get a better understanding of the feeding and swallowing impairments in relation to their normal counterparts.
- The majority of the participants included in the study were those with spastic type of CP and the variations of feeding and swallowing problems could not be studied across different types of CP. Hence future studies can compare feeding and swallowing problems across different types of CP.

REFERENCES

Adams, M. S. (2009). *The management of feeding difficulties in children with cerebral palsy in Bangladesh* (Doctoral dissertation, University College London).

Aggarwal, S., Chadha, R., &Pathak, R. (2015).Feeding difficulties among children with Cerebral Palsy: A Review. *Children*, *1*(7), 9-12.

Archana, G., & Karanth, P. (2008). *Assessment of the oromotor skills in toddlers*. The Com DEALL trust, Bangalore.

Arvedson, J. C. (2008). Assessment of paediatric dysphagia and feeding disorders: Clinical and instrumental approaches. *Developmental disabilities research reviews*, *14*(2), 118-127.

Arvedson, J. C. (2013). Feeding children with cerebral palsy and swallowing difficulties. *European Journal of Clinical Nutrition*, *67*, S9-S12.

Arvedson, J. C., & Brodsky, L. (2002).*Paediatric swallowing and feeding: Assessment and management*. Albany, NY: Singular Publishing Group.

Arvedson, J. C., & Brodsky, L. (2002). *Pediatric swallowing and feeding:* Assessment and management. Albany, NY; Singular Publishing Group.

Ashwal, S., Russman, B. S., Blasco, P. A., Miller, G., Sandler, A., Shevell, M., & Stevenson, R. (2004). Practice Parameter: Diagnostic assessment of the child with cerebral palsy, report of the Quality Standards Subcommittee of the American Academy of Neurology and the Practice Committee of the Child Neurology Society. *Neurology*, *62*(6), 851-863.

Balandin, S., Hemsley, B., Hanley, L., & Sheppard, J. J. (2009). Understanding mealtime changes for adults with cerebral palsy and the implications for support services. *Journal of Intellectual and Developmental Disability*, *34*(3), 197-206.

Balandin, S., & Morgan, J. (1997). Adults with cerebral palsy: What's happening?. *Journal of Intellectual and Developmental Disability*, *22*(2), 109-124.

Benfer, K. A., Weir, K. A., & Boyd, R. N. (2012).Clinimetrics of measures of oropharyngeal dysphagia for preschool children with cerebral palsy and neurodevelopmental disabilities: A systematic review. *Developmental Medicine and Child Neurology*, *54*(9), 784-795.

Benfer, K. A. (2015). *Oropharyngeal dysphagia in preschool children with cerebral palsy: Relationship to gross motor function, dietary intake, and nutritional status*. A PhD Thesis submitted to The University of Queensland, Australia.

Benfer, K. A., Weir, K. A., Bell, K. L., Ware, R. S., Davies, P. S., & Boyd, R. N. (2012). Longitudinal cohort protocol study of oropharyngeal dysphagia: Relationships to gross motor attainment, growth and nutritional status in preschool children with cerebral palsy. *British Medical Journal open*, *2*(4), e001460.

Benfer, K. A., Weir, K. A., Bell, K. L., Ware, R. S., Davies, P. S., & Boyd, R. N. (2013). Oropharyngeal dysphagia and gross motor skills in children with cerebral palsy. *Pediatrics*, *131*(5), e1553-e1562.

Benfer, K. A., Weir, K. A., Bell, K. L., Ware, R. S., Davies, P. S., & Boyd, R. N. (2014). Oropharyngeal dysphagia in preschool children with cerebral palsy: Oral phase impairments. *Research in Developmental Disabilities*, *35*(12), 3469-3481.

Berker, N., & Yalçın, S. (2010). *The help guide to cerebral palsy*.Washington, USA: Rotamat Press Co. Ltd.

Björquist, E. (2013). *Living in transition to adulthood: Adolescents with cerebral Palsy and their Parents' experiences of health, wellbeing and needs*. A thesis submitted to Department of Health Sciences, Lund University, Sweden.

Bobath, K., & Bobath, B. (1954). Treatment of cerebral palsy by reflex inhibition and facilitation of automatic movements. *British Council for Welfare of Spastics*, 76-85.

Calis, E. A., Veugelers, R., Sheppard, J. J., Tibboel, D., Evenhuis, H. M., & Penning, C. (2008). Dysphagia in children with severe generalized cerebral palsy and intellectual disability. *Developmental Medicine and Child Neurology*, *50*(8), 625-630.

Carruth, B. R., & Skinner, J. D. (2002).Feeding behaviors and other motor development in healthy children (2–24 months). *Journal of the American College of Nutrition*, *21*(2), 88-96.

Claassen, A. A., Gorter, J. W., Stewart, D., Verschuren, O., Galuppi, B. E., &Shimmell, L. J. (2011). Becoming and staying physically active in adolescents with cerebral palsy: Protocol of a qualitative study of facilitators and barriers to physical activity. *Bio Med Central Pediatrics, 11*(1), 1-8.

Clancy, K. J., & Hustad, K. C. (2011). Longitudinal changes in feeding among children with cerebral palsy between the ages of 4 and 7 years. *Developmental Neurorehabilitation*, *14*(4), 191-198.

Cohen, J. T., & Manor, Y. (2011).Swallowing disturbance questionnaire for detecting dysphagia. *The Laryngoscope, 121*(7), 1383-1387.

Colver, A. (2006). Study protocol: SPARCLE – A multi-centre European study of the relationship of environment to participation and quality of life in children with cerebral palsy. *Bio Med Central Public Health*, *6*(1), 105.

Colver, A. F., & Dickinson, H. O. (2010). Study protocol: determinants of participation and quality of life of adolescents with cerebral palsy: a longitudinal study (SPARCLE2). *Bio Med Central Public Health*, *10*(1), 1-10.

Colver, A. F., & Dickinson, H. O. (2010). Study protocol: Determinants of participation and quality of life of adolescents with cerebral palsy: A longitudinal study (SPARCLE2). *Bio Med Central Public Health*, *10*(1), 280.

Colver, A., Rapp, M., Eisemann, N., Ehlinger, V., Thyen, U., Dickinson, H. O., ...& Marcelli, M. (2015). Self-reported quality of life of adolescents with cerebral palsy: A cross-sectional and longitudinal analysis. *The Lancet*, *385*(9969), 705-716.

Cooper, J., Majnemer, A., Rosenblatt, B., & Birnbaum, R. (1995).The determination of sensory deficits in children with hemiplegic cerebral palsy. *Journal of Child Neurology*, *10*(4), 300-309.

Cooper, P. J., & Stein, A. (2006). *Childhood feeding problems and adolescent eating disorders*.Routledge.NY: Taylor & Francis group.

Cruickshank, W. M. (1955). Cerebral Palsy, its Individual and community problems. Syracuse NY: University Press.

Da Costa, S. P., & Van Der Schans, C. P. (2008).The reliability of the Neonatal Oral-Motor Assessment Scale. *Acta Paediatrica*, *97*(1), 21-26.

Dahlseng, M. O., Finbråten, A. K., Júlíusson, P. B., Skranes, J., Andersen, G., & Vik, T. (2012).Feeding problems, growth and nutritional status in children with cerebral palsy. *Acta Paediatrica*, *101*(1), 92-98.

De Oliveira Lira Ortega, A., Ciamponi, A. L., Mendes, F. M., & Santos, M. T. B. R. (2009). Assessment scale of the oral motor performance of children and adolescents with neurological damages. *Journal of Oral Rehabilitation*, *36*(9), 653-659.

Denhoff, E., & Robinault, I. P. (1960). *Cerebral palsy and related disorders: A developmental approach to dysfunction*. McGraw-Hill.

Diwan, S., & Diwan, J. (2013). A study of feeding problems in children with cerebral palsy. *National Journal of Integrated Research in Medicine, 4, 78-86.*

Dodds, W. J., Stewart, E. T., & Logemann, J. A. (1990).Physiology and radiology of the normal oral and pharyngeal phases of swallowing. *American Journal of Roentgenology*, *154*(5), 953-963.

Donkervoort, M., Wiegerink, D. J., Van Meeteren, J., Stam, H. J., &Roebroeck, M. E. (2009). Transition to adulthood: Validation of the Rotterdam Transition Profile for young adults with cerebral palsy and normal intelligence. *Developmental Medicine and Child Neurology*, *51*(1), 53-62.

Erasmus, C. E., van Hulst, K., Rotteveel, J. J., Willemsen, M. A., &Jongerius, P. H. (2012). Clinical practice. *European Journal of Paediatrics*, *171*(3), 409-414.

Field, D., Garland, M., & Williams, K. (2003). Correlates of specific childhood feeding problems. *Journal of Paediatrics and Child Health*, *39*(4), 299-304.

Fung, E. B., Samson-Fang, L., Stallings, V. A., Conaway, M., Liptak, G., Henderson, R. C., ...& Chumlea, W. (2002). Feeding dysfunction is associated with poor growth and health status in children with cerebral palsy. *Journal of the American Dietetic Association*, *102*(3), 361-373.

Gangil, A., Patwari, A. K., Bajaj, P., Kashyap, R., &Anand, V. K. (2001).Gastroesophageal reflux disease in children with cerebral palsy. *Indian Paediatrics*, *38*(7), 766-770.

Gantasala, S., Sullivan, P. B., & Thomas, A.G. (2013). Gastrostomy feeding versus oral feeding alone for children with cerebral palsy. *Cochrane Database of Systematic Reviews*, 7, 1-17.

Gisel, E. G. (1988).Chewing cycles in 2 to 8 year old normal children: A developmental profile. *American Journal of Occupational Therapy.* 42, 40-46.

Gisel, E. G. (1994). Oral-motor skills following sensorimotor intervention in the moderately eating impaired child with cerebral palsy. *Dysphagia,* 9, 180-192.

Gisel, E. G., Alphonce, E., & Ramsay, M. (2000). Assessment of ingestive and oral praxis skills: Children with cerebral palsy vs. controls. *Dysphagia*, *15*(4), 236-244.

Haak, P., Lenski, M., Hidecker, M. J. C., Li, M., &Paneth, N. (2009).Cerebral palsy and aging. *Developmental Medicine and Child Neurology*, *51*(s4), 16-23.

Katzman, D. K. (2005). Medical complications in adolescents with anorexia nervosa: A review of the literature. *International Journal of Eating Disorders*, *37*(S1),

S52-S59.

Kenny, D. J., Koheil, R. M., Greenberg, J., Reid D., Milner, M., Moran, R., Judd, P. L. (1989).Development of a multidisciplinary feeding profile for children who are dependent feeders. *Dysphagia*, 4, 16–28.

Kim, J. S., Han, Z. A., Song, D. H., Oh, H. M., & Chung, M. E. (2013). Characteristics of dysphagia in children with cerebral palsy, related to gross motor function. *American Journal of Physical Medicine & Rehabilitation*, *92*(10), 912-919.

Krigger, K. W. (2006). Cerebral palsy: An overview. *American Family Physician*, *73*(1), 91-100.

Kummer, A. (2008). *Cleft palate & craniofacial anomalies: Effects on speech and resonance*. (2nd Ed.). Newyork NY: Cengage learning.

Livingston, M. H., Rosenbaum, P. L., Russell, D. J., & Palisano, R. J. (2007). Quality of life among adolescents with cerebral palsy: What does the literature tell us?. *Developmental Medicine and Child Neurology*, *49*(3), 225-231.

Logemann, J. A. (1998). The evaluation and treatment of swallowing disorders. *Current Opinion in Otolaryngology & Head and Neck Surgery*, *6*(6), 395-400.

Love, R.J. & Webb, W.G. (1992). *Neurology for the speech language pathologist.* Butterwoth Hienemann Limited. Ann Arbor, Michigan.

Malavika, A.A. (2014). *An Investigation of feeding problems in children with down syndrome.* A dissertation submitted as a part of fulfillment of Master's degree

(Speech Language Pathology), University of Mysore, Mysore.

Matsuo, K., & Palmer, J. B. (2008). Anatomy and physiology of feeding and swallowing: Normal and abnormal. *Physical Medicine and Rehabilitation Clinics of North America*, *19*(4), 691-707.

Minear, W. L. (1956). A classification of cerebral palsy. *Pediatrics*, 18, 841-52.

Morris, C. (2007). Definition and classification of cerebral palsy: A historical perspective. *Developmental Medicine and Child Neurology*, *49*(s109), 3-7.

Motion, S., Northstone, K., Emond, A., Stucke, S., & Golding, J. (2002). Early feeding problems in children with cerebral palsy: Weight and neuro-developmental outcomes. *Developmental Medicine and Child Neurology*, *44*(1), 40-43.

Mus, L. J. E. (2010).*Clinical Assessment of Dysphagia in Children with Cerebral Palsy using DDS and DMSS.*A thesis submitted as a part of fulfillment of Master's degree (Clinical Language, Speech & Hearing Sciences), Utrecht University, Netherlands.

Newman, C. J., O'Regan, M., &Hensey, O. (2006). Sleep disorders in children with cerebral palsy. *Developmental Medicine and Child Neurology*, *48*(7), 564-568.

Nystrand, M., Beckung, E., Dickinson, H., & Colver, A. (2014). Stability of motor function and associated impairments between childhood and adolescence in young people with cerebral palsy in Europe. *Developmental Medicine and Child Neurology*, *56*(9), 833-838.

Odding, E., Roebroeck, M. E., & Stam, H. J. (2006). The epidemiology of cerebral

palsy: Incidence, impairments and risk factors. *Disability and rehabilitation*, *28*(4), 183-191.

O'Neil, K. H., Purdy, M., Falk, J., & Gallo, L. (1999). The dysphagia outcome and severity scale. *Dysphagia*, *14*(3), 139-145.

Oskoui, M. (2012).Growing up with cerebral palsy: Contemporary challenges of healthcare transition. *The Canadian Journal of Neurological Sciences*, *39*(1), 23-25.

Ottenbacher, K., Bundy, A., & Short, M. A. (1983). The development and treatment of oral-motor dysfunction: A review of clinical research. *Physical & Occupational Therapy in Pediatrics*, *3*(2), 1-13.

Palisano R, Rosenbaum P, Walter S, Russell D, Wood E & Galuppi B. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine and Child Neurology,* 39, 214–23.

Palisano, R. J., Rosenbaum, P., Bartlett, D., & Livingston, M. H. (2008). Content validity of the expanded and revised Gross Motor Function Classification System. *Developmental Medicine and Child Neurology*, *50*(10), 744-750.

Pirila, S., van der Meere, J., Pentikainen, T., Ruusu-Niemi, P., Korpela, R., Kilpinen, J., & Nieminen, P. (2007). Language and motor speech skills in children with cerebral palsy. *Journal of Communication Disorders*, *40*(2), 116-128.

Pohl, J. F., & Cantrell, A. (2006). Gastrointestinal and nutritional issues in cerebral palsy. *Practical Gastroenterology*, *19*(5), 14-22.

Rapp Jr, C. E., & Torres, M. M. (2000).The adult with cerebral palsy. *Archives of*

Family Medicine, *9*(5), 466-472.

Redstone, F., & West, J. F. (2004). The importance of postural control for feeding. *Pediatric nursing*, *30*(2), 97.

Reilly, S., Skuse, D., & Poblete, X. (1996). Prevalence of feeding problems and oral motor dysfunction in children with cerebral palsy: a community survey. *The Journal of Pediatrics*, *129*(6), 877-882.

Reilly, S., Wisbeach, A., & Carr, L. (2000).Assessing feeding in children with neurological problems. *Feeding Problems in Children: A Guide for Health Professionals. Oxford: Radcliffe Medical Press. p*, 153-170.

Rosenbaum, P. L., Palisano, R. J., Bartlett, D. J., Galuppi, B. E., & Russell, D. J. (2008). Development of the gross motor function classification system for cerebral palsy. *Developmental Medicine and Child Neurology*, *50*(4), 249-253.

Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., ...& Jacobsson, B. (2007). A report: The definition and classification of cerebral palsy April 2006. *Developmental Medicine and Child Neurology Suppl*, *109* (suppl 109), 8-14.

Rupela,V. (2008). *Assessment of oral motor, oral praxis and verbal praxis skills in persons with Down Syndrome.* A doctoral dissertation submitted as a part of fulfillment of doctoral degree (Speech Language Pathology), University of Mysore, Mysore.

Sankar, C., & Mundkur, N. (2005). Cerebral palsy-definition, classification, etiology and early diagnosis. *Indian Journal of Paediatrics*, *72*(10), 865-868.

Schenk-Rootlieb, A. J. F., Nieuwenhuizen, O., Graaf, Y., Wittebol-Post, D., & Willemse, J. (1992).The prevalence of cerebral visual disturbance in children with cerebral palsy. *Developmental Medicine and Child Neurology*, *34*(6), 473-480.

Sellers, D., Pennington, L., Mandy, A., & Morris, C. (2014). A systematic review of ordinal scales used to classify the eating and drinking abilities of individuals with cerebral palsy. *Developmental Medicine and Child Neurology*, *56*(4), 313-322.

Shabnam, S. (2014). *Development and validation of Feeding Handicap Index.*A dissertation submitted as a part of fulfilment of Master's degree (Speech Language Pathology), University of Mysore, Mysore.

Shabnam, S., & Swapna, N. (2016). Relationship between feeding and oro-Motor skills in children with cerebral Palsy**.** *International Journal of Multidisciplinary Research Review*, 1(5), 98-103.

Shahanawaz, S. D., Palekar, T. J., & Shah, N. (2015). Effect of Swiss ball on balance in children with spastic diplegia: A case study. *Journal of Paediatrics, 1(*1), 8-11.

Sharma, P., Sharma, U., & Kabra, A. (1999). Cerebral palsy-clinical profile and predisposing factors. *Indian Pediatrics*, *36*(10), 1038-1042.

Sheppard, J. J., Hochman, R., & Baer, C. (2014). The dysphagia disorder survey: Validation of an assessment for swallowing and feeding function in developmental disability. *Research in Developmental Disabilities*, *35*(5), 929-942.

Shimony, J. S., Lawrence, R., Neil, J. J., & Inder, T. E. (2008). Imaging for diagnosis

and treatment of cerebral palsy. *Clinical Obstetrics and Gynecology*, *51*(4), 787-799.

Shyamala, K. C. (1987). *Speech and language behaviour of the cerebral palsied*. Ph.D. Thesis submitted to the University of Mysore, Mysore.

Sjakti, H. A., Syarif, D. R., & Wahyuni, L. K. (2008). Feeding difficulties in children with cerebral palsy. *Paediatrica Indonesiana*, *48*(4), 224-9.

Stamer, M. H. (2015). *Posture and movement of the child with cerebral palsy*. Pro.ed publication, Austin, Texas.

Stevenson, R. D., & Allaire, J. H. (1991).The development of normal feeding and swallowing. *Paediatric Clinics of North America*, *38*(6), 1439-1453.

Stratton, M. (1981). Behaviorial Assessment Scale of Oral Functions in Feeding. *American Journal of Occupational Therapy*, *35*(11), 719-721.

Sullivan, P. B. (2013). Nutrition and growth in children with cerebral palsy: Setting the scene. *European Journal of Clinical Nutrition*, *67*, S3-S4.

Troughton, K. E. V., & Hill, A. E. (2001).Relation between objectively measured feeding competence and nutrition in children with cerebral palsy. *Developmental Medicine and Child Neurology*, *43*(3), 187-190.

Venkatesan, S. (2011).Socio Economic Status Scale-2011. *AIISH, Mysore. Revised version of "Socio Economic Status scale-1993".Secundrabad: NIMH*.

Verity, C., & Firth, H. (2003). Congenital abnormalities of the central nervous system. *Journal of Neurology, Neurosurgery & Psychiatry*, *74*(suppl 1), i3-i8.

Vyas, A. G., Kori, V. K., Rajagopala, S., & Patel, K. S. (2013). Etiopathological study

on cerebral palsy and its management by Shashtika Shali Pinda Sweda and Samvardhana Ghrita. *An International Quarterly Journal of Research in Ayurveda*, 34(1), 56.

Weir, K. A., Bell, K. L., Caristo, F., Ware, R. S., Davies, P. S., Fahey, M., ...& Boyd, R. N. (2013). Reported eating ability of young children with cerebral palsy: Is there an association with gross motor function?. *Archives of Physical Medicine and Rehabilitation*, *94*(3), 495-502.

Wilson, E. M., & Hustad, K. C. (2009). Early feeding abilities in children with cerebral palsy: a parental report study. *Journal of Medical Speech-Language Pathology*, 17, 31-34.

Yekutiel, M., Jariwala, M., & Stretch, P. (1994). Sensory deficit in the hands of children with cerebral palsy: A new look at assessment and prevalence. *Developmental Medicine and Child Neurology*, *36*(7), 619-624.

Yilmaz, S., Basar, P., & Gisel, E. G. (2004). Assessment of feeding performance in patients with cerebral palsy. *International Journal of Rehabilitation Research*, *27*(4), 325-329.

Appendix I

Gross Motor Function Classification System – Expanded and Revised (Palisano et al., 2008)

GMFCS Level I

• Can walk indoors and outdoors and climb stairs without using hands for support

• Can perform usual activities such as running and jumping

• Has decreased speed, balance and coordination

GMFCS Level II

• Can climb stairs with a railing

• Has difficulty with uneven surfaces, inclines or in crowds

• Has only minimal ability to run or jump

GMFCS Level III

• Walks with assistive mobility devices indoors and outdoors on level surfaces

• May be able to climb stairs using a railing

• May propel a manual wheelchair and need assistance for long distances or uneven surfaces

GMFCS Level IV

• Walking ability severely limited even with assistive devices

• Uses wheelchairs most of the time and may propel own power wheelchair

• Standing transfers, with or without assistance

GMFCS Level V

• Has physical impairments that restrict voluntary control of movement

• Ability to maintain head and neck position against gravity restricted

• Impaired in all areas of motor function

• Cannot sit or stand independently, even with adaptive equipment

• Cannot independently walk but may be able to use powered mobility

Appendix II

Assessment of Oral Motor, Oral Praxis and Verbal Praxis Skills in Persons with Down Syndrome (VaniRupela, 2008)

ORAL MOTOR ASSESSMENT

A.POSTURE

1. Scoring: '1' if answer is 'yes', and '0' if answer is 'No'

   a) Does your child sit up straight? Yes/No
   b) Are his/her shoulders symmetrical Yes/No
   c) Is the child's neck in a normal alignment with shoulders Yes/No

2. Scoring: '1' if answer is 'yes', and '0' if answer is 'No'

   a) Are there any involuntary movements present in the child's head , shoulders and /or trunk Yes/No

   b) Does the child's mouth position improve when placed in 90 degree hip, knee and ankle flexion ? Yes/No

3. Instruct the child to imitate the following movements.
   Circle the choice found appropriate for each
   Score 1 for 'adequate' and 0 for 'inadequate'

   a) Forward and backward movement of the head Inadequate/Adequate
   b) Rotation of the head Inadequate /Adequate
   c) Left - right movement of the head Inadequate /Adequate
   d) Left - right movement of the shoulders Inadequate /Adequate
   e) Left - right movement of the trunk Inadequate /Adequate
   f) Forward and backward (bending front and back) movement of the trunk Inadequate /Adequate

B.ORAL STRUCTURES AT REST

Score 2 for 'a', 1 for 'b' and '0' for 'c'

1. The child's jaw is :
   a) In normal alignment
   b) Slightly protracted or retracted
   c) Noticeably protracted or retracted

2. The child's jaw at rest is:
   a) Closed
   b) Slightly open
   c) Noticeably open

3. The child's lips are :
   a) In a normal position
   b) Slightly protruded or retracted

c) Obviously protruded or retracted

4. The child
   a) Does not drool
   b) Drools, but tries to swallow it
   c) Drools and does not use any strategy to clear it

5. The child's tongue is :
   a) Placed appropriately inside the mouth
   b) On the bottom of the lower lip
   c) Outside the mouth

6. Based on the interpretation from the five items above, the oral structures seems to show
   a) Normal tone
   b) Mildly abnormal tone
   c) Moderately abnormal tone

7. Involuntary movements are :
   a) Absent
   b) Present but rarely noticeable
   c) Apparently present

8. When the child moves his/her oral structures :
   a) Other parts of the body do not move
   b) Other parts of the body move minimally
   c) Other parts of the body move noticeably and hinder in speech production

C. FUNCTION OF THE ORAL MECHANISM FOR SPEECH

Score 1 for 'adequate' and 0 for 'inadequate'

1. The intra-oral build-up for stops is Adequate/Inadequate

2. Air build up and precision of fricatives is Adequate/Inadequate

3. Oral - nasal distinction is Adequate/Inadequate

The following activities have to be observed without asking the client to imitate or do these activities:

4. When the child spreads his lips, the range of movements of lips is Adequate/Inadequate

5. When the child opens and closes his/her mouth ,range of movement of jaw is Adequate/Inadequate

6. When the child moves the tongue form side to side, The range of movement is Adequate/Inadequate

D. ORAL SENSORY BEHAVIOUR

The following questions regarding the child are explained to the parent(s) or caregiver and asked how frequently the behaviours are exhibited based on the key given below.

0 - (N) Never
1 - (O) Occasionally
2 - (F) Frequent
3 - (A) Always
0 - (NA) Not applicable

Questionnaire		N	O	F	A	NA
1.	Reacts aversively to new foods , tastes , or textures – limited repertoire					
2.	Avoids certain texture of food					
3.	Has poor lip closure (due to discomfort of closing lips)					
4.	Is uncomfortable when touched on face /cheeks /lips					
5.	Likes only highly textured or crunchy foods					
6.	Has trouble handling liquids					
7.	Chews or swallows ineffectively due to lack of awareness of food in the mouth					
8.	Constantly puts things in the mouth					
9.	Bites himself or others					
10.	May not notice if food offered is hot or cold					
11.	Demonstrates poor oral motor skill development (biting , chewing , swallowing)					
12.	Is unaware of the food stuck in the teeth or on side of the lips/face					
13.	Is unaware of the pooled saliva and drooling					
14.	Chews hard on things					
15.	Explores food by tasting					
16.	Chews constantly on non –food items –wants to taste everything					
17.	Acts as though all foods taste same –disinterested or bored with eating –poor appetite –fussy while eating					
18.	Only seems to taste foods that are highly spiced					
19.	Messy eater –frequently spills					

Appendix III
Feeding Handicap Index (Shabnam, 2014)

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

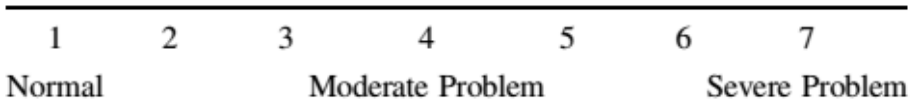
15.	P	My child's weight gain is inappropriate (under/over-weight) and/or has nutritional deficiency due to feeding issues.	0	1	2		
16.	P	My child keeps the food in the mouth without swallowing for a long time	0	1	2		
17.	P	My child has difficulty in swallowing solid/ semi-solid or mashed/ liquid food	0	1	2		
18.	P	The food/liquid comes through the nose during swallowing	0	1	2		
19.	P	My child gags when solid/liquid food is given	0	1	2		
20.	P	My child vomits when solid/liquid food is given	0	1	2		
21.	P	My child chokes while feeding	0	1	2		
22.	F	My child eats less because of the feeding problem	0	1	2		
23.	F	I avoid giving solid food to my child because of the feeding problem	0	1	2		
24.	F	My child spills a considerable portion of the solid food/liquid during feeding (E.g. spilling the food near the mouth or spilling the food while taking it from the plate).*Specify the quantity of food spilled in percentage.*	0	1	2		
25.	F	My child strongly refuses newly introduced food or certain food based on the taste/temperature/ texture/ smell.	0	1	2		
26.	F	My child needs to be placed in a specific position/special chair during feeding	0	1	2		
27.	F	My child requires smaller meals more often due to the feeding problem	0	1	2		
28.	F	I push the food to back of the mouth of my child so that s/he can swallow it easily	0	1	2		
29.	F	My child takes longer to be fed	0	1	2		
30.	F	I pour water/milk to ensure	0	1	2		

		that the food is swallowed					
31.	F	My child needs specific utensils (his/her own spoon, plate, etc.) and/or special feeding equipment/aids (e.g., feeding tube, special feeding bottles etc.)	0	1	2		
32.	F	I pinch my child's nose to make him/her swallow the food	0	1	2		
33.	F	I shake my child/close the lips/jaw for easy swallow	0	1	2		
34.	E	My child refuses to open his/her mouth while feeding	0	1	2		
35.	E	My child exhibits frustration or temper tantrums before/during feeding	0	1	2		
36.	E	My child does not like being dependent on others for feeding	0	1	2		
37.	E	My child feels upset that s/he cannot eat food like other children/does not like to eat with other children	0	1	2		
38.	E	My child feels embarrassed/is not comfortable to eat food in social gatherings	0	1	2		

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

Other significant findings:

Rating scale for parent/caregivers:



Parent perception – 3 to 4 (Towards moderate)

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

Appendix IV

Behavioral Assessment Scale of Oral Functions in Feeding

(Stratton, 1981)

FUNCTION		‘0’ PASSIVE	1	2	3	‘4’ FUNCTIONAL	‘5’ NORMAL
Jaw Closure	Extension	Jaw remains open .No noticeable movement in response to utensil	Jaw thrust opens as far as possible . Difficult to close.	Jaw thrust : Jaw opens less than 2": difficult to close	Jaw thrust opens less than 2": closes easily with manual assistance	Jaw thrust: corrects itself within few seconds.	Able to open to close jaws smoothly over utensil.
	Flexion	Jaw remains open .No noticeable movement in response to utensil	Bite reflex: Holds spoon tightly; cannot voluntarily release	Bite reflex: easily corrected by jaw control	Bite reflex: immediate active release without use of jaw control	Bite reflex : not strong enough to retain the utensil in the mouth	Able to open to close jaws smoothly over utensil.
	Freq	Response occurs every time	7 out of 10 times per meal	5 out of 10 times per meal	3 out of 10 times per meal	1 out of 10 times per meal	No abnormal response
Lip closure over spoon		Mouth remains open : No noticeable movements in response to utensil	Initial jaw thrust or bite reflex on contact with utensil	Slight active movement of lower jaw toward spoon	Jaws close over spoon but not lips.	Lips approximate the spoon with no attempt to remove food	Lips purse together to actively remove food from bowl of the spoon
Tongue control		Tongue remains at bottom of the mouth : no	Tongue rolls to side or retracts back ,	Tongue protrudes horizontally forward & out	Tongue protrudes horizontally forward (but	Tongue moves forward and upward in	Tongue elevates in the roof of the mouth (behind

	noticeable response to food	not functional for swallow	between lips in swallowing	remains in the mouth) when swallowing	attempt to swallow	front teeth) and moves food back to swallow
Lip closure while swallowing	Mouth remain open; no noticeable movement during swallowing	Slight active movement of lower jaw /lip during swallow	Lip partially close during swallow ; tongue may occlude opening	Lips open and close repeatedly during swallow	Lips approximate during swallow ; no tight seal	Lips close tightly to prevent food loss during swallow
Swallows Food without excess loss **Amt**	100 % food loss	70% food loss	50 % food loss	30 % food loss	10 % food loss	No excess food loss with average sixed spoon
Freq	Excess loss with every swallow	Excess loss 7 out of 10 times	Excess loss 5 out of 10 times	Excess loss 3 out of 10 times	Excess loss 1 out of 10 times	
Chews food (Tongue/jaw control)	No noticeable movement of jaw or tongue in response to food	No jaw movement	Minimal jaw movement; not functional for chewing	Vertical jaw movement some lateral tongue control	Vertical movement with minimal rotary movement	Able to bite solid piece of food and chew functionally . Tongue able to control position of bolus
Sips liquid	No active movement of jaws , lips and tongue in response to liquid	Initial jaw thrust or bite reflex on contact with glass	Slight active movement of lower jaw toward the rim of glass	Lips approximate rim of glass ;does not initiate intake	Lips over rim of glass ;sips liquid but cannot swallow repeatedly	Lips over rim of glass

Swallows Liquid without excess loss amt	100 % liquid loss	70% loss	50 % loss	30 % loss	10 % loss	No excess liquid loss
Freq	Excess loss with every swallow	Excess loss 7 out of 10 times	Excess loss 5 out of 10 times	Excess loss 3 out of 10 times	Excess loss 1 out of 10 times	No excess loss
Swallows Food without coughing sensitiv	Coughing or hypersensitivity regardless of food sensitivity		Coughing or hypersensitivity noted with Textures, temperature changes		Coughing or hypersensitivity only with textures	No coughing or hypersensitivity noted
Freq	Coughs every mouthful	Coughs 70% of the time	Coughs 50% of the time	Coughs 30% of the time	Coughs 10% of the time	No coughing or gagging noted

Appendix V

Dysphagia Outcome and Severity Scale (DOSS)

(O'Neil, Purdy, Falk, & Gallo, 1999)

Full per-oral nutrition (P.O): Normal diet

Level 7:

- Normal in all situations
- Normal diet
- No strategies or extra time needed

Level 6:

- Within functional limits/modified independence
- Normal diets, functional swallow
- Patient may have mild oral or pharyngeal delay, retention or trace epiglottal undercoating but independently and spontaneously compensates/clears
- May need extra time for meal.
- Have no aspiration or penetration across consistencies

Full P.O: Modified diet and/or independence

Level 5: Mild dysphagia: Distant supervision may need one diet consistency restricted

May exhibit one or more of the following

- Aspiration of thin liquids only but with strong reflexive cough to clear completely
- Airway penetration midway to cords with one or more consistency or to cords with one consistency but clears spontaneously.
- Retention in pharynx that is cleared spontaneously
- Mild oral dysphagia with reduced mastication and/or oral retention that is cleared spontaneously

Level 4: Mild–moderate dysphagia: Intermittent supervision/cueing, one or two consistencies restricted

May exhibit one or more of the following

- Retention in pharynx cleared with cue
- Retention in the oral cavity that is cleared with cue
- Aspiration with one consistency, with weak or no reflexive cough

- or airway penetration to the level of the vocal cords with cough with two consistencies
- or airway penetration to the level of the vocal cords without cough with one consistency

Level 3: Moderate dysphagia: Total assist, supervision, or strategies, two or more diet consistencies restricted

May exhibit one or more of the following

- Moderate retention in pharynx, cleared with cue
- Moderate retention in oral cavity, cleared with cue
- Airway penetration to the level of the vocal cords without cough with two or more consistencies
- Or aspiration with two consistencies, with weak or no reflexive cough
- Or aspiration with one consistency, no cough and airway penetration to cords with one, no cough

Nonoral nutrition necessary

Level 2: Moderately severe dysphagia: Maximum assistance or use of strategies with partial P.O. only (tolerates at least one consistency safely with total use of strategies)

May exhibit one or more of the following

- Severe retention in pharynx, unable to clear or needs multiple cues
- Severe oral stage bolus loss or retention, unable to clear or needs multiple cues
- Aspiration with two or more consistencies, no reflexive cough, weak volitional cough
- or aspiration with one or more consistency, no cough and airway penetration to cords with one or more consistency, no cough

Level 1: Severe dysphagia: NPO: Unable to tolerate any P.O. safely

May exhibit one or more of the following

- Severe retention in pharynx, unable to clear
- Severe oral stage bolus loss or retention, unable to clear
- Silent aspiration with two or more consistencies, nonfunctional volitional cough
- or unable to achieve swallow
